Hull Child Death

OVERVIEW PANEL

Annual report 2023/24

Hull City Council

NHS Humber and North Yorkshire Integrated Care Board (ICB)

Hull Health and Care Partnership
Creating a healthier Hull

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1. CHAIR'S FOREWORD

In her book about the loss of her baby son, *Ask me his name,* Elle Wright says, "this wasn't how it was supposed to be". It's beautifully understated, but sums up the overwhelming sense of 'wrongness' of losing a child. Our hearts go out to the families and loved ones of the children in this report.

Our child death overview panel reviews are the last in a series of meetings, reviews, reports and analyses that take place when a Hull baby or child has died. Our job, for each child, is to learn about and understand what happened and then to consider how others locally and nationally can use the learning to make future deaths less likely.

We take great care every year writing this report to try and get the right balance between sharing the learning from each individual review, and the synthesis of our findings over the year (and in recent years) so that we can see the big picture around child deaths in Hull too. As in previous years, the report tells us that the families who already have the most challenges are the most likely to lose a child. In particular, we have been concerned about over-representation of migrant families in our child death reviews and the multiple barriers that need to be addressed to change this.

Please do use this report to inspire changes – however small – that might save lives in the future, and get in touch if you would like more information or to discuss any of the learning.

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.

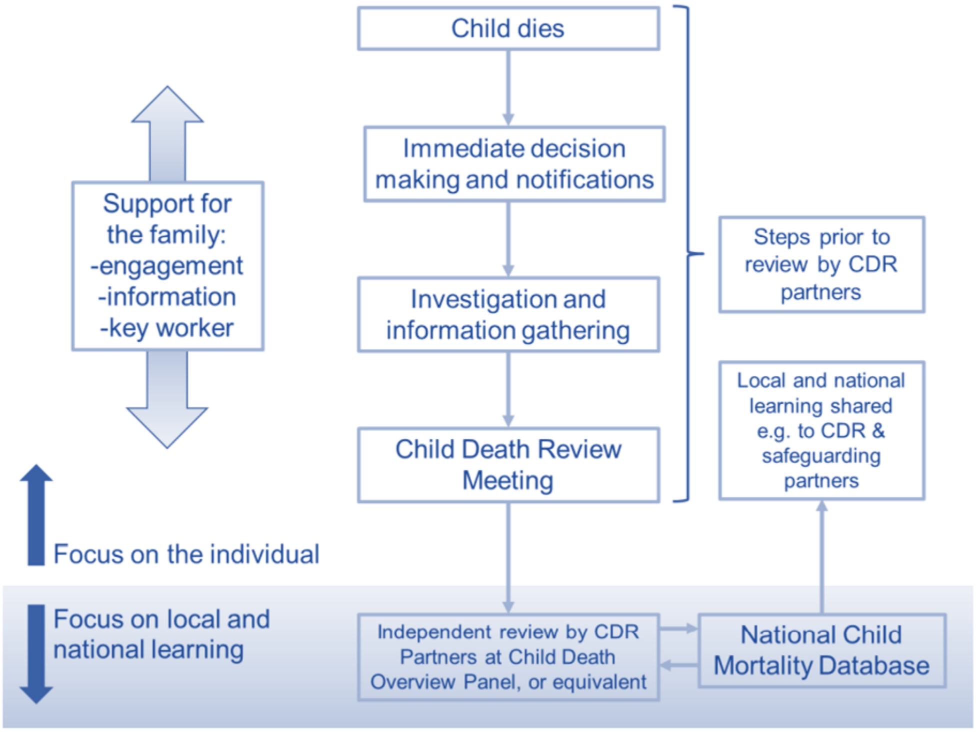
The publication of the Child Death Review Statutory and Operational Guidance in 2018 builds on the requirements set out in Chapter 5 of Working Together to Safeguard Children 2018 (updated in 2023) and details how individual professionals and organisations across all sectors involved in the Child Death 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 Executive Group to ensure our arrangements comply with statutory guidance and are working effectively. The group meet regularly to progress a local delivery plan. The Child Death Review Executive Group also provides a 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:

- [1]Perinatal Mortality Review Tool (for infants under 28 days or older who died on Neonatal Intensive Care (NICU)
- [2]Patient Safety Incident Response Framework (PSIRF)
- [3]Post Mortem examination
- [4]Inquest
- [5]Coroner's Regulation 28 report to prevent future deaths
- Police criminal investigation
- Road Traffic Collision investigation

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[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] The Patient Safety Incident Response Framework (PSIRF) sets out the NHS's approach to developing and maintaining effective systems and processes for responding to patient safety incidents for the purpose of learning and improving patient safety.

[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.

- [6]Learning Disabilities Mortality Review (LeDeR) - to avoid duplication, as of 1st July 2023, there is no longer 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.
- [7]Child Safeguarding Practice Review (CSPR) undertaken by Local Safeguarding Children Partnerships when a child dies (including death by suspected suicide) or is seriously harmed, and abuse or neglect is known or suspected
- [8]National 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.

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[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.

[7] The prime purpose of a CSPR 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. 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, Child Death Review partners have learned from the following NCMD themed reports and research paper using child death overview panel data:

Infection related deaths of children and young people in England and Personal stories and case studies – December 2023 – this thematic report aims to identify common characteristics of children and young people who died with and because of an infection, investigate factors associated with these deaths and identify common themes, to help inform policymakers, commissioners, those providing services to children and young people, and those involved in reviewing deaths of children and young people.

Vulnerability in infants: a study of sudden and unexplained deaths – September 2023 – this report aims to describe and evaluate the factors which may increase the vulnerability of infants to this kind of death, examining pre-existing risk factors in the child, their family or their social or physical environment, which make them more vulnerable than average to poor outcomes or harm.

Deaths of children and young people due to traumatic incidents – July 2023 – this thematic report focuses on traumatic injuries, which can occur as a result of vehicle collisions, drowning, violence or maltreatment and a number of other events. It aims to identify common characteristics of children and young people who die as a result of physical trauma, investigate factors associated with these deaths and identify common themes to help inform policymakers, commissioners, those providing services to children and young people, and those involved in reviewing deaths of children and young people.

4. CHILD DEATH OVERVIEW PANEL (CDOP)

The Child Death Overview Panel is a multi-agency panel with differing areas of professional expertise. Core membership of Hull's CDOP can be found on page 8. 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. This timescale is rarely met, and there are a number of cases awaiting review . CDOP meets monthly but limiting factors include capacity to prepare cases for review and the number of cases that can be discussed in any one meeting. During 2023/24, Hull CDOP met ten times and reviewed 23 child deaths.

These deaths occurred in the following years:

2016/17	2019/20	2020/21	2021/22	2022/23	2023/24
1	1	6	5	8	2

At the year-end, Hull CDOP had reviewed 94% of child death notifications received since the process commenced on 1st April 2008. Going into 2024/25 there were 22 child deaths pending review, at various stages of the process:

- Three deaths were undergoing parallel processes and pending conclusion of enquiries and investigations
- 17 deaths were waiting for child death review meetings to be organised; 7 deaths were within the timeframe of three months from notification/conclusion of parallel process and 10 were outside of this timeframe. 2 child death review meetings were completed and pending CDOP review.
- Fifteen child death review meetings had taken place during the year.

During 2023/24, we had hoped to increase the number of reviews taken to CDOP meetings and reduce delays. We have made some progress, but not as much as we had hoped.

The CDR Executive Group has continued to maintain oversight of the scheduling of CDRMs during 2023-24. 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 2024-25.

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)
Designated Doctor, Safeguarding Children and Young People	Hull University Teaching Hospitals Trust
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

6. HULL CHILD DEATH OVERVIEW PANEL DATA ANALYSIS

This section of the report outlines Hull child deaths that were notified (deaths that occurred during 2023/24) and those reviewed by our local Panel between 1st April 2023 and 31st March 2024. 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.

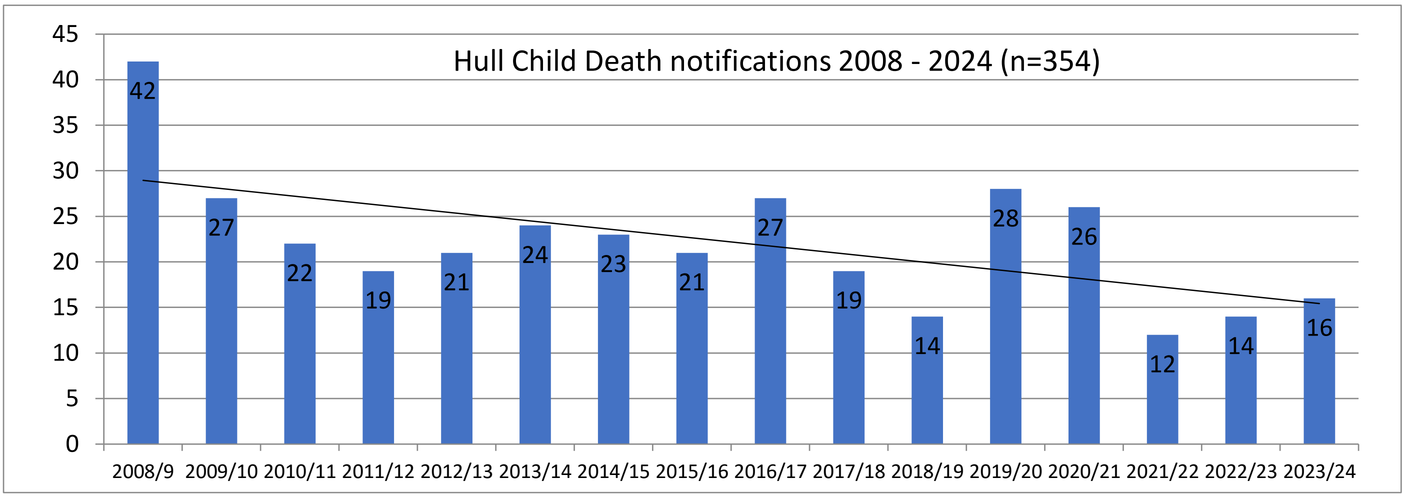
NOTIFICATIONS

The deaths of 16 children from Hull were notified in 2023/24. This is similar to the number of children in the previous two years but significantly less than in 2019/20 and 2020/21 and less than half when records began in 2008 (see chart 1). The 5-year average is 19 child deaths per year in Hull.

Six deaths were unexplained and/or unexpected so met the criteria for a multi-agency professionals' Joint Agency Response meeting.

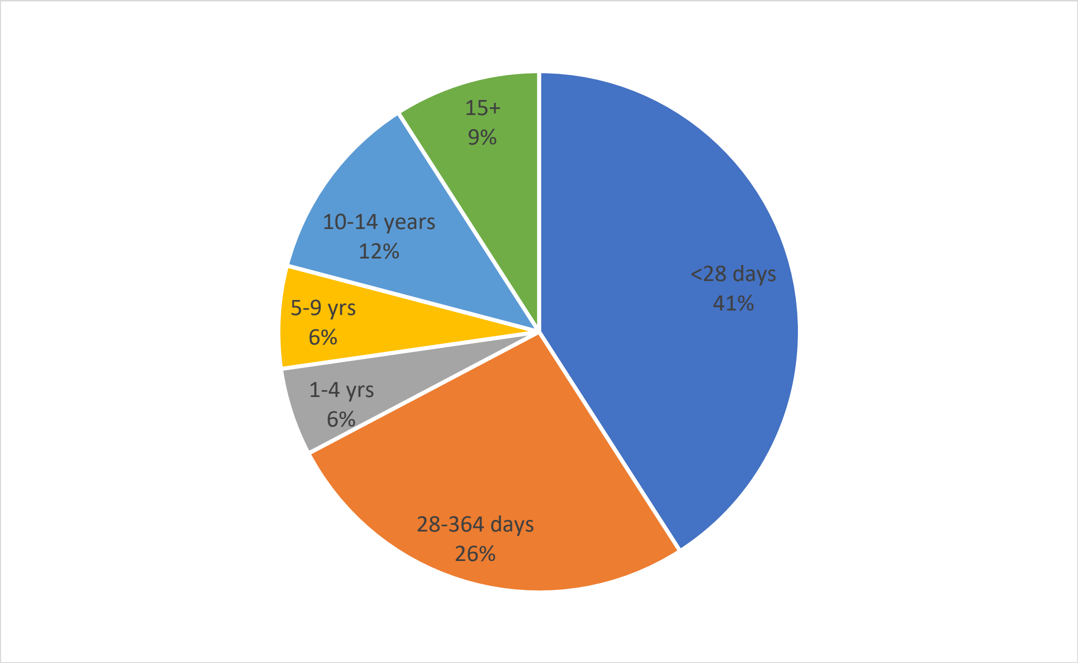
Two of the 16 deaths had their reviews completed at CDOP during the year, the remainder will be reviewed during 2024/25 where possible, subject to completion of parallel processes.

Chart 1 – Hull child death notifications 2008 - 2024



There were 16 notifications of child deaths among those aged 0-17 years in Hull during 2023/24. This gives a rate of 26.6 deaths per 100,000 population. Information for 2023/24 is published for England in autumn 2024, so is not yet available, and comparisons have been made with England data for 2022/23. For 2022/23, the England mortality rate was 31.8 deaths per 100,000, and whilst the mortality rate is lower in Hull it is not statistically significantly different (ie, the difference could be due to chance).

Chart 2 - Age Range of child death notifications 2018-24 (n=110)



The data in Chart 2 summarises age at time of death over the past six years. A child is most at risk of death when under the age of one.

During 2023/24, the proportion of ages of child deaths notified were:

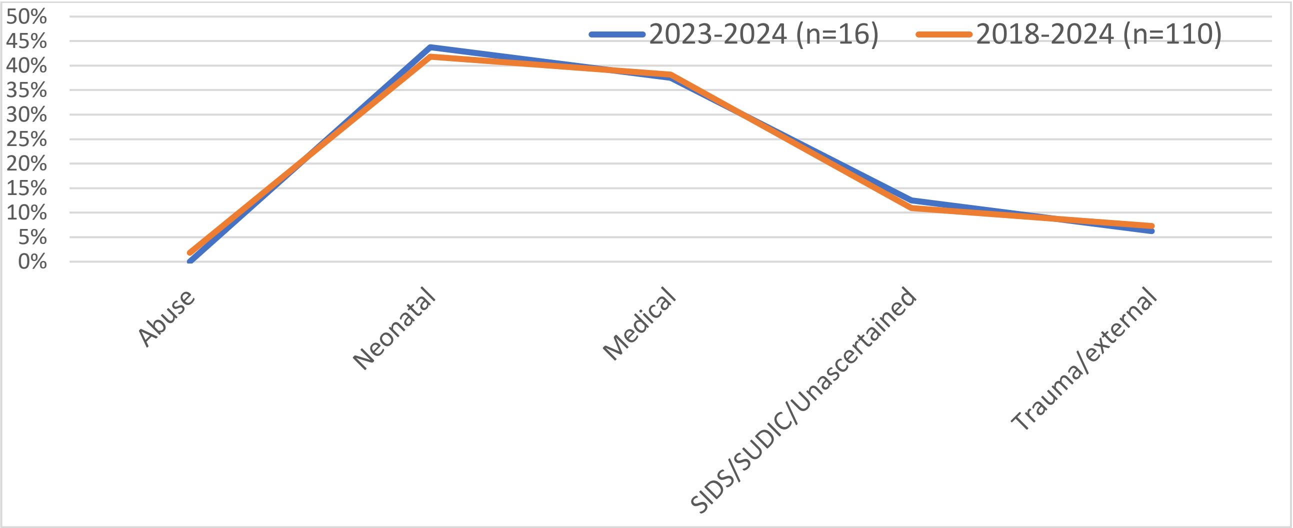
- Infants under the age of 28 days - 38%
- 28-364 days - 38%
- 1-4 years - 6%
- 5-9 years - 6%
- 10-14 years - 6%
- 15-17 years - 6%

Categories of death

The type of deaths are summarised into five categories at the time of death, and these are further refined at CDOP into one of 10 categories defined in the statutory guidance.

The proportion of our child deaths within these broad categories fluctuates year on year, but the proportional trend for 2023/24 is similar to the type of deaths notified over a six-year period.

Chart 4: Category of death at notification



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.

Six of the 16 child death notifications in 2023/24 were classified as unexpected. Over the past six years there have been 110 child death notifications and 44% of these were regarded as unexpected.

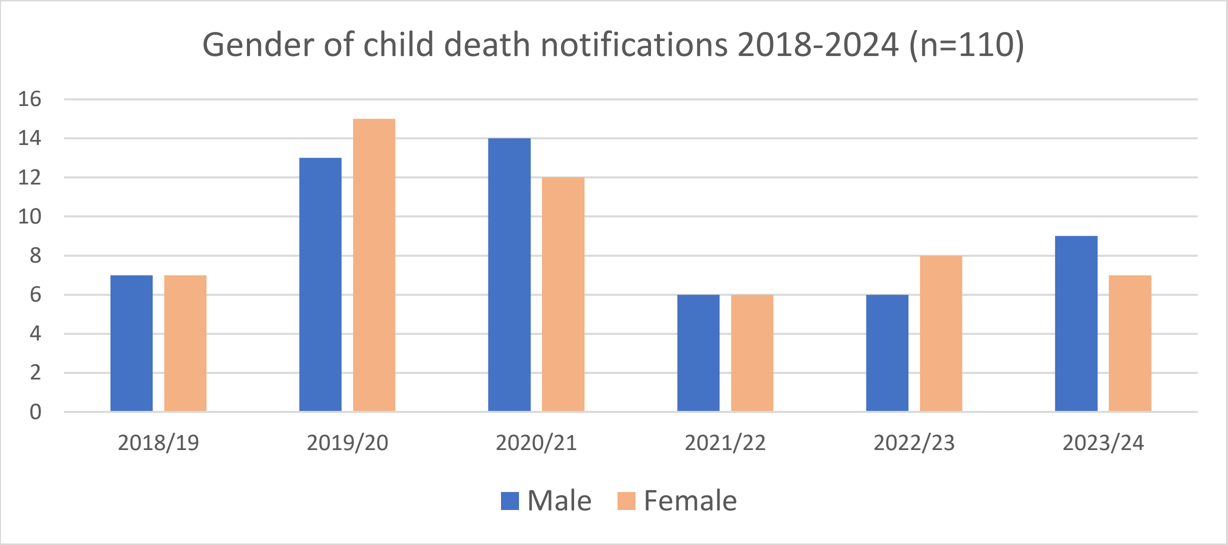
Location of death

Of the 16 deaths notified to Hull CDOP in 2023/24, most occurred in hospital, and a small number at home or in public places.

Infant and child deaths by gender

During 2023/24 there were slightly more male child deaths than female, this was the opposite to the previous year. Nationally, child mortality for males is higher than females but in Hull there have been similar mortality rates for males and females. The mortality rate among females in Hull was similar to England, and whilst the mortality rate in Hull among males was lower than England, it was not statistically significantly lower.

Chart 5 – Gender of Hull child death notifications 2018-2024



Ethnicity

Of the 16 children whose deaths were notified to Hull CDOP in 2023/24, 62.5% were recorded as White British ethnicity and 37.5% were from a range of other ethnic backgrounds. The average over the last six years has been 68% White British and 32% from other ethnic backgrounds (12% children were White-other and 20% were Mixed, Black or Black British, Asian or Asian British). 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 2023 school census, 17.9% of children and young people were not of White British ethnic heritage, the breakdown of ethnicity is as follows (%):

White British	82.1
Irish	0.1
Gypsy/Roma	0.2
Any other White background	7.9
Mixed	3.2
Asian or British Asian	1.7
Black or Black British	1.6
Any other ethnic group	2.3
Unclassified	1.0

Compared to white British children, mortality rates in Hull were twice as high for children in the White Other category, almost three times as high for Black or Black British children and seven times as high for Asian or Asian British children for deaths notified in 2023/24. One years' data is not enough to be confident statistically that these differences haven't occurred by chance. However, the stark difference is mirrored in other indicators of inequality.

Over the last six years, 6 of the 13 children from the ‘White-other’ category, were recorded as being Roma, Romanian or both. Whilst we recognise that Roma and Romanian heritage are not the same, this is still a far greater number of deaths than would be expected and required further exploration and action.

Nationally, mortality rates were higher for children who are Asian or Asian British, Black or Black British or from other minority ethnic groups relative to children who are white British.

Children with learning disabilities

There were no deaths of children with learning disabilities notified in Hull in 2023/24.

Health inequalities

Although the numbers of deaths in a year in Hull mean that it’s difficult to know for sure whether patterns occur by chance, we know that nationally, there is a strong association between living in a deprived area and child death. Nationally, children living in the most deprived tenth of areas of England have a mortality rate of 13.6 deaths per 100,000 population compared to a rate of 8.5 deaths per 100,000 for children living in the least deprived tenth of areas of England.

All six Hull neonatal deaths in 2023/24 were from families living in areas classified as the most deprived fifth of areas of England (though it’s worth noting that more than half of Hull’s population lives in areas that fall into the most deprived fifth nationally).

Overall, Hull’s child mortality rate is not very different to the England rate.

CHILD DEATH REVIEWS

Categories of child deaths reviewed and deprivation

Between April 2023 and March 2024 Hull Child Death Overview Panel (CDOP) reviewed 23 child deaths. The total number of reviews has varied each year from 10 to 24 with a total of 103 reviews over the last six years.

The review of deaths during the CDOP meeting require members to categorise each child death using a pre-determined list, which are recorded locally and reported to the National Child Mortality Database for national analysis (NCMD). These numbers of deaths falling into each category vary year on year, and there is no clear pattern.

Eighteen of the 23 reviews were for children living in the most deprived fifth of areas of England, two for the second most deprived fifth and three for the middle fifth of areas of England.

Reviews undertaken between 2018/19 and 2023/24 for each ward was small but all 21 wards in Hull had at least one child death reviewed over the six-year period. Due to the small numbers, none of the wards were statistically significantly different compared to the Hull average. St Andrew's & Docklands and West Carr wards had the highest child death review rate.

Of the 103 child deaths that have been reviewed by the Hull Child Death Overview Panel over the past six years, the main categories are:

Perinatal/neonatal event = 33%

Sudden unexpected or unexplained death = 12%

Chromosomal, genetic and congenital abnormalities = 25%

National comparison

Over the six-year period 2018-19 to 2023-24, the two categories of deaths with the highest number of reviews were similar for Hull and England; Perinatal/Neonatal and Congenital/Genetic, and this is also the same for Hull this year. For the six-year period, Perinatal/neonatal events was the highest (33%) followed by Chromosomal/Genetic/Congenital conditions (25%); the third highest for Hull was Sudden Unexpected or Unexplained death at 12%, whereas nationally it was Malignancy.

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

- Suicide or deliberate self-inflicted harm
- Malignancy,
- Acute medical or surgical condition
- Chronic medical condition
- Perinatal/neonatal event.

Compared with England over the last six years, Hull has had a higher proportion of reviews in categories:

- Deliberately inflicted injury, abuse or neglect
- Trauma and other external factors
- Chromosomal, genetic and congenital anomalies
- Infection
- Sudden unexpected or unexplained death

Some of these differences are very small. Also, reviews do not usually take place within the same year as the death, so it is difficult to accurately assess comparisons with national proportions.

Modifiable factors

During the review of each death, modifiable factors are identified and analysed to enable learning and preventative action at a population level. 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 and 2023). 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. 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 – it’s something that could help prevent future deaths.

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. Usually 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.

Twenty three child deaths were reviewed by Hull CDOP during 2023/24. Overall, 18 (78%) of the reviews undertaken in 2023/24 had at least one modifiable factor. This compares with 43% of reviews for England for 2023/24, although different CDOPs may record the presence or absence of modifiable factors differently. In Hull, 15 (65%) of the deaths had modifiable service or organisational issues identified in their reviews.

A small number had smoking in pregnancy and high maternal body mass index as modifiable factors. Six deaths had one modifiable factor, seven had two modifiable factors, two had three modifiable factors, one had four modifiable factors and one had five modifiable factors.

During the six-year period 2018/19 – 2023/24, 60% of child death reviews recorded modifiable factors. Service or organisational issues was the most common modifiable factor, identified in 31% of reviews, followed by smoking in pregnancy (24%), high maternal body mass index (11%), household smoking (10%) and unsafe sleeping (9%). There was no significant difference in the percentage of deaths with modifiable factors across genders, age, cause of death, ethnicity or deprivation.

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

7. CDOP Learning and Actions from Child Deaths Reviewed in 2023/24

As described above, one of the most important elements of the entire CDR process is learning. Hull CDR arrangements ensure any learning identified is fed back both locally, via the multi-agency representatives involved, and regionally and nationally, through E-CDOP to the National Child Mortality Database, at each stage of the CDR process.

The role of CDOP, as the culmination of the CDR process, is to seek to analyse learning from all child deaths to identify common themes, ways of working and strategies to minimise the risk of future deaths and inform continuous quality improvement. It is important to note that CDOP does not do this alone. There is a system of interconnected multi-agency review process that are designed to ensure that we come together to learn wherever a child dies. These include the Perinatal Mortality Review, Learning from lives and deaths – People with a learning disability and autistic people (LeDeR), The Patient Safety Incident Response Framework (PSIRF), Child Safeguarding Practice Reviews (CSPR), Healthcare Safety Investigation Branch (HSIB) reviews, amongst others. These all have different methodologies and approaches but share a commonality in that they are all focused on improving systems and processes wherever possible to ensure every family receives the best care in the future.

This chapter describes the summary of the learning that has been recorded by Hull CDOP during 2023/24.

Good Practice

Hull CDOP regularly hear about good practice and effective multi-agency working with a child and family prior to and after a child’s death and we are very grateful to hear from bereaved families’ and learn from their experiences. Where appropriate, specific feedback is shared with the teams and individuals involved.

General reflections on learning

Domestic Abuse features often in the lives of the children, young people and families reviewed by Hull CDOP. Whilst usually not directly linked to the cause of death, domestic abuse is notable for its frequency as being a significant factor in their life.

The **impact of health inequalities** continues to be evident, particularly in relation to deprivation, ethnicity and where English is an additional language. Hull CDOP has been working with other system partners such as the Local Maternity and Neonatal System to support awareness raising and work to develop appropriate and accessible information for specific population groups.

The benefits of **early access to antenatal care** continue to be raised in relation to learning.

Learning from local child death reviews continues to highlight the absence of the role of a **Keyworker** as a single point of contact and advocate for families involved in the child death review process. This has been acknowledged by the Child Death Review Executive Group and the issue is on their Risk Register with ongoing discussions with key system partners about how to progress the development of this role locally.

More specific learning

In response to some of the more specific learning Hull CDOP has:

- Worked with partners through the local Unintentional Injuries and Safer Sleep Service to re-promote the use of cycle helmets for children.
- Continued to work with regional partners to promote the use of the What3Words app to support accurate location of incidents.
- Strengthened links with local independent providers including independent schools, post 16 education provision, early years providers and independent health providers.
- Worked with a range of partners to ensure accurate and efficient information pathways are in place, particularly for key statutory decision makers, in the event of a child death notification needing to be shared.
- Worked with NCMD, Epilepsy Action and local Unintentional Injuries and Safer Sleep Service to review and refresh training in relation to safer sleep advice for parents/carers with epilepsy.

- Further developed the shared understanding across the partnership about some of the challenges in accessing services faced by families seeking asylum or who are new to the UK.
- Contributed to national learning in relation to the impact of the pandemic – specifically in relation to the need to ensure future planning for such global events, takes account of the holistic needs of children, young people and families needing to access end of life care in the context of national lockdowns.
- Through the regular Hull CDOP ebulletin, supported awareness raising of local, regional and national resources that are available including the Together for Short Lives charity 'Butterfly Fund' which provides parents with £300 when their child, with a life limiting condition, dies before their 19th birthday, and the regional Healthier Together website which provides parents, carers, pregnant women and birthing people, babies, children and young people with consistent and high-quality advice from local health professionals.
- Supported the development of a joint epilepsy and respiratory consultant led clinic to further enhance holistic care planning.
- Supported the development of a paediatric cardiac specialist nursing role with a specific focus on working with schools to support children, young people and their families when needed.
- Contributed to the ongoing review, refresh and development of clinical training sessions for medical staff and informed the purchase of specialist training equipment to support this.

National/Regional learning

In considering learning that has been described through local CDR processes, Hull CDOP has had the opportunity to consider learning themes that may be relevant to wider regional or national learning as described below.

- Accessing services outside of local area or typical/familiar care pathway, both in terms of impact for families (e.g. having to travel significant distances to access hospice care) and services in terms of information sharing outside of established/familiar local systems (e.g. with independent providers, or in an adult focused settings etc).
- Hull CDOP reflected on the potential benefits of the introduction of minimum standards for smoke alarms as are already in place in Scotland. Hull CDOP have liaised with the NCMD who are progressing discussions in relation to this with ROSPA National Home Safety Committee.
- Ongoing feedback and work with key agencies and system partners in relation to continuous review and improvement of systems, processes and design of infrastructure to optimise safety (e.g. high rise buildings, bridges, roads etc).
- Contributing to regional working group led by NHSE for review of specific clinical interventions (e.g. Coroner Regulation 28 re use of Keilands Forceps).
- Learning from Hull CDOP contributing to development of ICS wide Palliative and End of Life Care Strategy – with particular emphasis on the needs of older teenagers and their families.

8. PARENT AND CARER INVOLVEMENT IN CHILD DEATH REVIEWS

Although parents and carers do not attend review meetings, their knowledge of their child's life, illness, and their perspectives of care may enhance learning and ensure improvements to save children's lives and support services to children and families in the future.

Parents and carers are informed of the review process and invited to meet face to face with the Designated Paediatrician and CDOP Co-ordinator, to ask questions about their child's death and the child death review process and share their experiences of services and support; this will include any positive or negative comments they would like to express.

By listening to parents/carers and being their advocate, we can appreciate and reflect on their journey through the trauma of a child death. Families receive feedback on how CDOP will share the learning, as a legacy to their beloved child.

Within this year's reviews, parents are influencing:

- CDOP's continued drive to advocate for a keyworker for families to guide them through the child death review process, provide updates on aspects of the review, be an advocate in meetings and signpost to appropriate bereavement support;
- training to acknowledge that parents/carers know their child best so we should ensure they are listened to, to inform lines of enquiry and aid completeness of enquiries;
- enhanced support to families from the Coroner's office;
- further opportunities to consider support for parents/carers and their families;
- learning for more hospital staff about the child death review process;
- more compassionate considerations for parents/carers leaving hospital after their child has died;
- recognition of need for professionals to consider support needs for all significant family members;
- the accurate reflection/voice of parents and carers to be heard in various settings; and
- information gathered nationally in an effort to prevent future child deaths and improve support services to children and their families.

9. 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.

10. TRAINING

In-person Joint Agency Response training resumed in 2023/24, with 8 dates scheduled across Hull and East Riding of Yorkshire during calendar years 2023 and 2024. The Designated Paediatrician for child death has also undertaken some single agency training with police officers and hospital doctors.

At 31/3/24, 736 professionals (across Hull and East Riding area), predominantly from health, police and children's social care, had 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.

11. PROGRESS AGAINST LAST YEAR'S RECOMMENDATIONS

In the 2022/23 CDOP annual report we made the following recommendations for action this year:

> *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.*

Some progress has been made to reduce the number of cases awaiting a child death review and a CDOP review; at the end of last year there were 29 reviews pending and this year there are 22 reviews awaiting a Child Death Review Meeting and/or CDOP final review. In 2023/24 there were 16 notifications, 15 Child Death Review Meetings and 23 reviews were finalised at CDOP.

12. PRIORITIES FOR 2024/25

- 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.
- Work with other local CDOPs to develop joint analysis of data, wider sharing of learning, and processes for sharing review outcomes where a child has died outside of their home area.
- Develop a process for ‘real time’ CDOP consideration of child death notifications to ensure timely identification of changes to patterns or new and emerging concerns.
- Use the forthcoming Association of Child Death Review Professionals quality standards for Child Death Review, including CDOP, to undertake a self assessment across the child death review system, and identify areas for quality improvement.

The Child Death Review Executive Group will oversee and provide assurance for the outcomes and priorities set out in the CDOP annual report.

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APPENDIX 1 – Child death review professionals' meetings

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.