NCMD
National Child Mortality Database

Knowledge, understanding and learning to improve young lives

Understanding consanguinity-related child deaths

National Child Mortality Database Programme Thematic Report

Data from April 2019 to March 2023

Published February 2026

HQIP

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Information on data tables, methodology, limitations, and references, is available in the Supporting Material.

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Contents

Introduction

The terms 'child' or 'children or young people' are used interchangeably in this report to represent all children aged 0–17 years inclusive. The term 'infant' refers to children aged under 1 year.

The terms 'close relative marriage' and 'consanguineous' are used in this report to describe parents who are blood related (i.e. share a recent common ancestor) to each other.

This report explores consanguinity-related deaths, describing the characteristics of the children who have died, and presents an analysis of the themes and learning that are recorded in completed reviews by the Child Death Overview Panels (CDOPs). Our report summarises data from child death reviews in England of children who died in the period between 1 April 2019 and 31 March 2023 and were recorded on the National Child Mortality Database (NCMD). The period was restricted to ensure that most (95%) of the deaths that occurred in the period had been reviewed by CDOP. Stillbirths or lawful terminations of pregnancy are not included, as they are not subject to the child death review process. Further information on the methodology, including how consanguinity was identified within the record, and on the limitations of the analysis, is available in the Supporting Material.

Close relative marriages are a risk factor for children being born with genetic disorders[1], amongst others such as advanced maternal age.

The Born in Bradford study has highlighted evidence of increased risk of mortality, morbidity and intellectual and developmental disability for children whose parents are first cousins[2]. Even when there is no family history of genetic conditions, consanguineous parents have an increased risk of having a child with a genetic disorder. Once a consanguineous family has a child with a genetic disorder, the risk of having any further children similarly affected is increased[1,3].

Consanguineous families are often part of communities that face multiple challenges that contribute to poorer outcomes, including stigma, socio-economic deprivation and inequitable access to services[2,4].

Every child who dies is a precious individual and their death represents a devastating loss for parents, siblings, grandparents, carers, guardians, extended family, and friends. With all child deaths there is a strong need to understand what happened and why. We must ensure that anything that can be learned to improve services and support families at increased risk is identified and acted upon.

1 Sheridan et al. (2013)
2 Small et al. (2024)
3 Teeuw et al. (2014)
4 Salway et al. (2016)

1. Characteristics of deaths of children born to consanguineous parents

This section reports the number and characteristics of children born to consanguineous parents who died between 1 April 2019 and 31 March 2023 in the context of all child deaths in this period. Further data on demographics is available in the data tables in the Supporting Material.

Of all child deaths (n=13045), 7% (n=926) were children who died due to any cause and who were born to consanguineous parents. This proportion was fairly consistent across the time period: 8% in 2019-20, and 7% in the latest year (2022-23).

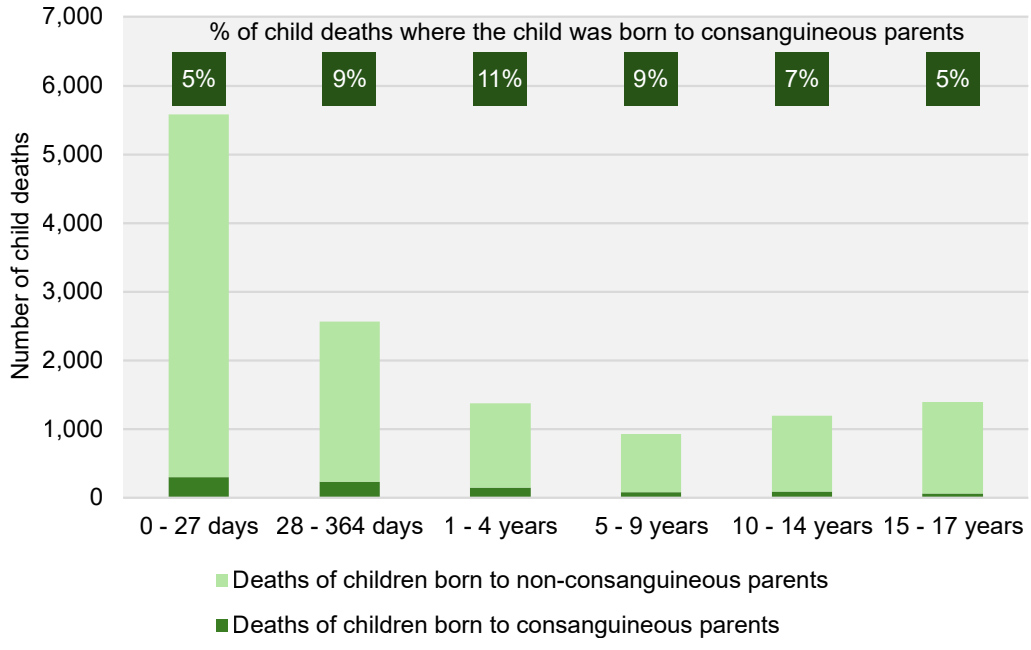
It is important to note that this proportion reflects the number of deaths in which this characteristic was present, regardless of whether it was considered unlikely to have contributed to the death or may have contributed to the death. An analysis of deaths due to chromosomal, genetic and congenital anomalies is presented in Sections 2 and 3.

Age

Of all child deaths, the proportion of these where the child was born to consanguineous parents was highest for children who were aged 1-4 years (11%) and the lowest in those aged 0 – 27 days (5%) and 15-17 years (5%) (Figure 1).

The highest number of deaths of children born to consanguineous parents was in the neonatal (0–27 days) age group (n=303), followed by those aged 28–364 days (n=235).

Figure 1: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous or non-consanguineous parents, by age at death



Deprivation

Overall, there were higher numbers of deaths of children in the most deprived neighbourhoods in comparison to the least deprived neighbourhoods. This was the case for children born to consanguineous and non-consanguineous parents.

There was a higher proportion of child deaths where the child was born to consanguineous parents in the most deprived neighbourhoods (11%, n=476/4467) than in the least deprived neighbourhoods (3%, n=43/1481) (Figure 2).

In addition, for children who died who were born to consanguineous parents, 52% (n=476/919) were resident in the most deprived neighbourhoods, compared to 5% (n=43/919) in the least deprived neighbourhoods.

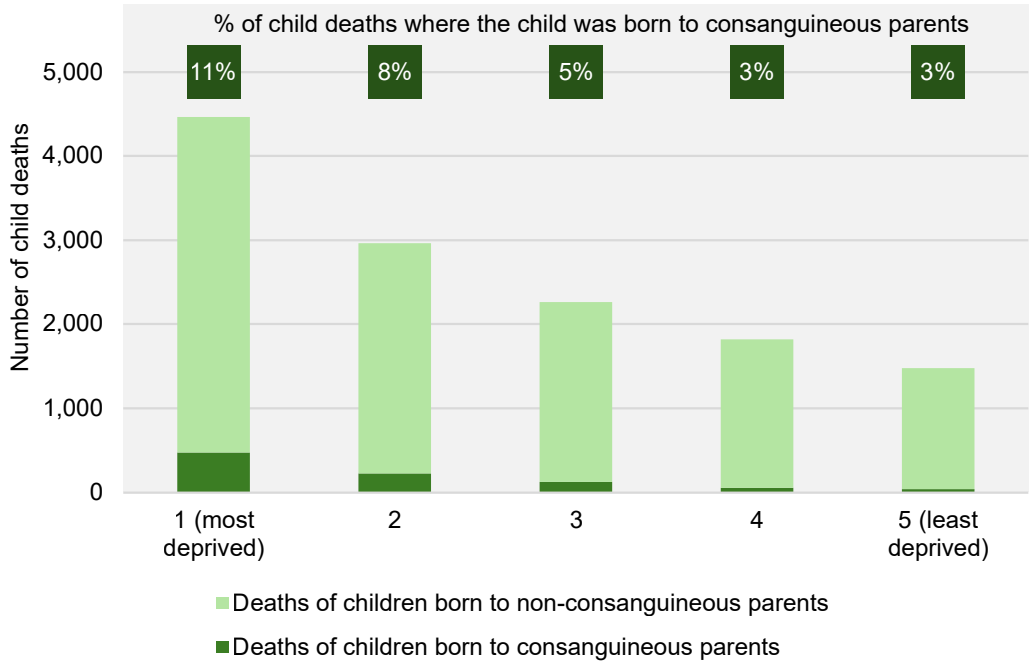
This may reflect the socio-economic disadvantage of mothers in consanguineous relationships as reported elsewhere[1,5].

Previous research has found that consanguinity remained a major risk factor for congenital anomaly, even after adjustment for deprivation, suggesting consanguinity is a risk factor independent of deprivation[1].

Region

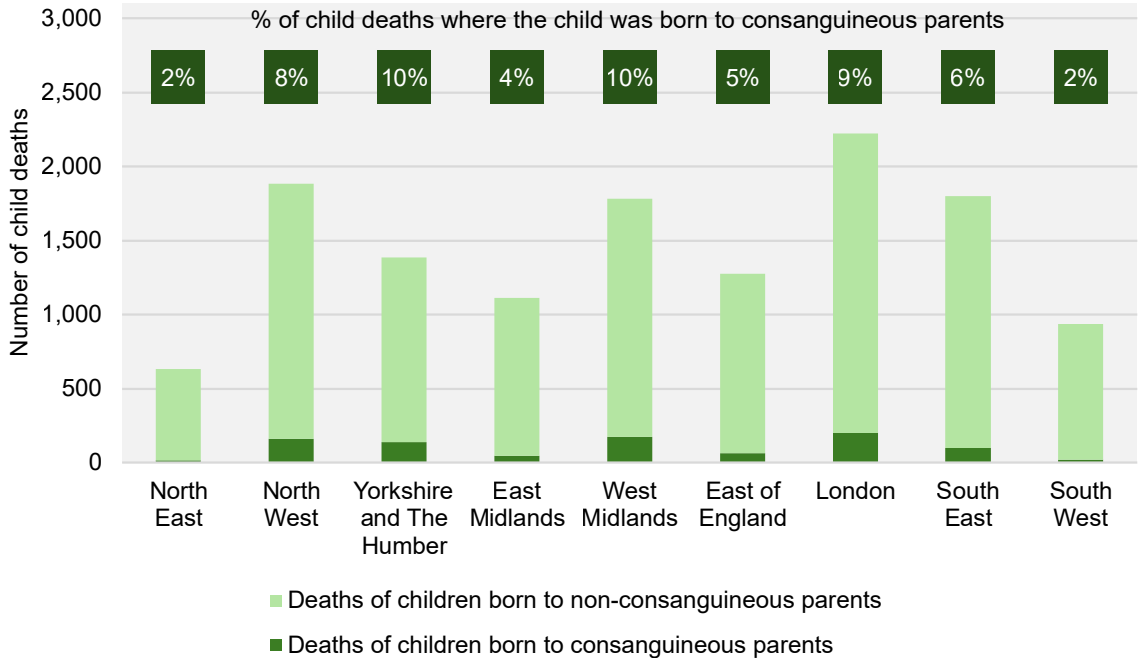
The proportion of child deaths where the child was born to consanguineous parents ranged from 10% (in Yorkshire and The Humber, and West Midlands regions) to 2% (in North East and South West regions) (Figure 3).

Figure 2: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous or non-consanguineous parents, by social deprivation



5 Bhopal et al. (2014)

Figure 3: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous or non-consanguineous parents, by region

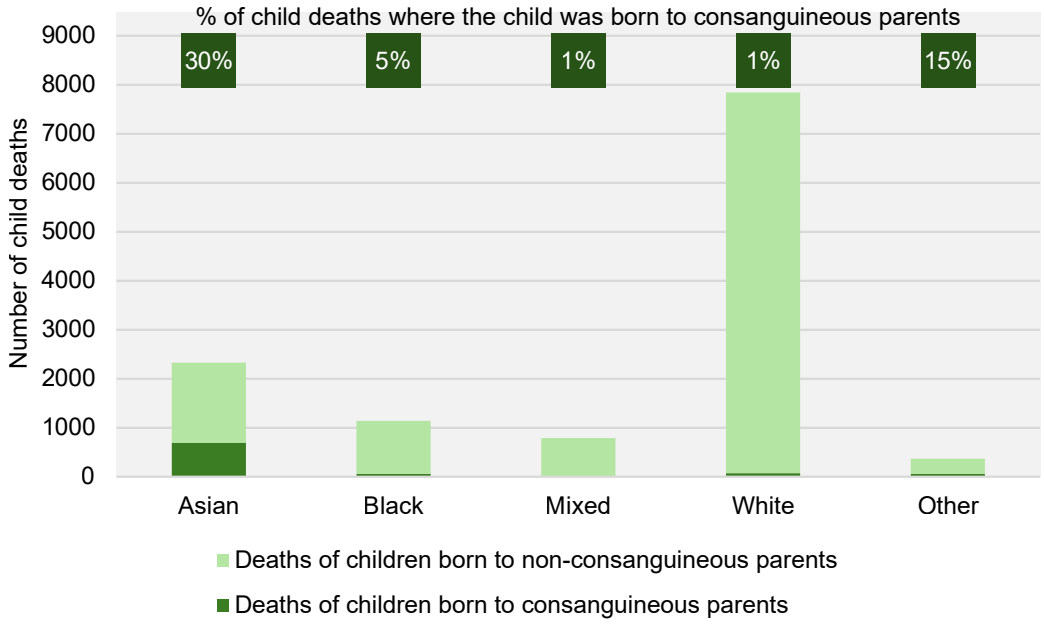


Ethnicity

An analysis of all the children who died showed that children from various ethnic backgrounds are born to consanguineous parents (Figure 4):

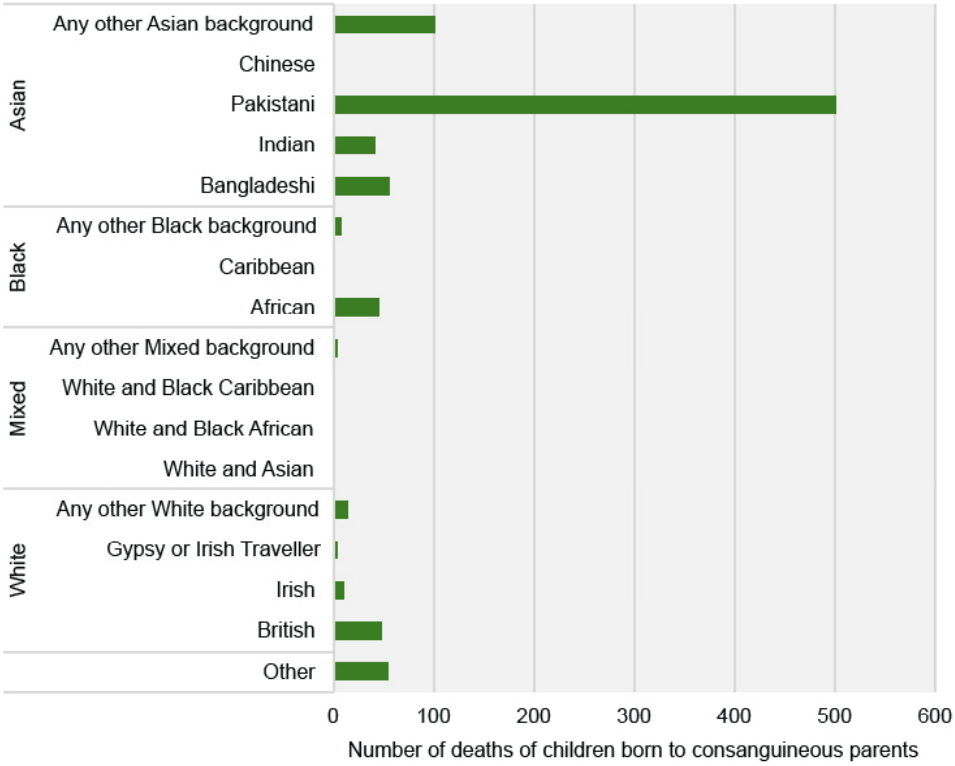
- 30% (n=699/2335) of children from Asian ethnic backgrounds who died, were born to consanguineous parents.
- 5% (n=54/1139) of children from Black ethnic backgrounds who died, were born to consanguineous parents.
- For children who died from Mixed (n=6/795) or White (n=74/7846) ethnic backgrounds, 1% were born to consanguineous parents for each of these ethnic groups.
- For children from Other ethnic backgrounds who died, 15% (n=54/367) were born to consanguineous parents.

Figure 4: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous or non-consanguineous parents, by ethnic group



Of the children who died who were born to consanguineous parents, 79% were reported to be from Asian ethnic backgrounds. The most common ethnic background was Pakistani (56%, n=501/888), followed by any other Asian background (11%, n=101) and Bangladeshi (6%, n=56) (Figure 5).

Figure 5: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous parents, by ethnicity



N.B. 'Roma' was not added to data collection forms until April 2023, therefore is not reported as a separate category. In April 2021 'Gypsy or Irish Traveller' was added to 'White', therefore may be underestimated.

Household violence, abuse or neglect concerns, and social care status

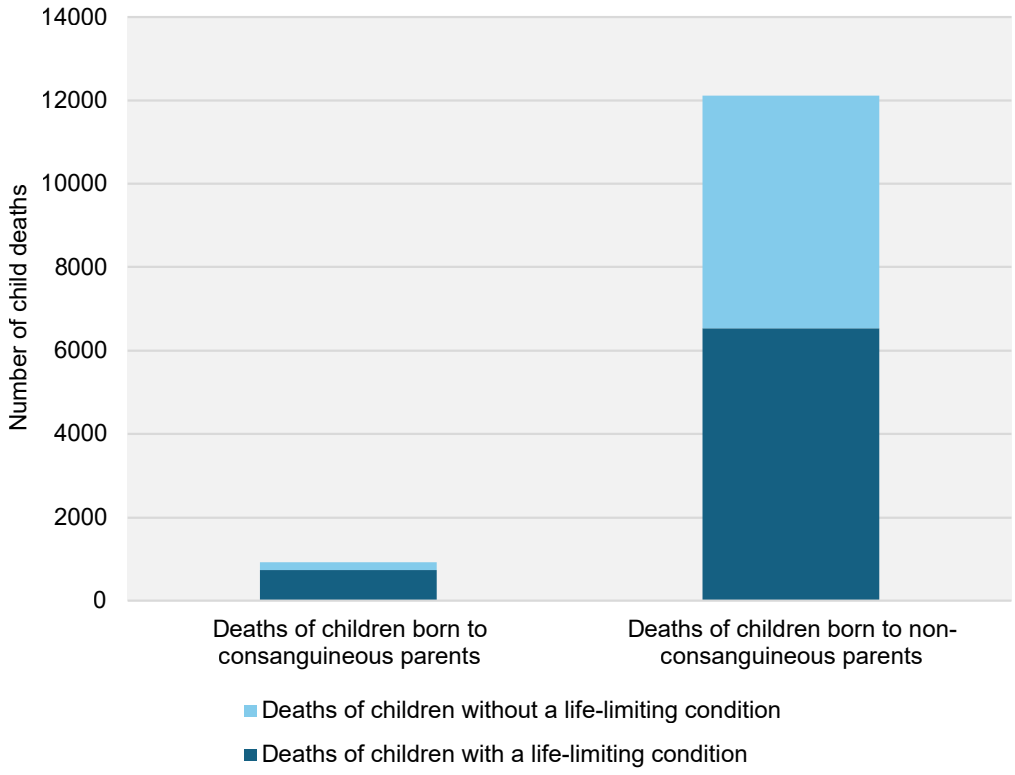
For deaths of children born to consanguineous parents, where the information was known, 9% (n=83/907) of the reviews recorded known domestic violence/abuse in the household and 1% (n=12/827) recorded concerns around child abuse or neglect. In comparison, where the information was known, 21% (n=2462/11666) of death reviews of children born to non-consanguineous parents recorded known domestic violence/abuse in the household and 4% (n=456/10677) recorded concerns around child abuse or neglect.

Where the information was known, 17% (n=157/919) of the children who died born to consanguineous parents were known to social care at the time of their death, compared to 15% (n=1772/11932) of deaths of children born to non-consanguineous parents.

Life-limiting conditions

Life-limiting conditions are defined as those for which there is no reasonable hope of cure and from which children may die[6], and they may be underpinned by genetic conditions or susceptibilities. For children who died born to consanguineous parents, 79% (n=734/926) had a life limiting condition compared to 54% (n=6537/12119) of deaths of children born to non-consanguineous parents (Figure 6).

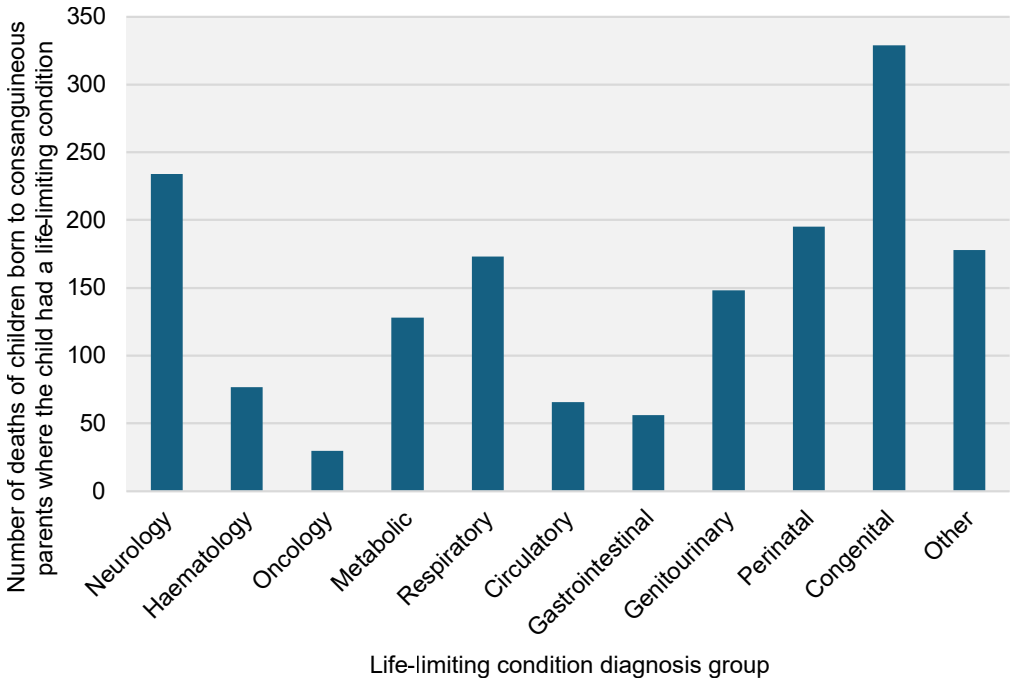
Figure 6: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous parents, by presence of a life-limiting condition



6 Together for Short Lives (2018)

For the deaths of children born to consanguineous parents, the highest number of deaths occurred in children with an underlying congenital (36%, n=329) or neurological (25%, n=234) life-limiting diagnosis (Figure 7). In addition, 50% (n=453/893) of the deaths of children born to consanguineous parents had a life-limiting condition in two or more diagnosis groups. This proportion was higher than deaths of children born to non-consanguineous parents (30%, n=3546/11962).

Figure 7: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous parents, by life-limiting condition diagnosis group



N.B. Life-limiting condition diagnosis groups are non-exclusive; a death may be recorded under multiple groups. Life-limiting condition diagnosis group was derived from ICD-10 diagnoses recorded in Hospital Episode Statistics data. Further information is available in the Supporting Material.

Category of death

CDOPs are required to assign a category to each death. Information on this categorisation process can be found in the child death analysis form. While more than one category can be applied, the primary category of death is the uppermost category of death selected.

For all child deaths, the most common primary category of death recorded by CDOP was *Perinatal / neonatal event,* followed by *Chromosomal, genetic, and congenital anomalies* (Figure 8).

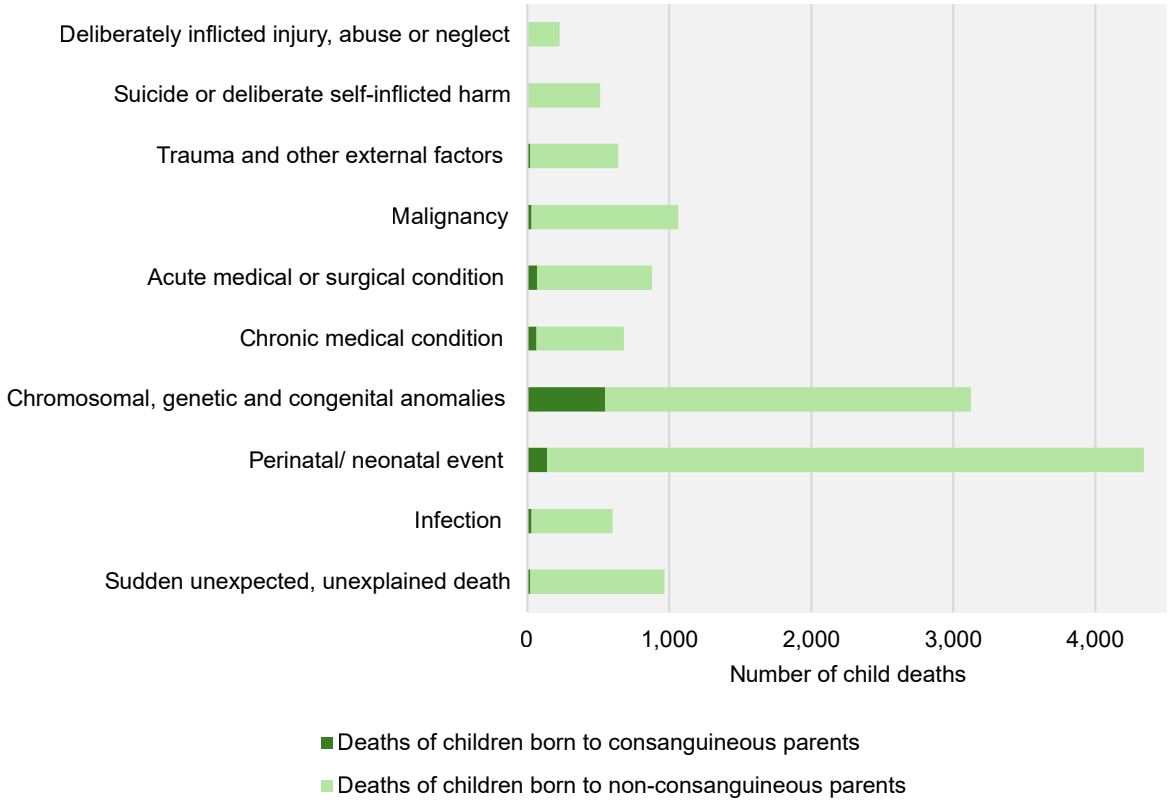
For children born to non-consanguineous parents, the most common primary categories of death recorded by CDOP were *Perinatal / neonatal event* (35% of deaths of children born to non-consanguineous parents), followed by *Chromosomal, genetic, and congenital anomalies* (21%).

For children born to consanguineous parents, the most common primary categories of death recorded by CDOP were *Chromosomal, genetic, and congenital anomalies* (59% of deaths of children born to consanguineous parents) and *Perinatal / neonatal event* (15%). The least common categories were *Deliberately inflicted injury, abuse or neglect, Suicide or deliberate self-inflicted harm*, and *Trauma and other external factors* (in total n=24, 3%), though limitations around reporting biases of consanguinity should be considered (see Supporting Material).

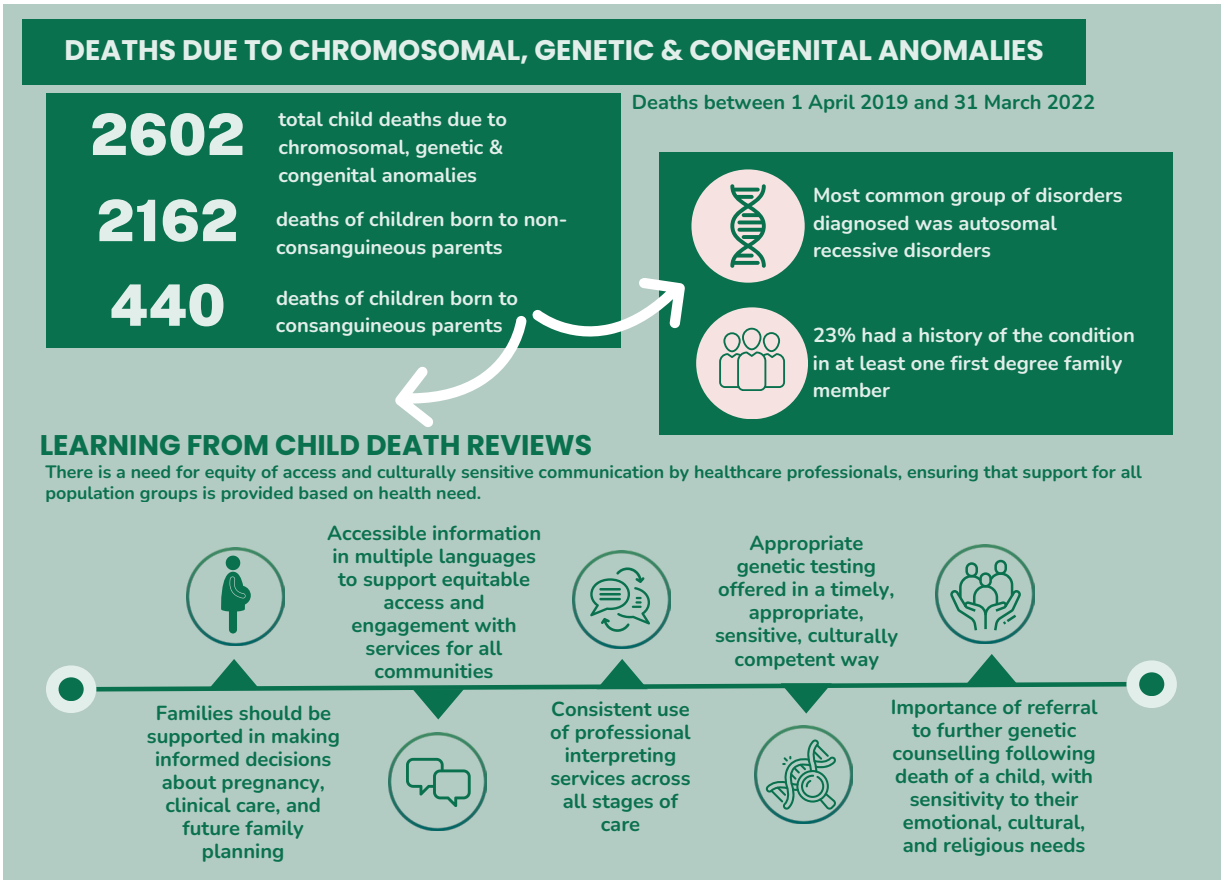
In 65% (n=605) of deaths of children born to consanguineous parents, *Chromosomal, genetic and congenital anomalies* was selected as **any** category of death (i.e., including those where it was selected alongside another category).

For the deaths due to *Chromosomal, genetic and congenital anomalies* as a proportion of the total number of deaths, 5% (n=605/13043) were in children born to consanguineous parents and 23% (n=3025/13043) in children born to non-consanguineous parents.

Figure 8: Number of child deaths between 1 April 2019 and 31 March 2023 where the child was born to consanguineous or non-consanguineous parents, by primary category of death



2. Deaths of children due to chromosomal, genetic and congenital anomalies



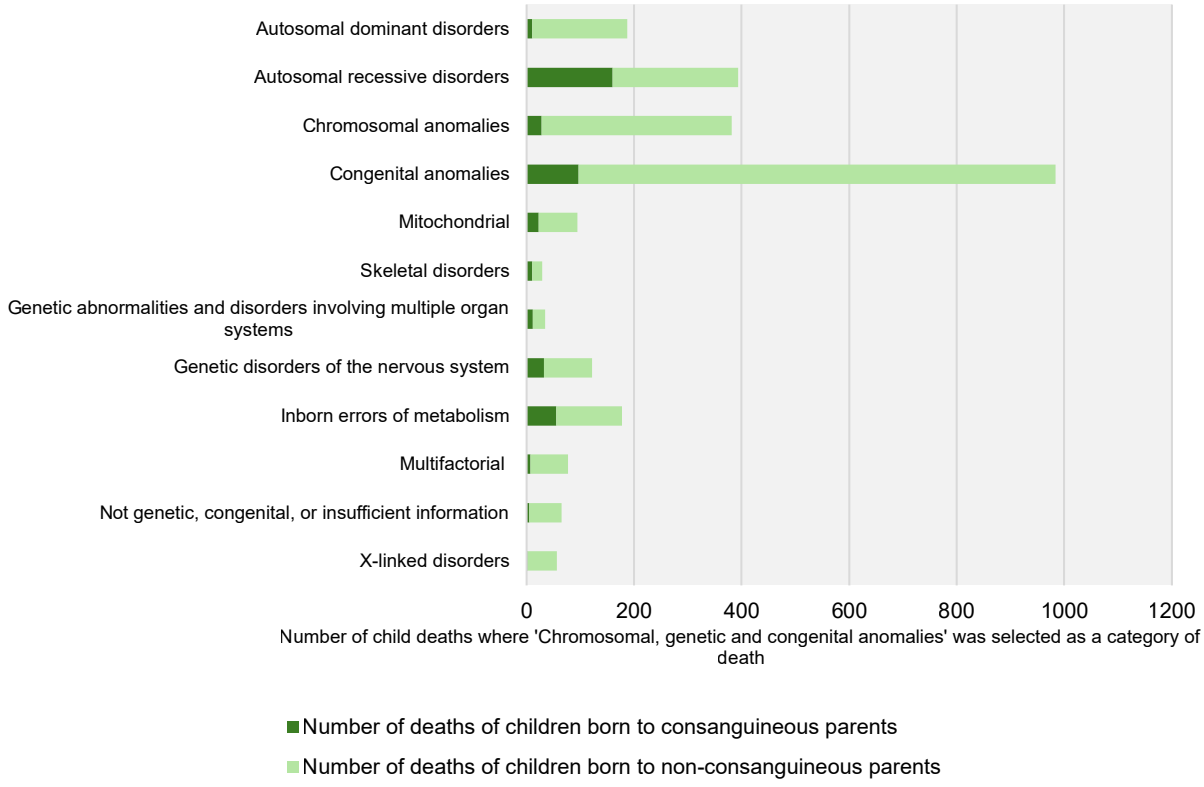
This section provides further analysis of the deaths between 1 April 2019 and 31 March 2022 (3 years) where *Chromosomal, genetic and congenital anomalies* was selected as **any** category of death by the CDOP. In total, there were 2,602 deaths which met this criterion. In most cases (2162, 83%), there was no recorded evidence of consanguinity, and in 440 (17%) cases evidence of consanguinity was recorded. The 2,602 cases were then further reviewed and categorised into more specific disease groups, which are reported in this section. Further information on how the conditions were identified and categorised is available in the Supporting Material.

Chromosomal anomalies involve changes in the structure or number of chromosomes, usually occurring at random during the formation of eggs or sperm. In contrast, genetic conditions (e.g., autosomal recessive disorders and autosomal dominant disorders) are caused by changes within individual genes.

For deaths of children born to consanguineous parents, the most common group of disorders diagnosed was autosomal recessive disorders (a condition that occurs when a child inherits a faulty gene from both parents) (36%, n=160/440) (Figure 9), compared to 11% of deaths of children born to non-consanguineous parents (n=234/2162). This is consistent with previous research findings. This is because relatives are more likely to carry the same gene change. In 13% (n=55/440) of the deaths of children born to consanguineous parents, the child had an identified inborn error of metabolism (a condition that leads to dangerous deficiencies or excesses of chemicals in the body), compared to 6% of the deaths of children born to non-consanguineous parents. Most inborn errors of metabolism are inherited in an autosomal recessive manner as well but for the purposes of our report were included as a specific category. Therefore, in total, 53% (n=235/440) of the deaths of children born to consanguineous parents were of children with an autosomal recessive disorder, inborn error of metabolism, skeletal autosomal recessive disorder, or a mitochondrial autosomal recessive disorder. In comparison, these four condition groups accounted for 18% (n=392/2162) of the deaths of children born to non-consanguineous parents.

22% (n=97/440) of the deaths of children born to consanguineous parents were of children with congenital anomalies, 6% (n=28/440) had chromosomal anomalies, and 2% (n=10/440) had autosomal dominant disorders (compared to 41%, 16% and 8%, respectively in the deaths of children born to non-consanguineous parents).

Figure 9: Number of child deaths between 1 April 2019 and 31 March 2022 where 'Chromosomal, genetic and congenital anomalies' was selected as a category of death, by presence of consanguinity and genetic condition group



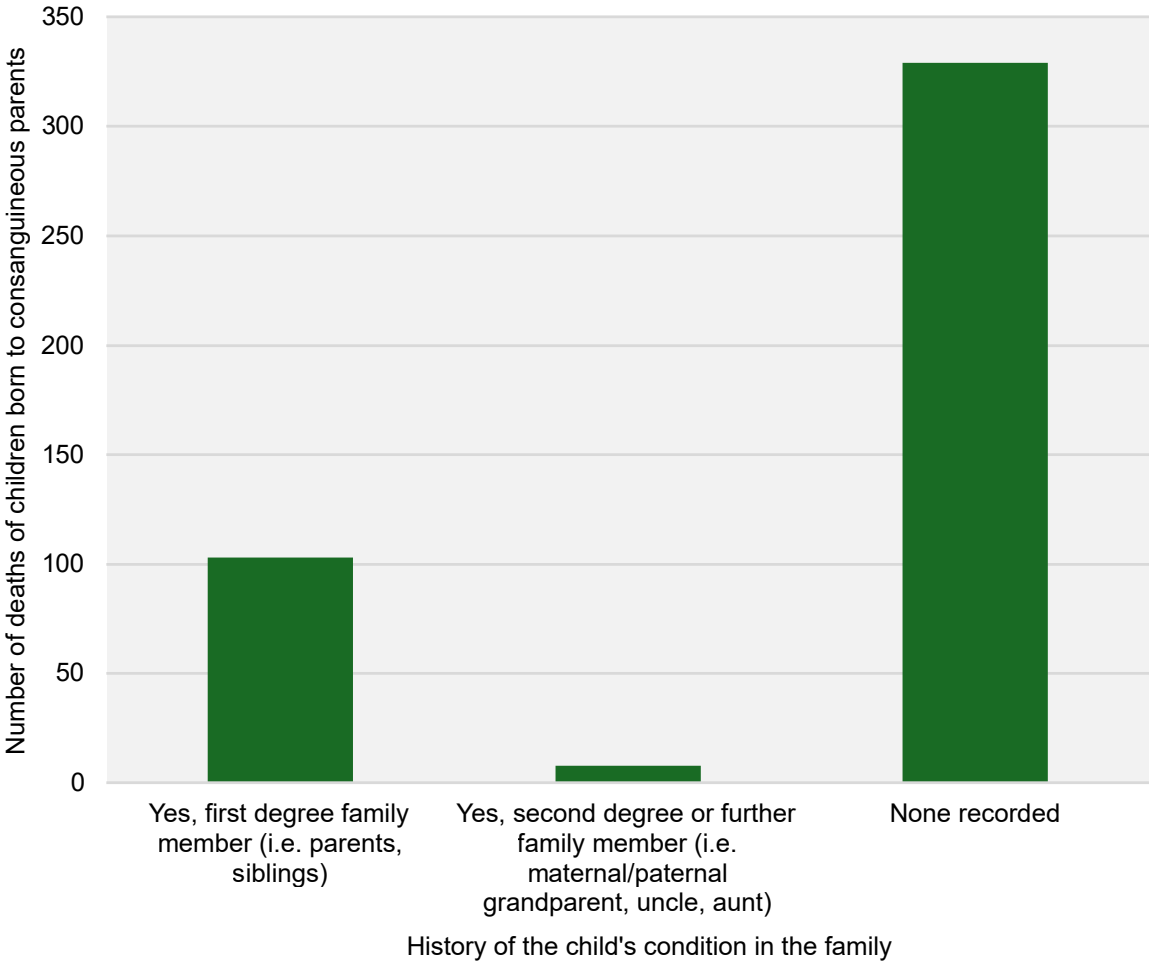
Where the information was recorded (n=843), 42% (n=356/843) of the reviews recorded that the condition was diagnosed antenatally. For deaths of children born to consanguineous parents, 25% (n=39/156) were diagnosed antenatally, and for deaths of children born to non-consanguineous parents, 46% (n=317/687) were diagnosed antenatally.

Recurrence

For deaths of children born to consanguineous parents, 23% (n=103/440) had a history of the condition in at least one first degree family member, and a further 2% (n=8/440) in a second degree family member (Figure 10). This included cases where there were one or more affected siblings within the same family, including one or more previous deaths of siblings.

This was higher than the proportion in the non-consanguineous group, where 5% (n=113/2162) of the cases had a history of the condition in a first degree family member.

Figure 10: Number of child deaths between 1 April 2019 and 31 March 2022 where the child was born to consanguineous parents and 'Chromosomal, genetic and congenital anomalies' was selected as a category of death, by whether there was a history of the child's condition in the family



3. National themes identified from CDOP reviews

This section focuses on the contributory factors and learning identified from CDOP reviews of deaths of children between 1 April 2019 and 31 March 2022 (3 years) who were born to consanguineous parents where *Chromosomal, genetic and congenital anomalies* was selected as any category of death (n=440). Of these reviews, 61% (n=270/440) were of children aged under 1, while 39% (n=170/440) were of children aged 1 – 17 years.

Referral to further genetic counselling following the death

Genetic counselling is a professional service provided by trained genetic counsellors who help families understand and make decisions based on genetic information. The purpose is to help families interpret genetic test results, explain the implications for health and family planning, provide emotional support and guidance, and help them to decide whether testing is appropriate. It is particularly important after the death of a child due to a genetic condition, as it can enable them to understand why their child died and the risks of a future pregnancy being affected.

Where data was available in the supplementary reporting form (n=92/440, 21%), 42 families were offered and accepted genetic counselling after the death of their child, 10 families were offered genetic counselling and declined this, and 12 families were not offered genetic counselling. A further 28 reviews reported that genetic counselling was not yet offered, but this was intended.

CDOPs recorded the importance of ensuring a referral for genetic counselling is made, and for the service to be offered in a way that understands the holistic requirements of the family, including religious and cultural beliefs, which could help to improve engagement.

In 3 cases (out of 102 where data was available) the family was not offered the opportunity to discuss a plan for future pregnancies, and in a further 15 cases this was offered but was declined by the family.

Referral for genetic testing

Antenatal and postnatal genetic testing can help families to make informed decisions about pregnancy, clinical care, and future family planning. Genetic testing is a medical procedure to analyse DNA, chromosomes or proteins to identify genetic changes or variations. The purpose of genetic testing is to diagnose genetic conditions, assess the risk of developing certain diseases, determine the carrier status for inherited conditions, individualise the recurrence risk and to guide treatment decisions.

CDOPs commented on the importance of an early referral to clinical genetics, and reported some instances where an earlier discussion, and referral to clinical genetics, may have led to an earlier diagnosis and treatment. Where information was available (n=103), an urgent genetics referral was not offered in 8 cases, and in a further 13 cases an urgent genetics referral was offered and declined by the family.

It is important for appropriate genetic testing to be offered in a timely, appropriate, sensitive, and culturally competent way. Not offering genetic testing for a baby when clinically appropriate can limit the ability to assess the risk to future pregnancies and provide advice to the family. Timing can be crucial as in many instances a woman may be pregnant again before a diagnosis has been made in the affected child.

CDOPs recorded the importance of genetic testing results being communicated with families in a timely manner and ensuring access to appropriate and culturally competent genetic counselling.

Communication with families

Language barriers with families whose first language is not English and inconsistent use of appropriate interpreters was recorded by CDOPs. This leads to poor communication between families and healthcare services, which has been described as leading to poorer access to, and experience of, healthcare services.[7]

The importance of using professional interpreting services across all providers and stages of care for women during pregnancy and beyond, including genetic services, was recorded. This should be communicated between healthcare providers when this need is identified antenatally. This would enable staff and families to access the information in a wide variety of languages. In addition, it is important that written information is available in multiple languages to ensure information is accessible to all communities.

7 NHS England (2025)

4. Recommendations

There is a need for equity of access and culturally sensitive communication by healthcare professionals, ensuring that support for all population groups is provided based on health need.

SUPPORT FOR BEREAVED PARENTS AND FAMILIES

Recommendation 1: Ensure that all bereaved parents, following the death of a child due to a suspected or confirmed genetic condition, are proactively offered genetic counselling, with sensitivity to their emotional, cultural, and religious needs, and are provided with the opportunity to discuss future pregnancy planning.

Action: Lead healthcare professional

TIMELY ADVICE FOR PARENTS AND FAMILIES

Families should be supported in making informed decisions about pregnancy, clinical care, and future family planning, which may lead to improvements in outcomes through earlier diagnosis and treatment. The Healthy Child Programme schedule of interventions offers guidance and resources for commissioners to design health services that reflect local needs and the characteristics of inclusion health groups. Online courses from the NHS Genomics Education Programme cover topics such as how to talk to patients about genomics and how to record a family history. Training about close relative marriage and genetic risk is available for midwives and health visitors. It explains how to initiate sensitive, appropriate conversations with patients and family members affected by autosomal recessive genetic conditions linked to consanguinity.

Recommendation 2: Improve awareness and consistency of pathways for early referral to clinical genetics by ensuring that antenatal and postnatal genetic testing is consistently offered when clinically appropriate, communicated in a timely and culturally competent manner, and supported by access to genetic counselling. Healthcare providers should ensure that clear information is provided to clinicians about when and how to refer to genetics services. This includes:

- providing accurate information about recurrence risks and options for future pregnancies.
- facilitating discussions about testing for wider family members where appropriate.

Action: Royal College of Obstetricians and Gynaecologists, British Maternal and Fetal Medicine Society, Royal College of Paediatrics and Child Health, Healthcare providers

Discussing genetic testing information can be challenging, as the subject is highly technical and there is a scarcity of accessible learning materials tailored for the needs of different audiences.[8]

Recommendation 3: Integrated Care Boards working with healthcare providers should ensure consistent use of professional interpreting services across all stages of care, particularly during pregnancy and in specialist services such as genetics, to improve communication and build trust with families whose first language is not English. This includes:

- proactively identifying language needs antenatally and clearly communicating them between healthcare providers.
- providing accessible written information in multiple languages to support equitable access and engagement with services for all communities, including information around genetic testing and counselling.

Action: Integrated Care Boards working with NHS Trusts

8 Lea et al. (2011)

SUPPORT FOR PROFESSIONALS

Timely, clinically appropriate genetic testing and clear communication can empower families to make informed decisions about pregnancy, clinical care, and future family planning.

Recommendation 4: Strengthen genetic testing pathways to improve awareness and consistency of antenatal and postnatal genetic testing by:

- » educating mainstream clinicians (e.g., neonatologists, paediatricians and fetal medicine specialists) on the NHS England National Genomic Test Directory expectations. This will support them in conducting informed consent conversations, particularly addressing complexities when English is not the first language, in ordering genetic tests, taking detailed family histories, and considering consanguinity when deciding on testing.
- » encouraging multi-disciplinary team discussions with clinical genetics and genomic laboratories as a mechanism for further support on complex cases.

Action: Royal College of Obstetricians and Gynaecologists, British Maternal and Fetal Medicine Society, Royal College of Paediatrics and Child Health, Genomics Education Programme

Recommendation 5: Strengthen preconception and early-pregnancy conversations between healthcare professionals and women, by ensuring midwives, obstetricians, general practitioners, health visitors and other frontline clinical staff receive up-to-date, evidence-based, and culturally sensitive training on genetic and family health factors. Existing training resources for professionals, the NHS Genomics Education Programme, Saving Babies Lives Care Bundle version 3, NICE Clinical Knowledge Summaries (CKS) and the RCOG Maternity Service Standards Framework emphasise the importance of taking a detailed, culturally informed family history and providing tailored, person-centred information beyond genetic advice to support informed reproductive decisions. Tommy's: Conception and your baby's genes provides evidence-based preconception health and care information for families.

Action: Office for Health Improvement and Disparities at the Department of Health and Social Care

Next steps and future priorities

Child death review process

Work by NCMD is ongoing to continuously improve data quality by further developing the child death review (CDR) data collection forms. This aims to better support the CDR process and provide more granular and comprehensive data for deeper understanding of child deaths.

Analysis for this report has identified the need for improvements to strengthen the information collected including:

1. The statutory analysis form should be updated to enhance data collection on the category of death assigned by CDOPs. For instance, additional sub-categories could be introduced under each category (such as 'Autosomal recessive condition' under the category 'Chromosomal, genetic, and congenital anomalies') which would allow for more granular data to be collected and enhanced analysis to be completed in future.
2. Improved data collection around consanguinity in the child death reporting form, including further detail on the level of relationship (e.g., first cousins, second cousins, other), and ensuring that this is collected for all child deaths.
3. Improved links between clinical genetics and the child death review process. The review process should incorporate a check to verify that appropriate clinical genetics assessment or referral occurred in cases where an inherited genetic condition may be relevant, following the pathway described in the NCMD guidance for CDR professionals on consanguinity. This will ensure the CDR meeting and CDOP discussions have all the information relating to each family's experience of care, in order to review the child's death in a comprehensive and consistent way.
4. The information collected within the statutory reporting forms (including supplementary forms) should be fully completed, reviewed, and validated by CDOPs before final submission of the full review information to the NCMD. This would support better completion rates of supplementary reporting forms, and improvements to data collection systems should be made to support this.
5. Further data linkage with routinely collected NHS England national datasets including the National Disease Registration Service datasets and the Maternity Services Data Set (MSDS), to complement data in NCMD and enable further analysis. The NHS has published guidance on how to submit data about consanguinity and pregnancy to MSDS.

Future priorities

Our findings demonstrated that over half of the children who died in consanguineous families were resident in the most deprived neighbourhoods. This could represent areas of intervention which could impact on child mortality rates. Further research is needed to explore the factors linked to deprivation that impact increased mortality in this group.

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