

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