Understanding consanguinity-related child deaths

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NCMD
National Child Mortality Database
Knowledge, understanding and learning to improve young lives

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The authors of this report wish to acknowledge that the death of each child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family members, friends and professionals.

Consanguinity

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.

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

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**.

* Sheridan et al. (2013) - Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study – ScienceDirect
** Small et al. (2024) - Mortality, morbidity and educational ... | Wellcome Open Research and Teeuw et al. (2014) - Consanguineous marriage and reproductive risk: attitudes and understanding of ethnic groups practising consanguinity in Western society | European Journal of Human Genetics

Thematic Report: Understanding Consanguinity-Related Child Deaths

Reports the number and characteristics of children born to consanguineous parents who died between 1 April 2019 and 31 March 2023 (4 years) in the context of all child deaths in this period.

Further analyses 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; focuses on the contributory factors and learning identified from CDOP reviews.

Methodology

- Children (0 – 17 years inclusive) who died between 1 April 2019 and 31 March 2023, where the death had been reviewed and finalised by a Child Death Overview Panel (CDOP) before 27 November 2025
- Deaths of children born to consanguineous parents were identified if:

  i. consanguinity was recorded as a factor on the analysis form completed by the CDOP. This included factors graded as ‘unlikely to have contributed to the death’ and also included those that ‘may have contributed to vulnerability, ill health or death’, or

  ii. the reporting form question ‘Are the child's parents related to each other (E.g. Cousin)?’ was answered yes, and there was other information in the case record to confirm consanguinity status.

Limitations

- NCMD is reliant on accurate data being inputted by professionals involved in submitting information for the child death review.
- The report describes the number and characteristics of deaths of children who were born to consanguineous parents in the context of all child deaths.
- There is no national population data on all children born to consanguineous parents, meaning the risk of child death is not reported, and the analysis is a description of the deaths that occurred only.
- Further, the report includes only children born to consanguineous parents who died before their 18th birthday, and does not include stillbirths or lawful terminations of pregnancy, as these are not subject to the child death review process.
- Any patterns observed in the data may reflect a complex interplay between consanguinity and other determinants of health, including maternal, socioeconomic, cultural, or health system factors, all of which may influence child mortality.
- More information can be found in the Supporting Material.

- Of all child deaths (n=13,045), 7% (n=926) were children who died due to any cause and who were born to consanguineous parents.
- This proportion was consistent across the time period: 8% in 2019-20, and 7% in the latest year (2022-23).

1. Characteristics of deaths of children born to consanguineous parents

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%).
- 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).

Ethnicity

- 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.

Ethnicity

- 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).

Social deprivation

- There were higher numbers of deaths of children in the most deprived neighbourhoods in comparison to the least deprived, 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)
- 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.

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).

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, 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.
- 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

- 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.

Life-limiting conditions

- The highest number of deaths occurred in children with an underlying congenital (36%, n=329) or neurological (25%, n=234) life-limiting diagnosis
- 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).

Category of death

- For the deaths due to Chromosomal, genetic and congenital anomalies as a proportion (28%) 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.

Additional data

- Additional data is available in the data tables, including breakdowns by sex, gestational age at birth.

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

Methodology

- 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.

DEATHS DUE TO CHROMOSOMAL, GENETIC & CONGENITAL ANOMALIES

Deaths between 1 April 2019 and 31 March 2022

2602 total child deaths due to chromosomal, genetic & congenital anomalies

2162 deaths of children born to non-consanguineous parents

440 deaths of children born to consanguineous parents

Most common group of disorders diagnosed was autosomal recessive disorders

23% had a history of the condition in at least one first degree family member

LEARNING FROM CHILD DEATH REVIEWS

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.

- Families should be supported in making informed decisions about pregnancy, clinical care, and future family planning
- Accessible information in multiple languages to support equitable access and engagement with services for all communities
- Consistent use of professional interpreting services across all stages of care
- Appropriate genetic testing offered in a timely, appropriate, sensitive, culturally competent way
- Importance of referral to further genetic counselling following death of a child, with sensitivity to their emotional, cultural, and religious needs

Category of death

- 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.

Antenatal diagnosis

- 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. parents.

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.
- 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.

2. National themes identified from CDOP reviews

Methodology

- 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

- 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.
- 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.
- 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.
- 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.

3. Recommendations

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

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

Timely advice for parents and families

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

Support for professionals

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

Support for professionals

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

Analysis in this report has identified a key area where further research is needed:

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.

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

- The statutory analysis form should be updated to enhance data collection on the category of death assigned by CDOPs. (e.g. by adding specific categories such as ‘Autosomal recessive condition’ under the category ‘Chromosomal, genetic, and congenital anomalies)

- On consanguinity – capture further detail on the level of relationship (e.g., first cousins, second cousins, other), and ensure this is collected for all child deaths.

Next steps and future priorities

- Improved links between clinical genetics and the child death review process
- 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.

Further information

The full thematic report can be found at:
Understanding consanguinity-related child deaths

Including:

Main Report

Supporting Material

Data Tables

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