CHILD DEATH **OVERVIEW PANEL** 2022/23







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1. CHAIR'S FOREWORD

This report sets out learning from the deaths of babies, children and young people in Hull that we reviewed during 2022-23.

Each death is a lifetime loss for the families and loved ones – our responsibility to them is to ensure that anything that can be learned to prevent future deaths is considered, shared and actioned.

The panel's sincere hope is that you can use the information in this report to improve practice, help families and professionals reduce risk, and that we prevent deaths as a result.

Helen Christmas, Public Health Consultant, Hull City Council CDOP Chair



2. INTRODUCTION & CHILD DEATH REVIEW PROCESS

The purpose of the child death review process is to try to ascertain why children die and put in place interventions to protect other children, prevent future deaths wherever possible as well as improving services to families and carers.

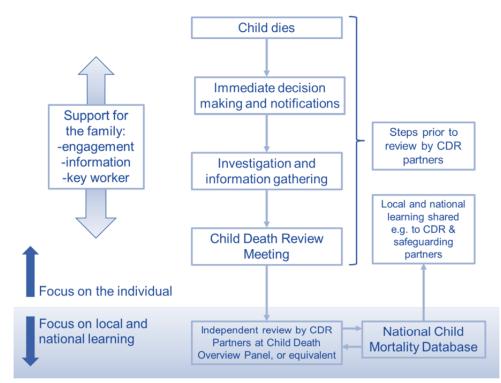
Child Death Overview Panels (CDOP) became statutory in April 2008. CDOP has a statutory responsibility to review the deaths of all children up to the age of 18 years old (excluding babies who are stillborn, late foetal loss and planned terminations of pregnancy carried out within the law) resident within the Local Authority area of Hull. It includes any infant death where a death certificate has been issued, irrespective of gestational age.

The publication of the <u>Child Death Review Statutory and Operational Guidance in 2018</u> builds on the requirements set out in <u>Chapter 5 of Working Together to Safeguard Children 2018</u> and details how individual professionals and organisations across all sectors involved in the Child Death Review should contribute to guided standardised practice nationally and enable thematic learning to prevent future child deaths. The process intends to;

- Document, analyse and review information in relation to each child that dies in order to confirm the cause of death, determine any contributing factors and to identify learning arising from the process that may prevent future child deaths
- To make recommendations to all relevant organisations where actions have been identified which may prevent future deaths or promote the health, safety and wellbeing of children
- To produce an annual report on local patterns and trends in child death, any lessons learnt and actions taken, and the effectiveness of the wider Child Death Review Process
- To contribute to local, regional and national initiatives to improve learning from Child Death Reviews

As part of our local arrangements Humber and North Yorkshire Integrated Care Board, Hull Place and Hull City Council as Child Death Review partners lead a Child Death Review Operational Group to ensure our arrangements comply with statutory guidance and are working effectively. The group meet regularly to progress a local delivery plan. A Child Death Review Executive Group provides strategic oversight for the local child death review process. Membership comprises of joint chairs, Director of Public Health, and Director of Nursing; CDOP chair, Designated Nurse Safeguarding Children and Young People, Designated Doctor for child deaths, Assistant Chief Nurse (HUTH) and the Child Death Review Co-ordinator.

Since January 2021 Hull has used an online notification, recording, casework and reporting system. The eCDOP system automatically transfers data at each relevant stage of the process into the National Child Mortality Database. This information is then used to analyse data nationally to improve learning and implement strategic improvements in care for children in England, with the overall goal to reduce child mortality. The chart below illustrates the full process of a child death review.



Processes ensure appropriate links are made with other statutory review processes, for example:

- ¹Perinatal Mortality Review Tool (for infants under 28 days or older who died on Neonatal Intensive Care (NICU)
- ➢ ²NHS Serious Incident investigations
- ³Post Mortem examination
- ➢ ⁴Inquest
- ▹ 5Coroner's Regulation 28 report to prevent future deaths

¹ The PMRT is a web-based tool that is designed to support a standardised review of care of perinatal deaths in neonatal units from 22+0 weeks gestation to 28 days after birth. It is also available to support the review of post-neonatal deaths where the baby dies in a neonatal unit after 28 days but has never left hospital following birth. The PMRT is integrated with the national collection of perinatal mortality surveillance data.

² Serious Incidents in health care are adverse events where there are significant consequences to patients, families and carers, staff or organisations and investigations are undertaken with the sole aim of learning about any problems in the delivery of healthcare services and in understanding the causes and contributory factors of those problems.

³ A PM is detailed physical examination of the child after he or she has died. A coroner may order a post-mortem examination, that is, without the permission of the family. Any other post-mortem examination will only take place with the consent of the family.

⁴ An Inquest is an investigation into a death which appears to be due to unknown, violent or unnatural causes, designed to find out who the deceased was, and where, when and how they died. It is different to other Courts because there are no formal allegations or accusations and no power to blame anyone directly for the death. At the end of the Inquest, the Coroner will give his/her Conclusion and this will appear on the final Death Certificate. The death can then be officially

registered.

⁵ If any information is revealed as part of the Coroner's investigation or during the course of the evidence heard at the Inquest, which gives rise to "a concern that circumstances creating a risk of other deaths will occur, or will continue to exist in the future;" and if the Coroner is of the opinion that action needs to be taken, under Paragraph 7 of Schedule 5 of the Coroner and Justice Act 2009, the Coroner has a duty to issue a report to a person, organisation, local authority or government department or agency. The Coroner's Regulation 28 Report will set out the concerns and request that action should be taken. All Regulation 28 Reports and the responses are sent to the Chief Coroner and in most cases these will be published on the judiciary.gov.uk website.

- Police criminal investigation
- Road Traffic Collision investigation
- ⁶Learning Disabilities Mortality Review (LeDeR) to avoid duplication, as of 1st July 2023, there will no longer be any requirement for deaths of children with a learning disability to also be notified to LeDeR; these deaths will be reviewed by the national mandated processes that look at the deaths of all children, with additional shared learning arrangements between the National Child Mortality Database and the LeDeR programmes.
- ▹ ⁷Child Safeguarding Practice Review completed by the Hull Safeguarding Children Partnership
- ⁸National Guidance on Learning from Deaths A Framework for NHS Trusts and NHS Foundation Trusts on Identifying, Reporting, Investigating and Learning from Deaths in Care

Each review at CDOP is informed by information collated from the notification and from a range of meetings, depending on the circumstances of the death.

CDOP is the culmination of the CDR processes and aims to draw together thematic learning.

⁶ (until June 2023) The LeDeR programme supports local areas to review the deaths of people with learning disabilities (aged 4+ years), identify learning from those deaths, and take forward the learning into service improvement initiatives. Its overall aims are to support improvements in the quality of health and social care service delivery and to help reduce premature mortality and health inequalities for people with learning disabilities.

⁷CSPRs are undertaken when a child dies (including death by suspected suicide) or is seriously harmed, and abuse or neglect is known or suspected. The prime purpose of a CPR is for agencies and individuals to learn lessons to improve the way in which they work, both individually and collectively, to safeguard and promote the welfare of children.

⁸ Guidance to help standardise and improve the way acute, mental health and community Trusts identify, report, review, investigate and learn from deaths, and engage with bereaved families and carers.



3. CHILD DEATH OVERVIEW PANEL (CDOP)

The Child Death Overview Panel is multi-agency with differing areas of professional expertise. Core membership of Hull's CDOP can be found on page 6. Panels meet several times a year to review all the child deaths in their area. Panels are not given the names of the children who died or the professionals involved in their care. The main purpose is to prevent similar deaths in the future.

CDOPs do not produce reports on individual child deaths, which is why parents do not receive any information from the panels about their individual child; however, they produce an annual report that is a public document.

The CDOP review ensures independent scrutiny by senior professionals with no named responsibility for the child's care during life. This is an anonymised secondary review of each death in order to:

- confirm or clarify the cause of death,
- determine any contributory factors, and to identify learning arising from the child death review process that may prevent future child deaths;
- make recommendations to all relevant organisations where actions have been identified which may prevent future child deaths or promote the health, safety and wellbeing of children.

Statutory guidance suggests CDOP reviews should take place approximately six weeks after a CDRM or after an Inquest. Hull CDOP schedule their meetings monthly but due to catching up with some historical cases, limited capacity to prepare cases for CDOP and a maximum number of cases that can feasibly be discussed in one meeting, meetings can take longer than six weeks to discuss. During 2022/23, Hull CDOP met nine times and reviewed 12 child deaths.

Six of these deaths occurred in 2021/22, two in 2020/21 and four in 2019/20.

At the year-end, Hull CDOP had reviewed 92% of child death notifications received since the process commenced on 1st April 2008. Going into 2023/24 there were 29 child deaths pending review, at various stages of the process:

- Four deaths were undergoing parallel processes and pending conclusion of enquiries and investigations
- 15 deaths were waiting for child death review meetings to be organised; one death was within the timeframe of three months from notification/conclusion of parallel process and 14 were outside of this timeframe.
- Eight child death review meetings had taken place and were pending final review at a future CDOP meeting in 2023/24 (this includes two pending Inquests, one pending a meeting with parents, one pending a decision on publication of a Child Safeguarding Practice Review and one pending collation of learning from published Serious Case Review).

The local child death review Operational Group and Exec Group track and monitor all pending cases and are aware of the impact of the COVID pandemic on slowing some progress against the intended objectives with key staff needing to take lead roles in the pandemic response, restoration and recovery.

During 2022-23, we had hoped to increase the number of reviews taken to CDOP meetings and reduce delays, but we have not made the progress we had hoped to due to the limited capacity available for child death review meetings and preparing for CDOPs.

The CDR Operational Group has continued to maintain oversight of the scheduling of CDRMs during 2022-23. In acknowledging the challenges, the group has continued to support a revised approach, commenced in 2021-22, to use virtual meetings and the option to `cluster` similar cases whereby the medical and clinical teams and professionals are the same. This approach has had the benefit of richer learning from themed meetings and will continue into 2023-24.



4. NATIONAL CHILD MORTALITY DATABASE (NCMD)

The NCMD is an NHS funded project, delivered by the University of Bristol and since 1st April 2019 it has undertaken real time surveillance of all child deaths in England. Using national standardised forms, CDOPs are required to input notifications, agency reporting forms and analysis forms into the database for them to gather and analyse the data with the aim to learn lessons that could lead to changes to improve and save children's lives in the future.

Child death review partners and CDOP members engage in the NCMD Webinars which are designed to provide detailed updates on the NCMD, discuss emerging issues and obtain information around the latest events and research publications.

This year, CDOP partners have learned from the following NCMD themed reports and research paper using NCMD data:

- <u>What is the relationship between deprivation, modifiable factors and childhood deaths?</u> - identifies links between social deprivation and childhood mortality, and identifies potential points where public health, social and education interventions, or health policy may be best targeted.
- <u>Sudden and Unexpected Deaths in Infancy and Childhood -</u> aims to quantify the number of sudden unexpected deaths of infants and children in England, the proportion of these deaths that remain unexplained following review by a Child Death Overview Panel (CDOP), and the demographics and characteristics of these children. It provides detailed analysis based on the unique data collected and held by the NCMD, as well as testimonies from the lived experience of families and comprehensive recommendations for policymakers and professionals to ensure positive change in the future.
- <u>The Contribution of Newborn Health to Child Mortality across England</u> draws on data from the NCMD to investigate how illness around the time of birth affects the health of children up to the age of 10, and to draw out learning and recommendations for service providers and policymakers.



5. MEMBERSHIPS AND PANEL MEETINGS

The Child Death Overview Panel meetings are held monthly. The membership at 31/3/23 can be seen below:

Public Health Consultant	Hull City Council (Chair)
Consultant Paediatrician for Deaths in Childhood	Hull University Teaching
	Hospitals Trust
Designated Nurse, Safeguarding Children and Young People	Humber and North Yorkshire
	ICB, Hull Place (Vice chair)
Named GP, Safeguarding Children and Young People	Humber and North Yorkshire
	ICB, Hull Place
Detective Chief Inspector, Safeguarding Governance Unit	Humberside Police
Head of Service (EHASH/Assessment/VEMT/EDT)	Hull Children, Young People
	& Families Services,
	Hull City Council
Assistant Coroner	East Riding and Hull
	Coroner's Service
Bereavement Midwife	Hull University Teaching
	Hospitals Trust
Child Death Review Co-ordinator	Hull City Council
Designated Doctor Safeguarding Children and Young People	Hull University Teaching
(post vacant May-Dec 2022)	Hospitals Trust



6. HULL CHILD DEATH OVERVIEW PANEL DATA ANALYSIS

This section of the report outlines Hull child deaths that were notified to CDOP and those reviewed by our local Panel between 1st April 2022 and 31st March 2023. Not all child deaths which occurred in the year they were notified will have their child death review completed in the same year; this is because it may take several months to gather sufficient information to fully review a child's death and some cases are subject to parallel processes which need to conclude prior to a review at CDOP, such as post mortem examinations, health reviews, Inquests and Child Safeguarding Practice Reviews.

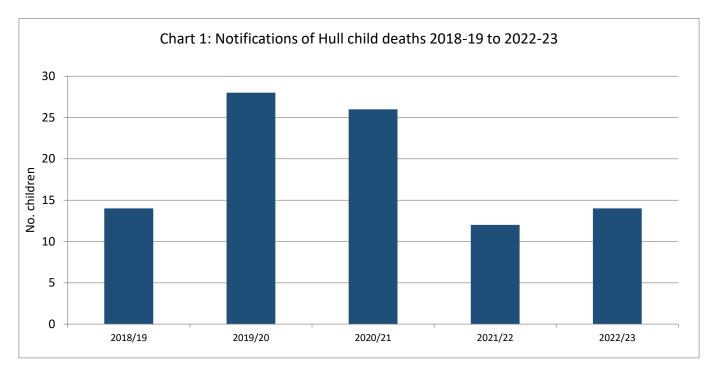
NOTIFICATIONS

Number of infant and child deaths

The latest comparative national data on mortality rates:

- Since 2010-12, the rate of neonatal deaths (up to 28 days) in Hull has been comparable to the rate in England (or lower) with the exception of 2017-19. The rate in Hull for 2019-21 is slightly higher than England (3.0 versus 2.8 per 1,000 live births and stillbirths).
- The mortality rate for 2018-20 for post-neonatal deaths (28 days up to one year of age) was slightly higher in Hull compared to England (1.4 versus 1.1 per 1,000 live births). However, the rate increased for 2019-21 to 17 deaths with a mortality rate of 1.8 per 1,000 live births which was considerably higher than England at 1.1 deaths per 1,000 live births, although the rate in Hull was not statistically significantly different than England.
- Between 2001-03 and 2018-20, there has been no statistically significant difference in the infant mortality rate between Hull and England. The mortality rate in Hull for babies under one year whose deaths were registered during the three year period 2019-21 was 4.8 per 1,000 live births, which was higher than England (3.9), although not statistically significantly different from the England average.
- Between 2018-20 Hull's child (age 1-17) mortality rate per 100,000 was slightly lower than England at 9.9 compared to 10.3.

14 children from Hull died in 2022/23. This is similar to the number of children in the previous year but significantly less than the year before (see chart 1). The 5-year average is 19 child deaths per year in Hull. Three deaths were unexplained and/or unexpected so met the criteria for a multi-agency professionals' Joint Agency Response meeting. Of the 14 deaths in 2022/23, none of the reviews were completed at CDOP due to the number of notifications from previous years still requiring final review.



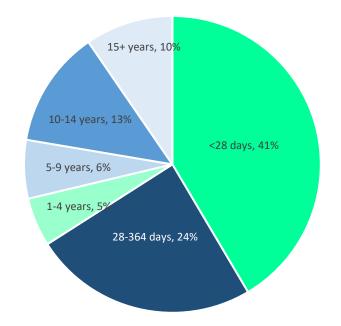


Chart 2: Age range of Hull child deaths 2018-19 to 2022-23

The data in Chart 2 summarises age at time of death over the past five years. As in previous years, a child is most at risk of death when under the age of one.

The ages of child who die fluctuates year on year, however the 10-14 year age group has seen a reduction year on year over the last four years (there were none in 2018-19).

During 2022/23, the proportion of ages of child deaths notified were:

Infants under the age of 28 days	- 29%
28-364 days	- 29%
1-4 years	- 14%
5-9 years	- 7%
10-14 years	- 7%
15-17 years	- 14%

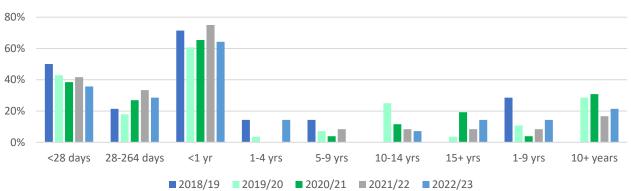
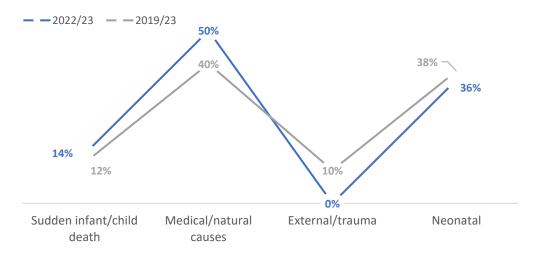


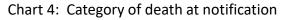
Chart 3: Percentage age range of annual child deaths 2018-19 to 2022-23

Categories of death

The type of deaths can be summarised into four categories at the time of death, but it is not until the final review at CDOP that the death can be recorded in one of 10 categories advised in the statutory guidance.

The proportion of our child deaths within these broad categories fluctuates year on year, but the proportional trend for 2022/23 is similar to the type of deaths notified over a five-year period.





Expected and Unexpected child deaths

There are two categories of child deaths:

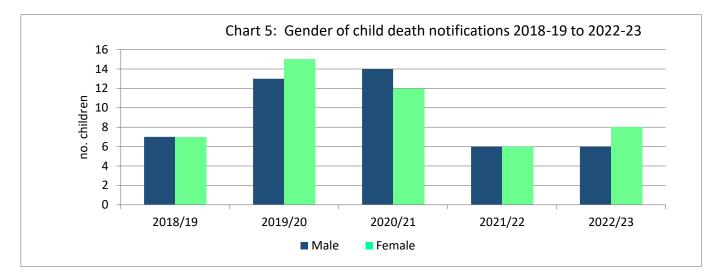
- A child death is an "expected" death where the death of an infant or child was anticipated due to a life limiting condition, including some deaths relating to prematurity and birth complications.
- A child death is an "unexpected" death where the death of an infant or child was not anticipated as a significant possibility, for example, 24 hours before the death; or where there was an unexpected collapse or incident leading to or precipitating the events which led to the death; these could be due to external causes or complications of a medical illness or intervention.
- Four of the 14 child death notifications in 2022/23 were classified as unexpected. Over the past five years there have been 94 child death notifications and 46% of these were regarded as unexpected.

Location of death

Of the 14 deaths notified to Hull CDOP in 2022/23, 10 (71%) occurred within a hospital trust, one occurred in a hospice and one occurred at home. Four deaths occurred at an out of area hospital trust, which is an increase in comparison to the previous two years.

Infant and child deaths by gender

During 2022/23 there were slightly more female child deaths than male. A breakdown of the number of child deaths by gender is outlined in Chart 5. Nationally, child mortality for males is higher than females.



Ethnicity

Of the 14 children whose deaths were notified to Hull CDOP in 2022-23, 64% were classified as being of "White British" ethnicity and 36% were from a range of other ethnic backgrounds. The average over the last five years has been 71% White British and 29% from other backgrounds. Although our numbers are too small to be statistically significant, this is disproportionate compared to the wider Hull children's population and appears to be a continued trend.

In the January 2021 school census, 21.9% of children and young people were not of White British ethnic heritage, the breakdown of ethnicity is as follows (%):

White British	78.1
Irish	0.1
Gypsy/Roma	0.3
Any other White background	9.4
Mixed	4.0
Asian or British Asian	1.8
Black or Black British	2.0
Any other ethnic group	3.0
Unclassified	1.4

Children with learning disabilities

Deaths of children who were known to have a learning disability are notified to the Learning Disabilities Mortality Review Programme (LeDeR) by CDOP. Everyone with a learning disability aged over four years is eligible for LeDeR review. The child death review process reviews the deaths of all children who are under the age of 18. This is the primary review process for children with a learning disability and autistic children; the results are then shared with LeDeR.

There were no deaths of children with disabilities notified in 2022/23.

CHILD DEATH REVIEWS

Categories of child deaths reviewed

Between April 2022 and March 2023 Hull Child Death Overview Panel (CDOP) reviewed 12 child deaths. The categories of child deaths from their review at CDOP meetings in the last five years are detailed in chart 6.

The review of deaths during the CDOP meeting require members to categorise each child death using a pre-determined list, which are then recorded locally and reported to the NCMD.

Two children tested positive for Coronavirus at the time of their death, but it was not regarded as a contributory factor in their death.

One child death reviewed also met the criteria for a Learning Disabilities Review (LeDeR). Since the LeDeR process was established in 2017, four children's reviews also contributed to the LeDeR review programme. One remains outstanding for review in 2023/4.

	2018/19	2019/20	2020/21	2021/22	2022/23	Hull Total for 2018/19- 2022/23	National % breakdown 2017/18- 2021/22* (*Latest published info)
1. Deliberately	0	0	1	0	1	2	
inflicted injury,						(20/)	30/
abuse or neglect -						(3%)	2%
includes numerous							
physical injuries,							
which may be							
related to							
homicide as well as							
deaths from war,							
terrorism or other							
mass violence or							
severe neglect							
leading to death.							
2. Suicide or	0	0	0	0	0	0	4%
deliberate self-							
inflicted harm -							

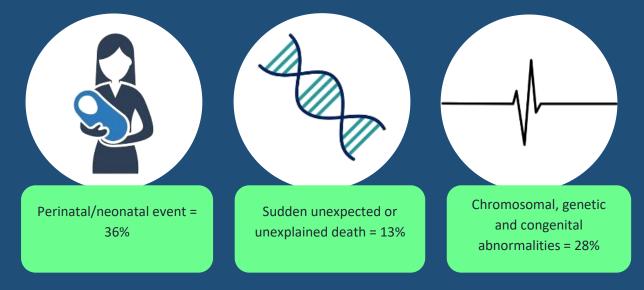
Chart 6: Category of child deaths reviewed by CDOP 2018-19 to 2022-23

includes any act intentionally to cause one's own death. It will usually apply to adolescents rather than younger children.							
3. Trauma and other external factors - relates to unintentional physical injuries caused by external factors. Not including any deliberately inflicted injury, abuse or neglect.	1	1	2	0	1	5 (6%)	5%
4. Malignancy - includes cancer and cancer like conditions such as solid tumours, leukaemia & lymphomas, and other malignant proliferative conditions, even if the final event leading to death was infection, haemorrhage etc.	0	0	1	3	1	5 (6%)	8%
5. Acute medical or surgical condition - A brief sudden onset of illness which resulted in the death of a child.	0	0	2	0	1	3 (4%)	6%

6. Chronic medical condition – A medical condition which has lasted a long time or was recurrent and resulted in a child death	1	0	0	0	0	1 (1%)	5%
7. Chromosomal, genetic and congenital anomalies – Medical conditions resulting from anomalies in genes or chromosomes as well as a defect that is present at birth.	6	1	1	9	5	22 (28%)	24%
8. Perinatal/neonatal event –death of child as a result of extreme prematurity, adverse outcomes of the birthing process, intrauterine procedure or within the first four weeks of life	8	6	4	9	2	29 (36%)	33%
9. Infection –can be any primary infection arising after the first postnatal week, or after discharge of a preterm baby.	2	0	0	0	1	3 (4%)	5%

10. Sudden unexpected or	1	2	4	3	0	10	7%
unexplained death – This is where pathological diagnosis						(13%)	
is either Sudden Infant Death Syndrome (SIDS) or 'unascertained', at any age.							
Unknown-not enough information						0	2%
Total number of child deaths reviewed by CDOP	19	10	15	24	12	80	

As detailed in Chart 6, of the 80 child deaths that have been reviewed by the Hull Child Death Overview Panel over the past five years, the main categories are:



National comparison

Over the five-year period 2018-19 to 2022-23, the two categories of deaths with the highest number of reviews were the same for Hull and England, and this is also the same for Hull this year. Perinatal/neonatal events was the highest (36%) followed by Chromosomal/Genetic/Congenital conditions (28%); the third highest for Hull in 2022/23 was Sudden Unexpected or Unexplained death at 13%. Each of these categories represented a greater proportion of the deaths in Hull than data collected nationally by the National Child Mortality Database (for reviews during 2021/22 - most recent published data): 34%, 23%, 7% respectively).

Using small numbers raises statistical issues regarding accuracy and usefulness so comparisons with national data should be treated with caution, but it is helpful to be aware and monitor areas of variance. Also, reviews do not necessarily take place within the same year as the death and in Hull we have themed some of our CDOP meetings, so it is difficult to accurately assess comparisons with national proportions.

Chart 6 shows the total number of child deaths by category in the five-year period 2018-19-2022-23.

Compared with England over the last five years, Hull has reviewed a lower proportion of reviews in categories:

- Suicide or deliberate self-inflicted harm
- Chronic medical conditions

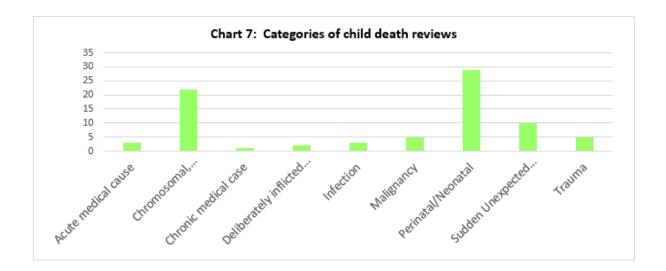
Hull's reviews categorised a higher proportion of our deaths as:

- Perinatal/ neonatal event
- Chromosomal, genetic and congenital anomalies
- Sudden unexpected/unexplained death

The categories which have a similar proportion (+/-2%) of reviews are:

- Deliberately inflicted injury, abuse or neglect
- Trauma and other external factors
- Malignancy
- Acute medical or surgical condition
- Infection

This was the same for Hull in 2021-22.



Modifiable factors

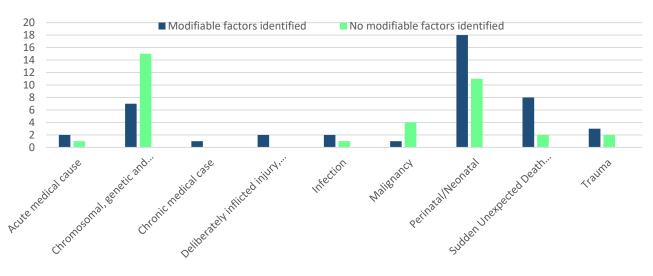
During the review of each death, modifiable factors are identified and analysed to enable learning and preventative action. It's important to be clear that when the CDOP identifies a modifiable factor during a review, it doesn't necessarily mean it was a causal factor in that particular child's death.

Modifiable factors are defined as "Factors which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future deaths." (Working together to safeguard children, 2018).

CDOP ensure that any issues identified, learning points and recommendations have been assigned to relevant agencies / professionals to enable them to take action as appropriate. Often this will already have happened earlier in the child death review process. All actions are monitored via an action log until the panel are assured that the necessary action has been completed. Twelve child deaths were reviewed by Hull CDOP during 2022/23; these deaths occurred in previous years. There were four deaths (33%) where modifiable factors were identified, in four categories:

- Deliberately inflicted injury, abuse, neglect
- Trauma
- Malignancy
- Acute medical cause

Chart 8: Modifiable and non-modifiable factors in categories of child deaths in Hull 2018-19 - 2022-23



The most recent <u>National Child Mortality Database Annual Report</u>, published in June 2021 highlighted the modifiable factors most frequently identified during CDOP reviews nationally in 2019-20.



The modifiable factors identified in Hull's reviews during 2022/23 were in the following categories:

- Smoking by parent/carer
- Quality of service delivery
- Poor communication
- Domestic abuse/coercive relationship
- Home conditions

Additional factors identified by Hull CDOP were:

- Parental supervision
- Seeking medical attention
- Adverse Life Experiences

These are based on the information available to us from the child death review(s) – and we are more likely to hear about factors that are routinely recorded in medical notes (such as a mum's smoking status during pregnancy) than we are about less-well documented challenges such as difficulty accessing services. Factors such as domestic abuse or poor home environment may feature in the reviews, but not always be listed as a modifiable factor if they are thought unlikely to have contributed to the death.



7. CDOP LEARNING AND ACTIONS FROM CHILD DEATHS REVIEWED IN 2022/23

This section of the report sets out some of the learning and actions that have been initiated from child death reviews in 2022-23 that could be useful to professionals both in preventing future deaths and improving care for families. Some examples may be specific to a single death and focussed on a particular set of circumstances – others are adding to our existing knowledge about wider societal harms. Many have already been identified in and report via other processes and relevant actions already embedded.

Deliberate Harm and trauma related deaths

- Domestic abuse features in a high proportion of child death reviews (in parental relationships or in previous relationships) and although not identified as a contributory factor in this year's reviews, it is notable for its frequency.
- Waterparks and beaches abroad have different safety regulations than England. Information about the importance of water safety, including parental supervision and taking time to review safety notices, what local signs and flags mean and looking for hazards was shared locally through the local Unintentional Injuries and Safer Sleep Service during their sessions with parents and professionals and during Child Safety Week and National water safety campaigns.

Perinatal / neonatal

- Accessing antenatal care early is recognised as having a positive impact in terms of health and social care outcomes for both mother and baby, and late booking has been identified in some neonatal and infant death reviews.
- The Specialist Midwife for Diabetes in pregnancy and local Consultant Obstetrician and Gynaecologist attended a CDOP meeting to deliver a presentation on local work to support and enable women with diabetes to have a healthier pregnancy, as the presence of maternal diabetes had been noted in a number of neonatal and infant death reviews in previous years. The CDOP chair wrote a letter of support to the hospitals trust, maternity lead and the LMS to acknowledge support for continuation of role on a longer term basis.
- NICU have introduced a new pathway for earlier parallel planning for palliative care to allow families to spend more time with their babies. The local bereavement checklist has been refreshed to build in these arrangements.
- A case highlighted the importance of connections between adult services and maternity and also the benefit of multi-agency Child Death Review Meetings, for all professionals to learn from parental and environmental factors on pregnancy and infant care. There was also increased awareness of adult/child agency crossover issues for parents with learning difficulties and the importance of maternity and pre-birth pathway considering adult safeguarding/mental capacity assessments and parent advocates. Adult Safeguarding workers are to be invited to Child Death Review Meetings in future where they are involved with the parents.

- Reviews highlighted the financial, emotional, and physical burden on families with infants in hospital for a long time, including those in hospital out of area. There are pathways for referring to the local authority if a child is in hospital for three months and over, to ensure that the child's welfare is "adequately safeguarded and promoted" early enough (Section 85 of the Children Act 1989). Hull hospital is a tertiary centre for neonates so the support pathway will apply to families out of our area too. A new paediatric unit opened in January 2023 and includes facilities for parents to stay with their children; the unit also includes accommodation for parents with children in the Neonatal Intensive Care Unit (NICU). These facilities will help reduce some of the practical and financial burden on local and out of area families.
- Children receiving care in Leeds hospitals refer children to a nearby provider for hospice care but this is not always convenient for our local families. CDOP reviewed a number of deaths of children who might have benefitted from a local provision. The local Designated Doctor is involved in a workstream to review end of life and palliative care for children.
- Families of Hull children who die in Leeds are referred to their children's bereavement specialists, which due to distance may not be the most convenient for families. The CDR Co-ordinator has prepared a list of local and national support contacts and organisations for Leeds clinicians (in cardiac, oncology and PICU) to have as an option to refer/ signpost Hull families to.
- The need to offer support to breastfeeding mothers following the death of their infant
 was identified in a review. The infant feeding lead has reminded colleagues in maternity
 and bereavement teams about available support in this situation. There is work within
 maternity and neonatal team to develop guidelines for consistency. The local policy will
 be shared with doctors, nurses and midwives throughout the hospital so that any
 professional can have a conversation with a bereaved mother about support for
 suppressing lactation.

Sudden and unexpected deaths:

- A need for a pathway around S47 decision making within the context of a child death was identified last year and work has now commenced on enhancing partners' understanding of the communication pathway of child death notifications and reviews. A flowchart was produced to help understand the interactions and information share needed with professionals/agencies, particularly where there are/may be safeguarding concerns and to ensure the learning and actions from any internal reviews are communicated to contribute to the CDOP review.
- Joint Agency Response meetings now also include consideration of:
 - Communication plan for keyworker (when in place), including feedback to parents after a meeting
 - Follow-up for parents by hospital consultants
 - Most appropriate means of providing contacts/details of support services to bereaved parents when they leave hospital (acknowledging a parent's experience of feeling too upset to open the memory box to obtain the list of support contacts)

- Medical research opportunities
- The 'What 3 words' grid reference app is used by Yorkshire Ambulance Service to quickly and accurately locate people in emergency situations and it has helped them in a number of cases reviewed by Hull CDOP. Hull CDOP is joining other CDOPs in the Humber and Yorkshire region to promote its use with professionals and the public.

Medical deaths:

- Feedback from a parent reminded us of the importance of sensitivity and compassion when collecting loaned specialist equipment and aids from families home after a child has died. Processes within provider organisations were checked and their reassurances were received.
- Links with LeDeR colleagues process have been maintained to ensure that their expertise feeds into child death reviews now that a separate LeDeR review is no longer held.
- Following an internal hospital review, orthopaedic follow ups will now include a consultant review of diagnosis.
- A CDRM meeting highlighted that the statutory data collection form for asthma related deaths asks questions about allergies and blood tests. CDOP learned that quality improvement work through the ICS has introduced a new proforma on the child's history and management of symptoms, and it considers allergies, which might lead to requiring a blood test.
- Designated Paediatrician is pursuing links with ICS asthma group to explore some suggestions for change, including a suggestion to develop a discharge letter containing:
 - o Advice that children with bronchial wheezes should have access to a blue inhaler.
 - \circ $\;$ Importance of complying with prescribed medication
 - Importance of families being familiar with a child's management plan even when they do not have symptoms
 - information to parents that wheezes can have a 7 year cycle so that they are mindful if their child's condition worsens and of the need to seek medical attention / reassessment
 - expectations of parents in bringing their children to clinic appointments, reasons why they are important, describe what they entail e.g holistic nature of respiratory conditions
- Hull has recruited a paediatric cardiac nurse which will be a helpful resource for children, their families and professionals working with a child.
- Dieticians in Hull and Leeds are to discuss linking up with the community health visitors to allow them to understand the clinical/logistical issues while a patient is unwell in hospital to ensure they are providing appropriate support based on all the information available.

Additional Learning:

- Some parents had advised that as well as verbal information, they would welcome written information to read in their own time about the child death review process, so CDOP re-introduced their condolence letter to parents, accompanied by the national leaflet after it was paused in favour of personal conversations with parents.
- Two reviews identified issues with insufficient information shared with the hospital in ambulance pre-alert before arrival; this has been identified through other routes, and work is underway to address.
- The local Joint Agency Response meetings ensure that following a death, vulnerable family members and peers are identified so that relevant agencies can urgently offer any crisis support.

<u>Keyworker</u>

There were a number of cases where families felt unsupported and not been kept informed about processes and information during ongoing enquiries into their child's death and this was a cause of stress for families. This highlights the lack of a local keyworker as a single point of contact and advocate for families involved in the child death review process and has been acknowledged by the Child Death Review Executive group.

Good Practice and Commendations

CDOP regularly hear about good practice and effective agency involvement with a child and family prior and after a child's death and we are very appreciative of hearing from families about their experiences. Below are some examples where CDOP members have acknowledged and thanked professionals/teams:

- CDOP members were impressed with the supportive response from schools and education provision to help poorly children continue their education; and to parents, siblings and the school community after a child has died, through assemblies and memory making projects.
- reviews highlighted effective working between housing and the children's disability team to provide appropriate support with housing adaptations and equipment to suit the children's disabilities and medical needs.
- evidence of effective parallel planning and engagement with palliative care, for example staff staying away from their own families during Covid to provide 24-hour care when needed



CDOP E-BULLETIN

Members continue to disseminate a locally produced e-bulletin within their respective agencies to share news and advice on learning from child deaths, recommendations from Coroners' inquests, as well as national guidance, research, publications and news from organisations working to prevent child deaths and accidents.

TRAINING

No Joint Agency Response training took place during 2022/23; the Designated Paediatrician for child death has undertaken single agency training with police officers and hospital doctors. There are ongoing discussions to reinstate multi-agency face to face training.

Since 2008, 663 professionals (across Hull and East Riding area), predominantly from health, police and children's social care, have attended training in responding to the unexpected death of a child which helps contribute to ensuring that each unexpected child death is investigated in a thorough and systematic way that is sensitive to and supportive of parents, carers and professionals.

PROGRESS AGAINST LAST YEAR'S RECOMMENDATIONS

In the 2021/22 CDOP annual report we made the following recommendations for action this year. These are set out below along with the progress made.

The main focus for 2021-22 is to overcome the backlog of reviews that developed during COVID-19 due to reduced system capacity, so that cases are being reviewed within expected timeframes (where this is within the CDOP's control).

Progress to reduce the number of cases awaiting a child death review and a CDOP review has not been made during 2022-23 due to the limited capacity available to prepare for and hold the meetings. The CRD Operational and Executive Groups have been fully sighted on the issues and have been in discussion about a workforce paper exploring the possibility of additional resource in a Key Worker role.

To undertake a more detailed review on Sudden and Unexpected Infant Deaths for the next annual report.

This piece of work has been postponed due to capacity challenges.

RECOMMENDATIONS FOR 2023/24

Our recommendation for 2023-24 is that the primary focus for CDOP should remain reducing the number of cases waiting for review, whilst seeking to ensure that a quality discussion continues to take place for every child.

The Child Death Review Operational Group will oversee and provide assurance for the outcomes and recommendations set out in the CDOP annual report. Any matters requiring escalation will be considered by the Child Death Review Executive Group.

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Below is a brief description of the professionals' meetings required within the child death review process:

- Joint Agency Response meetings (JARs) are a co-ordinated multi-agency response which is triggered if a child's death:
- is or could be due to external causes;
- is sudden and there is no immediately apparent cause (incl. Sudden and unexpected Death in Infancy/Childhood (SUDI/C);
- occurs in custody, or where the child was detained under the Mental Health Act;
- where the initial circumstances raise any suspicions that the death may not have been natural; or
- in the case of a stillbirth where no healthcare professional was in attendance

A JAR should also be triggered if children are brought to hospital near death, are successfully resuscitated, but are expected to die in the following days.

The "Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation (2016)" gives comprehensive advice and expectations of all agencies involved in a Joint Agency Response.

A JAR meeting is held within 72 hours of a child's death; it is an initial information-sharing and planning meeting to consider outstanding investigations, notification of agencies, arrangements for the post mortem examination, plans for a visit to the home or scene of collapse and consider if abuse or neglect is known or suspected (in which case, it may meet the criteria for a child safeguarding practice review). JAR meetings will be attended by professionals involved with the child prior to, at the time of death, and with the family immediately after the death.

Child Death Review Meeting (CDRM) - For every child death, agencies / professionals known to the child/family will be asked for Agency Reporting Forms to record their involvement, including medical information and support to the family; for contributing to a multi-agency meeting of professionals where all matters relating to an individual child are discussed by the professionals directly involved in the care of that child during life and those involved in the investigation and family support after death.

The CDRM focuses on local learning with the aim of:

- reviewing the background history, treatment, and outcomes of investigations, to determine, as far as is possible, the likely cause of death;
- ascertaining contributory and modifiable factors across domains specific to the child, the social and physical environment, and service delivery;

- describing any learning arising from the death and, where appropriate, to identify any
 actions that should be taken by any of the organisations involved to improve the
 safety or welfare of children or the child death review process;
- reviewing the support provided to the family and to ensure that the family are provided with:
 - the outcomes of any investigation into their child's death;
 - a plain English explanation of why their child died (accepting that sometimes this is not possible even after investigations have been undertaken) and any learning from the review meeting;
- ensuring that CDOP and, where appropriate, the coroner is informed of the outcomes of any investigation into the child's death; and
- reviewing the support provided to staff involved in the care of the child.

National guidance states that this should take place within three months following the death or receipt of post mortem report /conclusion of police and other investigations, but prior to an Inquest (if applicable). Locally, our timescales have exceeded three months due to a back log in cases created during the pandemic, the capacity of clinicians to contribute to review reports and meetings and administrative support to organise multi-agency reviews for all deaths. Grouping some cases of similar causes has alleviated some resource issues and has brought about rich learning.

All child death notifications and reports are recorded and reported on via a secure web-based software called e-CDOP, which allows the local child death review process to be managed efficiently, with confidential sharing of multi-agency information. e-CDOP is fully compliant to the data processing GDPR standards outlined by the ICO and with Working Together guidance. E-CDOP feeds into the National Child Mortality Database.