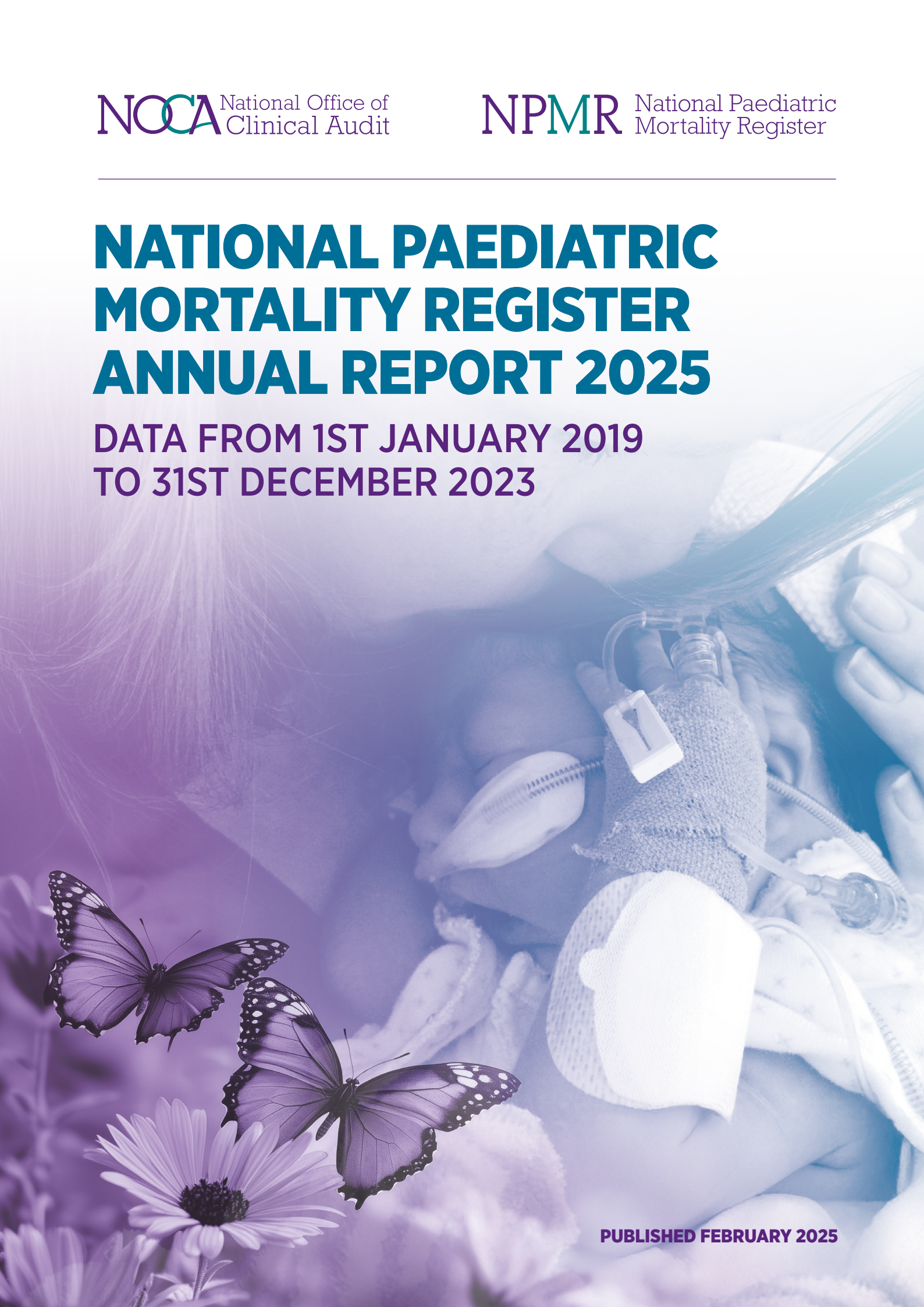
NCA National Office of Clinical Audit

NPMR National Paediatric Mortality Register

NATIONAL PAEDIATRIC MORTALITY REGISTER ANNUAL REPORT 2025

DATA FROM 1ST JANUARY 2019 TO 31ST DECEMBER 2023



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NATIONAL OFFICE OF CLINICAL AUDIT (NOCA)

The National Office of Clinical Audit (NOCA) was established in 2012 to create sustainable clinical audit programmes at national level. NOCA is funded by the Health Service Executive's Office of the Chief Clinical Officer and operationally supported by the Royal College of Surgeons in Ireland.

National clinical audit is defined as "a clinically led quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and acting to improve care when standards are not met. The process involves the selection of aspects of the structure, processes and outcomes of care which are then systematically evaluated against explicit criteria. If required, improvements should be implemented at an individual, team or organisation level and then re-evaluated to confirm improvements" (HSE NCCA, 2023). NOCA supports hospitals to learn from their audit cycles.

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ACKNOWLEDGEMENT OF KEY PARTNERS

This report would not have been possible without the support of many healthcare professionals in Children's Health Ireland (CHI), University Hospital Limerick and beyond. We are particularly indebted to National Paediatric Mortality Register (NPMR) Clinical Lead Associate Professor Martina Healy and to the Chair of the NPMR Governance Committee, Professor Michael Barrett, as well as to all the other members of the NPMR Governance Committee who guide the development of the NPMR and provided valuable contributions to this report. We are also grateful to the representatives from HUGG: Healing Untold Grief Groups, for their invaluable input and advice.

The National Office of Clinical Audit (NOCA) would like to thank all the providers of the data included in this report, including the staff in CHI at Temple Street for coordinating and monitoring local data submissions and the staff of the Vital Statistics Division of the Central Statistics Office.

Finally, we wish to acknowledge and remember all of the children who died and the families who cared for them. It is our hope that this work will succeed in its objective of reducing the number of child deaths in the future.

ACKNOWLEDGING SIGNIFICANT CONTRIBUTIONS FROM THE FOLLOWING:

RCSI

HSE

Sláinte Leanaí Éireann
CHI
Children's Health Ireland

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DESIGNED BY SWERVE

NOCA National Office of Clinical Audit

NPMR National Paediatric Mortality Register

National Paediatric Mortality Register

Annual Report 2025

We are aware that the content of this report, which includes some detail of methods of death, may be distressing for some readers.

SUPPORT

If you, or someone you know needs advice on grief, bereavement or loss visit www.hse.ie/grief.

Information on bereavement supports and services includes helplines, organisations for bereaved parents and families, and supports for people bereaved by suicide.

Anam Cara provides support for parents after bereavement. www.anamcara.ie

Irish Hospice Foundation Bereavement Support Line is a confidential space for people to speak about their experience or to ask questions relating to the death of someone.
Freephone 1800 807 077 — Monday to Friday, 10am to 1pm
www.hospicefoundation.ie

NOCA National Office of Clinical Audit

Associate Professor Martina Healy
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20th December 2024

Dear Assoc. Prof Healy,

On behalf of the NOCA Governance Board, I wish to formally acknowledge receipt of the *National Paediatric Mortality Register: Second National Report 2025*.

We extend our sincere congratulations to you and the entire team, including Audit Manager Dr Cliona McGarvey PhD, Chair of the Governance Committee Professor Michael Barrett, and Patient and Public Interest Representatives Kate Burke and Liz O'Donoghue, for their essential roles in developing this report. We also wish to acknowledge the children and young people represented by every statistic in this report and express our gratitude to Rebecca Maher for sharing Matilda's story.

This comprehensive analysis of paediatric mortality in Ireland builds on the findings of the inaugural report, offering important insights into trends, causes, and opportunities for quality improvement. It highlights both progress and areas demanding urgent attention, such as preventable conditions and the need for enhanced data collection systems.

This letter signifies the formal endorsement of the NOCA Governance Board for the *National Paediatric Mortality Register: Second National Report 2025*.

Yours sincerely,

Dr Brian Creedon
Clinical Director
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GLOSSARY OF TERMS AND DEFINITIONS

ACRONYM	FULL TERM
adolescent	The phase of life between childhood and adulthood, ranging from the ages of 10 to 18 completed years
CAMHS	Child and Adolescent Mental Health Services
CDR	child death review
Child mortality rate	The number of deaths of children aged 1–14 years per 1,000 live births
CHI	Children's Health Ireland
COVID-19	coronavirus disease 2019
CYP	children and young people
CSO	Central Statistics Office
ED	emergency department
ESRI	Economic and Social Research Institute
EU	European Union
EUROCAT	The European network of population-based registries for the epidemiological surveillance of congenital anomalies
Eurostat	The official European Union statistical office
External cause of death	Death due to accidents and violence, including environmental events, circumstances and conditions as the cause of injury, poisoning or other adverse effects
Filicide	The act of killing one's child
GDPR	General Data Protection Regulation
GRO	General Register Office
HIPE	Hospital In-Patient Enquiry
HIQA	Health Information and Quality Authority
HLHS	hypoplastic left heart syndrome
Homicide	The unlawful killing of one person by another
IHI	individual health identifier
IPCCA	Irish Paediatric Critical Care Audit
HSE	Health Service Executive
ICD-10	International Classification of Diseases, Tenth Revision
iPMS	integrated patient management system
IMR	infant mortality rate; the number of deaths in children aged under 1 year in a given period (usually 1 year) per 1,000 live births in that same period
infant	A child aged under 1 year
MTA	Major Trauma Audit
mortality rate	A measure of the number of deaths (in general or due to a specific cause) in some population, scaled to the size of that population, per unit of time
NCMD	National Child Mortality Database
neonate	A newborn aged ≤28 days
neoplasm	An abnormal growth of tissues that may or may not be cancerous

ACRONYM	FULL TERM
NOCA	National Office of Clinical Audit
neonate	A newborn aged ≤28 days
neoplasm	An abnormal growth of tissues that may or may not be cancerous
NOCA	National Office of Clinical Audit
NOSP	National Office for Suicide Prevention
NPEC	National Perinatal Epidemiology Centre
NPMR	National Paediatric Mortality Register
neonatal mortality rate	The number of deaths of infants aged ≤28 days in a given period (usually 1 year) per 1,000 live births in that same period
perinatal	The period immediately before and after birth
perinatal mortality rate	The number of stillbirths and deaths in the first week of life in a given period (usually 1 year) per 1,000 live births in that same period
PME	Post mortem examination
postneonatal	The period between the ages of 29 days and 1 year
PNMR	postneonatal mortality rate
postneonatal mortality rate	The number of deaths of infants aged 29 days to 1 year in a given period of time (usually 1 year) per 1,000 live births in that same period
RCSI	Royal College of Surgeons in Ireland
RMF	Research microdata file
RTC	road traffic collision
SNOMED	Systematized Nomenclature of Medicine
SPSS	Statistical Package for the Social Sciences
standardised death rate	A proportional comparison of the actual number of deaths with the number of deaths that would have been expected if the population had been standardised in terms of age, sex, etc.
SIDS	sudden infant death syndrome; the sudden, unexpected death of an infant aged under 1 year, with the onset of the fatal episode apparently occurring during sleep and which remains unexplained after a thorough investigation, including the performance of a complete autopsy and review of the circumstances of death and the infant's clinical history
SPC	statistical process control
SUDC	Sudden unexplained death in childhood
SUDI	Sudden unexplained death in infancy
sudden infant death syndrome rate	The number of deaths in children that are classified as being the result of SIDS in a given time period (usually 1 year) per 1,000 live births in that same period
UK	United Kingdom
under 5 mortality rate	The number of deaths in children aged under 5 years per unit of population (usually per 10,000 or 100,000 population)
WHO	World Health Organization

PREFACE

The loss of a child is a heartbreak no family should have to endure. Each child represents not only a life full of potential, but also countless possibilities for the future—possibilities that extend far beyond what we can imagine. They are the future adults, parents, teachers, scientists, artists, leaders, and innovators who could one day shape the world. Each child holds the potential to contribute uniquely to society, to experience the joy of learning, creating, and growing. Tragically, when a child's life is cut short, that potential, those dreams, are forever unfulfilled, and their families are left grappling with a loss that cannot be measured. This National Office of Clinical Audit (NOCA) National Paediatric Mortality Register (NPMR) report honours those young lives, recognising the immeasurable impact on the families, communities, and societies they leave behind. At the same time, it serves as a crucial tool in our ongoing efforts to understand the causes of paediatric mortality and identify ways to reduce preventable deaths in the future.

Under-investment in children and young people exists in Ireland, as stated at the inaugural Child Poverty & Well-Being Summit at Dublin Castle on 23 May 2024. Hope exists, as An Taoiseach Simon Harris stated:

"My ambition as Taoiseach is for Ireland to be the best country in Europe to be a child. I want a country where every child is treated equally, where every child can reach their full potential and their ambition is never limited; where children are protected and cared for; and where their parents are given the support they need to give their child the best start in life."

This ambition and vision not only underscores the Irish government's commitment to ending child poverty but also echoes our broader ambition to ensure that all children, regardless of their circumstances, are provided with the foundation for a healthy, fulfilling life. The findings of this report will help shape these efforts, driving policy decisions aimed at ensuring that Ireland remains a place where every child can reach their full potential.

The NPMR plays a pivotal role in gathering, triangulating, analysing, and presenting data on childhood mortality across the country. By combining rigorous data analysis with the personal stories of families, this report aims to offer both a clear-eyed understanding of where we stand and a hopeful path forward. Every statistic represents not just a number, but a child —a life with dreams and potential cut short far too soon.

The findings presented here build on the work of previous years, highlighting both progress and challenges. While we have seen dramatic improvements in the past in areas such as neonatal care, sudden infant death and public health interventions, the data also underscores a lack of more recent progress, particularly in preventable conditions such as mental health related deaths, infection related deaths and trauma deaths. These areas demand our attention and action, as we strive to reduce the number of families affected by the devastating loss of a child.

This report emphasises that the responsibility for reducing paediatric mortality lies not only with healthcare providers but with all of us—policymakers, public health officials, healthcare workers, families and the broader community. The data collected here provides actionable insights that can guide future developments, policies and inform critical interventions. It is our collective responsibility to ensure that every child, regardless of background or circumstance, has the opportunity to thrive.

One of the most important aspects of this report is the recognition of progress. Each year, as we work together, we move closer to creating a country where fewer children die from preventable causes or have a better death where it is inevitable. The stories of those we've lost inspire us to continue our work, while the data empowers us to take tangible steps toward preventing further tragedy.

We hope this NOCA National Paediatric Mortality Register Second Report 2025 will serve as both a reflection on where we have been and a roadmap for where we need to go. By better understanding the root causes of paediatric mortality and learning from the experiences of those affected, we can create a healthier, safer future for all children.

We invite policymakers, healthcare professionals, and families to engage with the findings and recommendations of this report, and to work together toward a future where every child is given the best chance.

Professor Michael J Barrett
Chair, National Paediatric Mortality Register Governance Committee, National Office of Clinical Audit
Paediatric Emergency Medicine Consultant, Children's Health Ireland at Crumlin
Adjunct Clinical Professor, Women's and Children's Health, School of Medicine, University College Dublin

EXECUTIVE SUMMARY

This is the second report of the National Office of Clinical Audit's (NOCA's) National Paediatric Mortality Register (NPMR) under the governance of NOCA, and it builds on the information and recommendations of the inaugural NPMR report to support the establishment of a national database for the collection and reporting of data on mortality in children and young people (CYP) in Ireland. Current and detailed mortality data are essential for informing healthcare policy, for monitoring population health outcomes and for driving improvements in the quality of care for both children and their families, including end-of-life care.

This report outlines the results of a retrospective review of available population mortality data (i.e. death certificate details) provided by Ireland's central death registration unit, the Central Statistics Office (CSO). It provides national estimates of CYP mortality in Ireland for the period 2019–2023 and outlines the main causes of death at various stages of childhood development. A review of annual trends based on revised year of occurrence data is also provided. The data show that despite a decline in many causes of CYP mortality, overall mortality in infants and older children has either plateaued or increased during the years covered by this report. The greatest number of deaths occur in infants and older adolescents, many of which are potentially preventable, such as those resulting from sudden infant death syndrome or trauma. Important areas of CYP mortality that warrant further review are highlighted along with opportunities for shared learnings.

This report highlights the limitations of the existing mortality datasets; due to delays in the registration of many CYP deaths, data for 2022 and 2023 are provisional, making it difficult to identify emerging public health issues, while the lack of information on the characteristics of these deaths (including any contributory risk factors), means that the identification of high risk groups or families and recommendations for prevention are not possible. Injury remains the leading cause of death among older adolescents aged 15–18 years, accounting for just over one-half of all deaths registered for this age group during 2019–2023. Unfortunately, due to the limitations of the data, it was not possible to provide a more informative description of these deaths. Additional data must be collected on CYP mortality in order to accurately establish the burden of both intentional and unintentional injury, and of sudden unexpected and unexplained deaths in the Irish CYP population, as well as to aid in the identification of contributory and modifiable risk factors.

Implementation of a standardised and timely reporting system for infant and CYP deaths nationally across the Irish healthcare system will enable a more accurate understanding of the causes of child death and provide the basis for quality improvements in the delivery of care and better outcomes for CYP. As recommended in the first NPMR report, statutory notification of all deaths to a national database would be required. The recommendations in this report are aimed at improving the accessibility and quality of CYP mortality data by progressing the development and national implementation of the NPMR child death notification process.

"IMPLEMENTATION OF A STANDARDISED AND TIMELY REPORTING SYSTEM FOR CYP DEATHS NATIONALLY ACROSS THE IRISH HEALTHCARE SYSTEM WILL ENABLE A MORE ACCURATE UNDERSTANDING OF THE CAUSES OF CHILD DEATH AND PROVIDE THE BASIS FOR QUALITY IMPROVEMENTS IN THE DELIVERY OF CARE AND BETTER OUTCOMES FOR CHILDREN AND YOUNG PEOPLE IN IRELAND."

KEY FINDINGS

Timely and more detailed data are required in order to provide an accurate account and review of mortality in children and young people (CYP), identify any emerging public health issues and inform policy aimed at reducing the number of CYP deaths. Direct notification of deaths to the National Paediatric Mortality Register (NPMR) will permit the review of annual trends based on timely year of occurrence data.

Utilisation of the individual health identifier (IHI) would enable the linkage of existing data sources and permit the efficient and more informative analysis of child mortality data by including important information relating to underlying conditions and pre-existing comorbidities.

The total number of deaths in infants aged under 1 year that were registered in Ireland during the period from 1 January 2022 to 31 December 2023 was 363. The average number of infant deaths registered per year in this period is the same as in the previous 3-year period from 2019 to 2021 (180 deaths per year).

Despite a decrease in the rate of fatalities from leading causes of infant death including congenital malformations and chromosomal abnormalities and diseases of the nervous system, the overall infant mortality rate in Ireland has not decreased since 2019 and is higher than some other European countries.

The provisional infant mortality rate in Ireland for the period 2022–2023 (3.2 per 1,000 livebirths) is slightly higher than in 2019–2021 (3.1 per 1,000) and is no longer below the European Union average.

The distribution of the main causes of postneonatal death varies from previous years; the number and rate of registered deaths that were certified as being the result of sudden infant death syndrome (SIDS) was higher in 2022–2023 (0.35 per 1,000 livebirths) than it was in 2019–2021 (0.24 per 1,000 livebirths) suggesting that SIDS is once again the leading cause of death in the postneonatal period.

Review of the annual mortality rates in Ireland from 2007 to 2023 shows that while mortality in children aged 1-4 years and 5-9 years have continued to decrease gradually over time, there has been no decrease in the mortality rate of older children (aged 10-14 years) since 2013, while mortality rates in young people aged 15–18 years have increased.

More boys than girls died across all age groups: boys comprised 54% of deaths among those aged 28 days or under, 51% of deaths among those aged 29 days to 1 year, 60% of deaths among those aged 1-14 years, and 68% of deaths among those aged 15-18 years.

KEY FINDINGS

Neoplasms accounted for one in four (25%) deaths in children aged 1–14 years that were registered during the period 2019–2023, followed by external causes of injury, which accounted for one in five deaths (20%) in this age group.

Trauma remains the leading cause of death in children aged 15–18 years accounting for 51% of all deaths in this age group. However, the number and proportion of registered deaths due to neoplasms in this age group have increased in recent years, from 12% in 2007–2018 to 16.3% during 2019–2023.

The greatest proportion of trauma deaths among children aged 1–14 years that were registered during 2019–2023 was due to road traffic collisions (RTCs) (27%) and suspected self-harm* (19%). The average number of registered deaths due to road traffic collisions has declined among children of all ages from 10 to 3.6 deaths per year among children aged 1–14 years and from 9.4 to 3.4 deaths per year among children aged 15–18 years.

Suspected self-harm* remains the leading cause of trauma fatalities among those aged 15–18 years, accounting for more than one-half (54%) of trauma deaths and 28% of all registered deaths in this age group during 2019–2023.

Additional data collections are required in order to provide a more detailed description of trauma-related deaths among CYP, including deaths due to RTCs and suspected self-harm*. This will help increase public awareness of these causes of death.

Data collected via the NPMR child death notification system from one large paediatric hospital in the period from 1 January 2022 to 30 September 2024 showed an increase in the proportion of notified CYP deaths that were due to sepsis/infection relative to the previous 3-year period from 1 January 2019 to 31 December 2021. A review of national data on incidence rates of childhood infections and crude mortality rates due to infectious diseases is required for accurate interpretation of this observation.

* The figure for suspected self-harm relates to a subset of injury deaths that in the absence of better data are most likely to be self-harm and are an estimate of the true number of self-harm deaths. This figure may vary from Central Statistics Office (CSO) published data on suicide deaths.

RECOMMENDATIONS

RECOMMENDATION 1

The National Office of Clinical Audit (NOCA) must urgently progress the implementation of an electronic data collection system in order to allow for the timely submission of CYP mortality data to the NPMR, and engage with the Health Service Executive (HSE) Access to Information Health Identifiers (A2i HIDs) team to request the utilisation of the IHI in paediatric settings in order to support the NPMR.

RECOMMENDATION 2

Detailed analysis of infection-related deaths in children is warranted. Statutory and other appropriate data sources should be interrogated and together with input from appropriate stakeholders, a review of infection-related CYP deaths included as a spotlight report in the next NPMR report.

RECOMMENDATION 3

NOCA should contribute to the evidence base required to inform policy around suicide prevention by reviewing data relating to the circumstances of potential suicide deaths among children and young people, to support stakeholders e.g. the HSE National Office of Suicide Prevention in their work.

RECOMMENDATION 4

Detailed, accurate, and timely information regarding the circumstances of SIDS deaths is required to make further improvements in the prevention of these deaths. NOCA should support the HSE Child Health Public Health function in its investigation of SIDS deaths in order to help establish the epidemiological profile of SIDS deaths in Ireland and identify any high-risk groups and supporting actions.

NATIONAL PAEDIATRIC MORTALITY REGISTER

KEY FINDINGS

This report provides estimates of CYP mortality in Ireland for the period 2022 and 2023 and compares with average figures for the previous three years (2019-2021). Where reporting on subcategories such as age, sex and cause of death, five year aggregate data for the period 2019-2023 is used and compared with historical data from 2007-2018.

Between 2022 and 2023, there were 363 deaths among infants aged under 1 year, 145 deaths in children aged 1–14 years and 104 deaths in young people aged 15–18 years registered in Ireland.

363	145	104
<1 Year	1-14 Years	15-18 Years

CHILD MORTALITY RATES

Mortality in children aged 1–4 years and 5–9 years continued to decrease gradually over time, however, there has been no decrease in the mortality rate of older children aged 10–14 years since 2013, while rates in young people aged 15–18 years have increased. Many potentially avoidable deaths continue to occur across all ages.

SIDS

The number and rate of registered deaths that were certified as sudden infant death syndrome (SIDS) was higher in 2022–2023 **(0.35 per 1,000 livebirths)** than it was in 2019–2021 (0.24 per 1,000 livebirths)

There was an increase in deaths from sudden infant death syndrome (SIDS)

CANCER

Cancer accounted for one in four deaths in children aged 1–14 years and has increased from 12% in 2007–2018 to **16% of deaths in young people aged 15–18 years** registered during the period 2019–2023.

Cancer accounted for one in four deaths in children aged 1–14 years

INFANT MORTALITY

The provisional infant mortality rate in Ireland for 2022-2023 was **3.2 per 1,000 livebirths**, which is slightly higher than in 2019-2021 (3.1 per 1,000) and is no longer below the EU average.

3.2 Infant deaths per 1000 live births

The overall **infant mortality rate in Ireland has not declined since 2019** and is higher than many other European countries. This is despite a decline in the rate of deaths from leading causes of infant death such as genetic disorders and diseases of the nervous system.

The overall infant mortality rate in Ireland has not declined since 2019

SEX

More boys than girls dies across all age groups (2019-2023)

- **54%** (less than 29 days)
- **51%** (29 days to 1 year)
- **60%** (1-14 years)
- **68%** (15-18 years)

NEONATAL DEATHS

75% of infant deaths occurred during the neonatal period (aged less than 29 days) from 2019–2023, as a result of conditions arising during pregnancy and in the first week of life (56%) and genetic disorders (38%).

75% of infant deaths occurred during the neonatal period

TRAUMA

Trauma accounted for one in five deaths in children aged 1–14 years, and one in two of deaths in young people aged 15–18 years during 2019–2023.

Trauma accounted for one in two of deaths in young people aged 15–18 years

Over one quarter (27%) of all trauma deaths in children aged 1-14 years and **14% of trauma deaths in older children 15-18 years were due to road traffic collisions (RTCs)**. The proportion of RTC deaths registered has declined from 10 to 3.6 deaths per year among children aged 1-14 years and from 9.4 to 3.4 deaths per year of children aged 15-18 years.

27% of all trauma deaths in children aged 1-14 years during 2019-2023 were due to road traffic collisions

SUSPECTED SELF-HARM

Among older children aged 15-18 years, suspected self-harm* remains the leading cause of trauma deaths, making up over half **of trauma deaths (54%) and 28% of all registered deaths** in this age group during the period 2019–2023.

54% of trauma deaths among older children aged 15-18 years are categorised as suspected self-harm

* The figure for suspected self-harm relates to a subset of injury deaths that in the absence of better data are most likely to be self-harm and are an estimate of the true number of self-harm deaths. This figure may vary from Central Statistics Office (CSO) published data on suicide deaths.

SEPSIS & INFECTION

NPMR data collected from one paediatric hospital showed an increase in the number of notifications relating to deaths due to sepsis and/or infection during the period from 1 January 2022 to 31 September 2024 when compared to the previous three years (2019–2021). Review of national data on incidence of childhood infections and crude mortality rates due to infectious diseases is required for accurate interpretation of this observation.

CAPTURING THE PARENT VOICE
MATILDA'S STORY

My name is Rebecca Maher, and I've been invited to tell you about our beautiful daughter Matilda Quinn who died in 2015 at the age of 8 months.

Matilda was our first baby, and like all other first-time parents, my husband Brendan and I had no idea what was in store for us, but looked forward to muddling our way through parenthood. At my 20-week scan, just before Christmas 2014, we were given the devastating news that Matilda was going to be born with a very serious heart condition called hypoplastic left heart syndrome (HLHS). Our baby's life was going to be very different than the one we had imagined.

Our baby daughter was born on Monday 13 April 2015. We called her Matilda, which means 'strength in battle'. Matilda was transferred to Children's Health Ireland (CHI) at Crumlin within 1 hour of being born, and had her first open-heart surgery, the Norwood procedure, when she was just 3 days old. Matilda was very sick in the days following her surgery and there were times when we thought that her tiny heart was not strong enough to get her through, but she lived up to her name and made a speedy recovery. We brought her home on 1 May, when she was two and a half weeks old.

Matilda went from strength to strength in her first few months. She was back in CHI at Crumlin for regular check-ups, but gained weight steadily and did all the things a little baby should do. She was full of smiles, and she loved when we sang songs and read stories. She listened intently and almost seemed wiser than her years. She was a placid, happy baby girl who brought us so much joy.

Following her second scheduled heart surgery (the Glenn procedure) at the end of July, we brought Matilda home again, hoping for a 3-year break until her next major heart surgery was due. This was when her life was due to begin properly. Up until then, we had had to shelter Matilda so much until she was strong enough for that second surgery. Now we could start introducing her to more family and friends and more life experiences, bringing her out and about to enjoy life.

Sadly, Matilda became unwell about 10 days later and we brought her back to CHI at Crumlin, where she was admitted and treated for postoperative complications. Matilda had developed chylothorax, and she had two lung surgeries and several cardiac catheterisations over the next few months, but she gradually became more and more unwell.

"SHE WAS FULL OF SMILES, AND SHE LOVED WHEN WE SANG SONGS AND READ STORIES. SHE LISTENED INTENTLY AND ALMOST SEEMED WISER THAN HER YEARS. SHE WAS A PLACID, HAPPY BABY GIRL WHO BROUGHT US SO MUCH JOY."

By then, Brendan had to go back to work, but I spent all my time in CHI at Crumlin with Matilda, reading her stories and singing her songs, and meeting musicians, play therapists, All-Ireland winning teams and other Irish celebrities who kindly took time out of their days to come and visit. Those visits mean the world to patients and their families, especially long-term patients whose lives are spent waiting for doctors' rounds, weekly meetings such as the Joint Cardiac Conference, and the results of tests and X-rays.

In early December, when Matilda was almost 8 months old, we met with her multidisciplinary team and talked about what lay ahead for Matilda. It was clear that she was a very sick little girl, her heart was failing, and she was not going to recover. On the advice of her medical team, we made the extremely difficult and devastating decision to withdraw the supports Matilda was on and let her go. Matilda passed away in our arms on 7 December 2015, aged almost 8 months old.

Losing a child is one of the most devastating things that can happen to a person and to a family unit. It has changed who I am entirely. Even more than 9 years later, the grief is not any less, I'm just better at carrying it. We are incredibly blessed to have three more children now, who know all about their big sister. She is regularly talked about in our house, and my son Leo sometimes calls on Matilda to guide him through tough tasks. We feel blessed to have been able to give someone else the chance to live a healthy life by donating Matilda's two tiny kidneys to a man in Leeds, which has brought us a lot of comfort.

Since Matilda passed away, we've received support from so many people, including trained professionals, family and friends. Anam Cara, which provides support groups for bereaved parents, has been instrumental in giving me hope that there is life after the loss of a child, and has allowed me to share common experiences with other bereaved parents. I've also been involved with the Health Service Executive's Organ Donation team in raising awareness of the importance of having the conversation, and with the Children's Health Foundation in raising funds for the Children's Heart Centre in CHI at Crumlin in memory of Matilda.

"IF MATILDA HAD BEEN BORN 30 YEARS EARLIER, WE MAY HAVE HAD MUCH LESS TIME WITH OUR BABY GIRL AND SHE LIKELY WOULD HAVE PASSED AWAY IN THE FIRST WEEK OF HER LIFE."

If Matilda had been born 30 years earlier, we may have had much less time with our baby girl and she likely would have passed away in the first week of her life. Thanks to the huge investment in research into paediatric cardiac surgeries, Matilda was given a chance at life and we were given hope of a future with our baby girl. Although Matilda's story ended prematurely, many other children have gone on to live fulfilling lives because of this research, with the oldest surviving patient with HLHS now nearly 40 years old. The importance of research into all aspects of children's medical needs, possible treatments, and even their deaths cannot be understated in the effort to constantly improve outcomes and give sick children and their families the best chance at life.

CHAPTER 1
INTRODUCTION

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CHAPTER 1: **INTRODUCTION**

WHAT IS THE NATIONAL PAEDIATRIC MORTALITY REGISTER?

The National Paediatric Mortality Register (NPMR) compiles and analyses data related to child deaths in Ireland. Existing datasets related to mortality in children and young people (CYP) have various shortcomings; therefore, a reliable national dataset of information on the circumstances and causes of infant and child deaths that is timely and complete for the population is necessary in order to identify issues and trends in child mortality and inform national policies. International practice has demonstrated that mandatory notification at the time of death to a central database is the optimal approach to ensuring the timely and complete capture of all infant and CYP deaths nationally in order to permit adequate reporting and Ireland must evolve to meet international standards (National Office of Clinical Audit, 2023a).

AIM

The aim of the NPMR is to provide a national database of standardised information on all CYP deaths in Ireland, generating high-quality data in order to provide an evidence base with which to drive improvements in the quality of care and services for children in Ireland and reduce the number of CYP deaths.

OBJECTIVE 1

Provide a system for continuous national surveillance of all deaths in children aged 0–18 years, regardless of cause, that occur both in hospital and in the community.

OBJECTIVE 2

Collect complete, standardised and timely data from multiple sources on the magnitude and characteristics of CYP deaths in Ireland.

OBJECTIVE 3

Build an epidemiological database of information on all CYP deaths and provide critical analysis of data in order to identify trends and subsequent recommendations on factors impacting on CYP mortality.

OBJECTIVE 4

Conduct audit, quality improvement and research studies relating to the occurrence and underlying causes of CYP deaths, and use this information to provide evidence for informing policy aimed at improving outcomes and reducing the number of CYP deaths.

OBJECTIVE 5

Liaise with senior decision-makers at both policy and operational level in order to implement recommendations.

RATIONALE FOR MONITORING CHILD MORTALITY

Although mortality in children has declined globally, many potentially avoidable deaths continue to occur among children of all ages. Beyond infancy, the most common cause of death in children and adolescents is accident and injury, with children in disadvantaged areas being disproportionately affected (Odd *et al*., 2022; Armour-Marshall *et al*., 2012; Pearson *et al*., 2011a; Peden *et al.*, 2008; Polinder, 2008; Sethi *et al.*, 2008; Dowswell and Towner, 2002). However, there is currently very little accurate contemporary data available on the circumstances and causes of death in children and on how many die every year, whether in hospital or at home, and from what causes (particularly for those aged over 5 years). Many deaths are avoidable, and there is now an urgent need to identify the factors that contribute to these deaths in Irish society so that appropriate intervention measures can be applied.

Currently available data (i.e. death certificate details provided by Ireland's central death registration unit, the Central Statistics Office (CSO)) cannot be used in order to identify avoidable causes of death due to their limited information on contributory factors. In addition, delays in the registration of deaths mean that data based on the year in which deaths occur are not available until several years following those deaths, and that these data are also subject to inaccuracies related to the categorisation of some deaths (Macken *et al*., 2015; Shilling *et al*., 2013; Corcoran *et al.*, 2006). Previous reviews of death certificates and of the causes of death in other jurisdictions have demonstrated errors, inaccuracies and misclassifications of infant and CYP deaths (Pearson *et al*., 2011b; Johansson *et al*., 2006; Hunt and Barr, 2000).

Other data sources – such as the National Cancer Registry Ireland, National Office of Clinical Audit (NOCA) audits (including the Major Trauma Audit (MTA) and the Irish Paediatric Critical Care Audit (IPCCA)), and the National Perinatal Epidemiology Centre (NPEC) – are specific to a disease, site or age and do not inform paediatric mortality reports. NPMR does not include deaths occurring in maternity units and does not make recommendations relating to neonatal deaths which is the remit of NPEC.

Narrowing the gap in child mortality rates remains a core objective of the global health community (WHO, 1999). The need for a robust health information system in order to better monitor health inequalities in Ireland was highlighted in a recent Economic and Social Research Institute (ESRI) report (Duffy *et al*., 2022). This study found that although mortality rates have fallen in Ireland since 2000, inequalities remain between different population groups; however, deficits in Irish data meant that it was not possible to examine socioeconomic inequalities among the infant and child populations in Ireland. Accurate data are required in order to generate improvements in the quality of care for children and their families. The WHO cites the collection of accurate national mortality data as an essential element of the paediatric mortality and morbidity auditing process (WHO, 2018).

BACKGROUND ON THE NPMR

The NPMR began as an evolution of the National Sudden Infant Death Register, which initiated data collection in 1992. The purpose of this register was to obtain accurate, up-to-date information on sudden, unexpected and unexplained deaths in infants and to promote and support research into the causes and prevention of sudden infant death syndrome (SIDS). The resulting epidemiological database provided the evidence base for the development of guidelines for parents and professionals on reducing an infant's risk of SIDS. This led to a substantial reduction in the number of SIDS deaths, from an average of 150 deaths per year in the late 1980s and early 1990s to fewer than 30 deaths per year by 2015 (NPMR 2015). Subsequently, the register's remit and data collection system were extended to include all paediatric deaths, regardless of cause and age, with the primary objective of addressing preventable deaths in all age groups; and it was renamed the National Paediatric Mortality Register in order to accurately reflect the dataset. The NPMR aims to implement a standardised system for the timely analysis and reporting of all child deaths nationally.

CURRENT DEATH REGISTRATION PROCESS IN IRELAND

Current legislation in Ireland requires that a death is registered within 3 months of the date of death (Part 5 of the Civil Registration Act 2004). This legal requirement is met in only four out of five deaths (Department of Social Protection: General Register Office, 2021). The obligation to register a death rests with the relatives of the deceased, who must complete a death notification form (Medical Certificate of the Cause of Death) provided by a medical practitioner. The Medical Certificate of the Cause of Death is submitted to the Register of Deaths, and a death certificate is then issued. Where a death is referred to a coroner, further investigations may be needed and a coroner's certificate is issued to the General Register Office (GRO). Where a death involves an inquest, the coroner determines the cause of death.

Delays in the registration of deaths mean that CSO annual data reflect statistics based on the year of registration only. These data may differ substantially from year of occurrence data, particularly in relation to sudden, unexpected and unexplained deaths in children. In any given year, the reported statistics from the CSO will include only deaths registered in that current year along with those registered in the previous year, and adjusted figures are published in subsequent years. This process varies from that observed in other European jurisdictions, where delayed registration is not permitted and deaths are registered within days of when they occur (Bird, 2012).

The Department of Social Protection has introduced changes to the Civil Registration Act 2004 that reduces the time frame within which a death must be notified and registered and improves the death registration process in Ireland. The Civil Registration (Electronic Registration) Act 2024 was published on 17 July 2024 and provides for the electronic notification of all deaths in Ireland. Under the provisions of the Act, deaths will be electronically notified to the GRO and to the Health Service Executive (HSE) within 5 working days from the date of death, and the next-of-kin will then be notified of their duty to register the death within 28 days using the existing in-person service or the new online facility that will be made available. Where a death is subject to an ongoing investigation or inquiry by a coroner, an interim death certificate will be made available to the bereaved family.

WHAT IS THE PURPOSE OF THIS REPORT AND WHY IS THIS REPORT IMPORTANT?

The first NPMR report under the governance of NOCA was published in October 2023 and outlined the deficits in existing paediatric mortality data and the need for a universal system for the notification of all CYP deaths to a central database for the analysis and reporting of data. The report also presented findings from an analysis of the currently available data on mortality in children. However, more granular detail is required in order to prescribe evidence-based change to reduce the number of premature CYP deaths. This report builds on the information provided in the inaugural NPMR report.

The NPMR is responsible for analysing national mortality metrics for the paediatric population. Critical to achieving this is the standardisation of data, data sources, and data input processes in order to ensure that data are quality assured, timely, robust, fit for purpose and actionable. The benefits and quality improvement potential of a national operational NPMR are that it:

- provides accurate national mortality rates for the CYP population in Ireland and improves accuracy in the reporting of child mortality statistics
- allows for population-based surveillance of child deaths for the purpose of monitoring trends
- provides baseline information for identifying broader areas of concern that requires further attention, and for informing the agenda for paediatric audit (e.g. highlighting differences between groups and identifying those who are at greater risk)
- provides actionable data in order to inform and evaluate public health policy that is relevant to CYP mortality in Ireland
- facilitates the incorporation of all relevant paediatric autopsy information
- allows for the evaluation of the accuracy and quality of cause of death registration information
- provides information to contribute to the development of benchmarks for reporting and categorising child deaths
- provides national data to support the development of the recommended child death review process.

GOVERNANCE AND MANAGEMENT OF THE NPMR

The NPMR sits within the governance framework of NOCA. NOCA enables the continuous improvement of the healthcare system in the Republic of Ireland by maintaining a portfolio of prioritised national clinical audits measured against national and international standards.

NOCA is funded by the HSE National Quality Improvement Team, is governed by an independent voluntary board, and is operationally supported by the Royal College of Surgeons in Ireland (RCSI).

The NPMR was transferred to NOCA from Children's Health Ireland (CHI) at Temple Street in October 2020, and a new Governance Committee was established in order to oversee the implementation of the NPMR's objectives. The NPMR Governance Committee supports and advises the NPMR clinical leads on the operation of the audit, and these clinical leads report to the NOCA Governance Board (Figure 1.1) In addition, the NPMR Governance Committee provides guidance on the strategic direction of the NPMR. Please refer to Appendix 1 for a list of NPMR Governance Committee members in 2023–2024.

WHO IS THIS REPORT AIMED AT?

The report has been presented in two parts:

1. The main *National Paediatric Mortality Register: Second National Report 2025* is primarily aimed at:
   - healthcare professionals, hospital managers and Health Regions
   - paediatricians and multidisciplinary teams in the HSE and voluntary hospitals and other units caring for families
   - coroners
   - policy-makers (e.g. the HSE Department of Public Health, the Tusla Early Years Inspectorate)
   - nursing, public health and midwifery colleges
   - bereavement support groups
   - researchers and academics.
2. The companion report, the *National Paediatric Mortality Register: Summary Report 2025*, is aimed at parents and families, carers and advocates, patient advocacy organisations, and the general public.

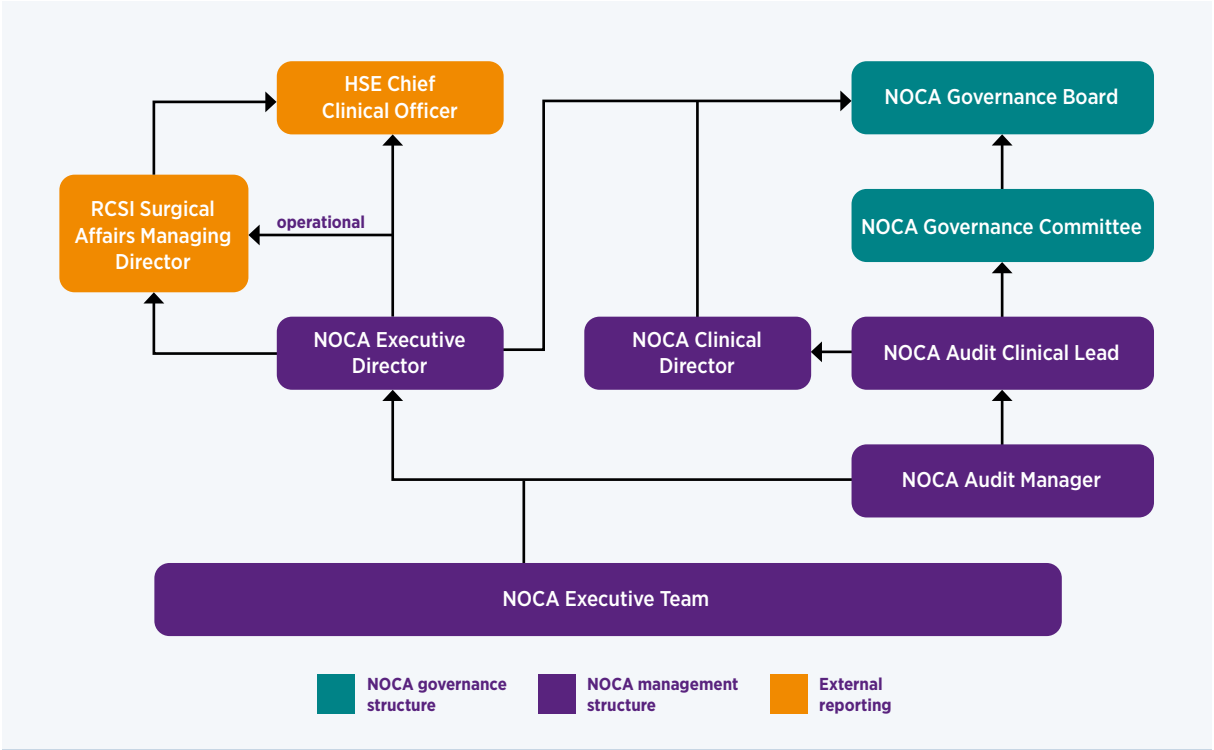

FIGURE 1.1: AUDIT GOVERNANCE AND MANAGEMENT FOR THE NATIONAL OFFICE OF CLINICAL AUDIT

CHAPTER 2
METHODOLOGY

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CHAPTER 2: **METHODOLOGY**

The purpose of this report is to provide an overview of CYP mortality data in Ireland and to support the implementation of an improved, centralised system for the notification of deaths that will permit the analysis and timely reporting of CYP mortality data.

There are several components to this report, which are presented in the following chapters,

Chapters 4, 5 and 6 present the results of the analysis of currently available mortality data.

Chapter 7 provides data captured through the NPMR child death notification process in one paediatric hospital as well as further description of development work that is currently ongoing in order to support implementation of an NPMR Child Death Notification form.

DATA SOURCES

The data included in this report are derived from the following sources:

1. CSO death registration information

2. NPMR Child Death Notification from data from one CHI hospital.

International figures were retrieved from the Eurostat and WHO websites for comparison, where available.

DATASET 1: CSO DEATH REGISTRATION INFORMATION

Data collection

The CSO compiles annual data files generated by the GRO relating to all live birth, stillbirth, death and marriage registrations in Ireland. As a registered research organisation, NOCA is granted access to the CSO death registration information files or Research Microdata Files (RMFs) via a memorandum of understanding between the CSO and the RCSI through NOCA (NOCA, 2022). Access to RMFs is granted to researchers who meet the conditions and criteria designated by the CSO. The CSO controls NOCA's access to the RMF data by means of a Researcher Data Portal, and all analysis takes place within the CSO's information and communication technology systems. The results of this analysis are tabulated as aggregate data and are subject to CSO approval prior to being extracted from the Researcher Data Portal for inclusion in this report. The researcher must apply the following rules to outputs:

- Identifiable details will not be presented.
- Cells containing values of less than 5 will not be presented.
- Data are to be disseminated in aggregates (i.e. a person should not be identifiable in the data).
- The tabular outputs should not contain age group, sex and location in the same output table.

Death registration details include demographic details (including age and sex), date of death, home address, place of death, cause of death, the coroner's region, and the name and place of occupation of the physician signing the death certificate (this applies only to deaths not involving a coroner).

Information governance

Data are collected under the Civil Registration Act 2004 and provisions of the Statistics Act, 1993, which permits access to RMFs under strict conditions in order to ensure that the integrity and confidentiality of the data collected under the Act is maintained. Access is granted for scientific and statistical purposes only. The national statistical confidentiality provisions are reinforced by European Union legislation, specifically Regulation (EC) No 223/2009 on European statistics. NOCA staff working with the CSO data are Officers of Statistics under the Statistics Act, 1993 and have signed a declaration of secrecy under that Act.

Inclusion criteria

All deaths of children and young people aged 0–18 years registered in Ireland for the period 2019–2023 are included in this analysis. These data are compared with data that were previously provided to the NPMR for the period 2007–2018.

Exclusion criteria

Any registered deaths where the age of the deceased is 19 years or over are excluded, as are late registrations of deaths that occurred more than 2 years prior to 2019. NPMR does not collect data from maternity units but does include neonatal deaths that occur in other hospitals.

Data validation

Data validation consists of a data analyst reviewing the dataset for errors, such as multiple entries of the same death, whether age correlates logically with the date of registration, or registrations that occurred more than 2 years after the date of death.

DATASET 2: NPMR CHILD DEATH NOTIFICATION FORM DATA

The NPMR Child Death Notification form was designed to facilitate the prompt notification of child deaths to a central unit for analysis and reporting. The use of this form produces a minimum core dataset of information on child deaths, the objective of which is to enable accurate, standardised and timely reports on which children die in CHI at Temple Street, the location of these deaths and the cause. These data provide an indicator of performance in relation to infant and CYP mortality. The data points and format of the pilot NPMR Child Death Notification form were produced following extensive consultation with key stakeholders. Completion of this form was approved by various relevant committees within CHI at Temple Street, and is embedded in hospital policy and included on a checklist of actions for staff whenever a child dies in the hospital (see Appendix 2 for a copy of the NPMR Child Death Notification form).

Data collection

Copies of the NPMR Child Death Notification form are contained in the bereavement boxes found in all hospital departments. Forms are completed by the hospital consultant in charge of the child's care at the time of death, and are forwarded directly to dedicated personnel at the NPMR in NOCA via a designated email address (npmr@noca.ie). On-site support from a coordinator is required in order to allow follow-up on data anomalies. The form is available in paper format or can be completed online and either scanned or directly attached to the email. A copy of the form is included in the patient chart. Upon receipt of the form, NOCA personnel enter the data into a Microsoft Excel spreadsheet using an associated coding system. Data are transferred to statistical software Stata for analysis.

Information governance

Data relating to deceased individuals are not subject to the General Data Protection Regulation (GDPR); however, the data are treated as sensitive information, and all appropriate privacy and security measures are adopted. Forms are sent via email to a designated email address with restricted access. Forms are saved to a restricted access location on the NOCA secure network, and the original associated emails are deleted.

Inclusion criteria

All deaths in children aged under 19 years, regardless of cause or where the child died and regardless of whether the death was a coroner's case, are included in this analysis.

Exclusion criteria

Any deaths where the age of the deceased is 19 years or over at the time of death are excluded from this analysis. Neonatal deaths that occur in maternity units are not captured by NPMR as data on these cases are collected by NPEC.

STATISTICAL ANALYSIS OF DATA

Analysis of numerical and descriptive data received from CSO death registration information and NPMR Child Death Notification forms was conducted in Stata.

As per the NOCA information governance policy (O'Donovan, 2022) and CSO guidance (Linehan and Dineen (n.d.)), all data included in this report were subjected to statistical disclosure control processes in order to ensure the suppression of data to acceptable levels. This included adherence to the following suppression/disclosure limitation rules:

- Identifiable quantitative data will not be presented.
- Only aggregate data will be included.
- No cell will contain more than 90% of the total number of units in a row or column.
- There is a threshold rule of 5 (cells containing values of less than 5 will be redacted).

Data are reported using population-based mortality rates and trends over time. Population estimates for various age groups used to calculate crude mortality rates were retrieved from the CSO interactive databases at http://www.cso.ie/en/statistics/population. The data were reported as:

- annual number of deaths by age and sex
- annual number of deaths by place of death (hospital versus elsewhere)
- annual number of deaths by cause of death category.

Annual trends in the number of deaths and the main contributory causes of death in each age group were examined in order to identify trends and events over time, and comparisons were made with international data where possible. Three-year moving average rates were used to address potential fluctuations due to random variation in order to smooth the data and provide a clearer picture of mortality patterns with minimal loss of information. Proportionate mortality due to external causes was calculated in order to determine the proportion of deaths in each age group due to specific causes, while cause-specific mortality rates were calculated in order to determine the risk of death due to injury within each age group. Crude mortality rates for various subcategories were expressed as aggregate blocks of data over the course of 2, 3 and 5 years in order to avoid disclosure issues and permit further analysis of the data. Overall percentage changes in mortality rates relative to baseline were estimated using the following calculation:

[(average comparative rate) − (average baseline rate) ÷ (average baseline rate)] × 100

STATISTICAL PROCESS CONTROL CHARTS

Annual trends in the main contributory causes of death among infants and among children aged 1–14 years were examined using statistical process control (SPC) charts. These charts were created using a Microsoft Excel template that contained underlying macros to create individual SPC charts. This tool, designed specifically for healthcare quality improvement, helped track death rates and distinguish between common cause variations (natural fluctuations) and special cause variations, which indicate significant improvements or causes for concern that require further attention. The importance and reliability of SPC charts is demonstrated by both the HSE and the National Health Service in the United Kingdom actively promoting their use as an essential tool for quality improvement in healthcare.

Data from the CSO database were used in order to calculate the death rates (deaths per 1,000 live births) for the main contributory causes of death in infants between 2008 and 2023. Similarly, the death rates (deaths per 100,000 population) were calculated for the main contributory causes of death among children aged 1–14 years between 2008 and 2023. The death rates were subsequently input into the SPC XmR tool, which generated SPC charts corresponding to each primary cause of death for the relevant age groups.

Each SPC chart was carefully examined in order to identify trends, shifts and patterns. This analysis highlights which main causes of death are improving or deteriorating over the specified period. It indicates to practitioners and clinicians where death rates are increasing at a concerning rate and need to be investigated further. It also highlights which death rates are significantly improving and would be worth examining in order to determine what led to this improvement.

Unfortunately, there were insufficient data with which to generate SPC charts for the main causes of death among older adolescents aged 15–18 years. For this age group, data were available for the period 2012–2023 only, which does not meet the minimum of at least 15 data points in order to create a robust SPC chart. Instead, basic run charts were generated. The main difference is that the run charts do not contain upper and lower control limits; otherwise, they abide by similar rules as SPC charts for identifying variation over time.

See Appendix 8 for a guide to interpreting the rules of SPC charts.

EVIDENCE SYNTHESIS & FORMATION OF RECOMMENDATIONS

A core writing group which included the NOCA Paediatric Programme Manager, the Clinical Lead for NPMR and Chair of the NPMR Governance Committee, reviewed the results of the data analysis. The interpretation of results, conclusions and recommendations from each component were discussed and agreed at writing group and NPMR Governance Committee meetings. Owners were identified for each recommendation and were contacted for comment and in order to aid implementation. Consultation with stakeholders – both from the NPMR Governance Committee and external stakeholders identified by the Chair of the writing group – ensured that recommendations were informed by relevant sources of information, knowledge and expertise. This ensured that the recommendations were factually correct and aided in the identification of appropriate owners.

CHAPTER 3
DATA QUALITY

Coverage of Data Release

Completeness of Data Release

Accuracy of Data Release

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CHAPTER 3: **DATA QUALITY**

This chapter is an assessment of the quality of the mortality data in this report using internationally agreed dimensions of data quality, as laid out in the Health Information and Quality Authority's (HIQA's) *Guidance on a data quality framework for health and social care* (HIQA, 2018) and outlined in Tables 3.1, 3.2 and 3.3.

TABLE 3.1: CONTEXT OF THE DATA QUALITY STATEMENT

SCOPE	This data quality statement provides an assessment of the data released for this report. This statement solely focuses on the data quality dimension of accuracy and reliability, and specifically on the following characteristics which are outlined in Table 3.2: • coverage of data release • completeness of data release • accuracy of data release. This can be used in conjunction with an assessment of the characteristics of this NPMR dataset.
PURPOSE	This statement will help the reader decide whether the data are fit for the user's specific purpose.
DATA SOURCE	The sources of data for this report are CSO death registration information, and NPMR Child Death Notification forms, which are forwarded directly to NOCA from CHI at Temple Street.
TIMEFRAME OF DATA RELEASE	**CSO death registration information:** 1 January 2019 to 31 December 2023 **NPMR Child Death Notification form**: 1 January 2019 to 30 September 2024
TYPE OF DATA	The NPMR datasets are final. CSO death registration information is subject to revision based on late registrations. Revised year of occurrence data used for reviewing trends in SPC charts is final.

TABLE 3.2: CHARACTERISTICS OF DATA QUALITY

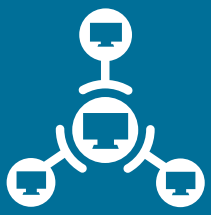
Coverage of data release 	**CSO death registration information:** The CSO collects details of all deaths registered nationally by the GRO. This report covers the 5-year period from January 2019 to December 2023. The CSO death registration information dataset is used to report on deaths in the following CYP age groups: infants aged under 1 year, children aged 1–4 years, children aged 5–9 years, children aged 1–14 years and young people aged 15–18 years. These age groups were chosen for comparability with international data on paediatric mortality. **NPMR Child Death Notification form**: The form is currently implemented in just one paediatric unit (CHI at Temple Street). This form was introduced in paper format as a pilot study to inform the feasibility and implementation of a national system for the timely collection of death notifications and will continue until the electronic data collection tool is introduced. All deaths occurring in CHI at Temple Street and pronounced in the emergency department or for those who die at home as patients of the hospital are included in the dataset.
Completeness of data release 	**CSO death registration information**: Details of 100% of CYP deaths registered during the period 2019–2023 are contained in the CSO dataset. Completeness of the dataset was no less than 99.4% for all variables included, with most variables being 100.0% complete. Validation checks by NOCA data analysts showed a high degree of completeness for all variables included in the CSO death registration information dataset. **NPMR Child Death Notification form**: Submitted forms were cross-checked with CHI at Temple Street's integrated patient management system (iPMS) and showed that 83.3% of inpatient deaths in CHI at Temple Street were notified to NOCA in 2019, 52.6% in 2020 and 72.7% in 2021. The lower capture rate in 2020 was due to dedicated staff absences during the coronavirus disease 2019 (COVID-19) pandemic. Data on identified missed cases were collected retrospectively by the dedicated local audit coordinator. The capture rate improved for the second period from 1 January 2022 to 30 September 2024, from 64% in 2022 to 78% in 2023 and 96% in 2024. A detailed breakdown of numbers is provided in Table 7.1. The data showed a high degree of completeness for all variables included: 90% of all variables included in the dataset had a capture rate of ≥80% (see Chapter 8 and Appendix 6).
Accuracy of data release 	**CSO death registration information**: All deaths in Ireland should be registered within 3 months from the date of death (Civil Registration Act 2004). However, unnatural deaths are the exception, as all such deaths are subject to a coroner's investigation, and some cases can take approximately 2 years to finalise. Provisional data are published on a quarterly basis. A large proportion of CYP deaths are sudden and unexpected, and as such, files based on year of registration will not account for all deaths that occurred in that particular year. Mortality statistics based on the year of occurrence are published by the CSO in subsequent years. Approximately one-third of CYP deaths in any particular year are registered in the following year, which renders the dataset incomplete with respect to the true number of annual deaths. Table 3.2.1 shows the number of late registrations for the population aged 0–18 years from 2019 to 2023.

TABLE 3.2: CHARACTERISTICS OF DATA QUALITY

Accuracy of data release

TABLE 3.2.1: PROPORTION OF LATE REGISTRATIONS FOR THE POPULATION AGED 0–18 YEARS DURING THE PERIOD 2019–2023

Year	Total deaths registered	Late registrations*	
	N	n	%
2019	311	106	34%
2020	268	89	33%
2021	299	123	41%
2022	299	108	36%
2023	313	145	46%

* Deaths registered in each year that occurred in a previous year (among those aged 0– 18 years).

The average proportion of late registrations was 36% in the period 2019-2021 v 41% in the period 2022-2023.

All cause of death coding strictly follows the WHO's International Classification of Diseases, Tenth Revision (ICD-10) guidelines to ensures statistics are internationally comparable (WHO, n.d.). The same variables are collected for the deceased irrespective of what region the deceased resided in. The GRO sends reconciliation sheets containing the reference number of each death to the CSO weekly and the number of deaths in the system are checked against this sheet.

Cause of death coding is complicated and has a subjective element meaning that variation may occur. Conventional categorisation of deaths based on ICD-10 coding is not optimal for use in the clinical setting in relation to CYP. These particular codes are not often used in the paediatric clinical setting; for example, using the term 'circulatory' in relation to coronary heart disease is reasonable in adults, but for infants and children, causes of death more often relate to congenital heart disease and anatomical lesions, which would be more appropriately classified as 'cardiac/coronary heart disease', despite the ICD-10 coding guidelines. Similarly, the classification of deaths as being due to diseases of the nervous system is more likely to be appropriate in adults than in CYP. Data for the CYP cohort of patients will have to be further classified in order to present them in a clinically meaningful way.

NPMR Child Death Notification form: Validation checks are carried out by NOCA staff upon receipt of the forms, and the hospital is consulted in relation to potential errors and omissions. Variables with a high degree of error were reviewed as part of the NPMR Child Death Notification Form pilot study. Data on the date on which the forms were completed were collected and compared with data on the date of death in order to determine the time lag between each death and the date of notification. For the period 2019–2021, almost one-half (48%) of cases were notified within 24 hours, 66% were notified within 3 days, 73% were notified within 1 week and 100% were notified within 1 month. Of the cases that were notified during the period 2022–end of Q3 2023, 71% were notified within 24 hours, 80% were notified within 2 days, and 85% within 1 week and all deaths (100%) were notified to the NPMR within 1 month (Appendix 7).

NPMR records will be defined as complete when all validation checks have been fulfilled.

TABLE 3.3: ASSESSMENT OF DATA QUALITY

Strengths of data in this report	**CSO death registration information:** Currently, this is the only dataset that is complete for the CYP population and can be readily stratified for this population. Because the information is identifiable it is possible to ensure that there is no double counting of patients. The data contain basic demographic information on all CYP deaths nationally, including cause of death. The cause of death data are based on a regulation that defines the scope, definitions of variables and characteristics of the data. Underlying cause of death is categorised according to the WHO's ICD–10 (WHO, n.d.) using an automated coding system called IRIS (CSO, n.d. a). There is ongoing training by senior mortality coders in order to ensure the consistency of coding. **NPMR Child Death Notification form**: The information obtained from the use of the initial paper-based NPMR Child Death Notification form in CHI at Temple Street has helped to inform the process for national implementation of a centralised system for the timely, standardised notification of CYP deaths. This system is being designed to capture all CYP deaths regardless of cause and age, and will be developed to include both in-hospital deaths and deaths that occur in the community. The data demonstrate that the capture and timely reporting of data on CYP deaths is feasible. The completion rate of the form was high and unlike the CSO death registration information, the data are reported based on year of occurrence and are final. Collection of suspected cause of death data allows information to be submitted that will permit the identification of emerging trends and clusters of deaths early on. Process mapping has identified multiple options for validation of the dataset, including inpatient management systems, pathology and social work department databases.
Limitations of data in this report	**CSO death registration information:** The quality of the cause of death coding depends on good medical information on the death certificate. Although the CSO data are population based, there are limitations to their use, including the following: • Delays in registration: result in discrepancies in figures based on year of death versus year of registration. This is particularly relevant to CYP deaths, many of which are coroner's cases, and particularly where there is an inquest into the death. This makes it difficult to identify any emerging public health issues (Table 3.2.1). • Lack of detail on the circumstances of death mean that it is not possible to provide an accurate description of the causes of death or to identify any contributory factors. Hence it is not possible to describe injury deaths according to intent. Systematic capture and review of this information provides learning opportunities and can inform intervention measures. • Lack of health equity stratifiers in the dataset prohibits the examination of health inequities within this dataset. • The CSO is currently unable to permit linkage to other data sources. **NPMR Child Death Notification form**: The proposed NPMR Child Death Notification form is not yet operational nationally. The optimal model for the NPMR Child Death Notification form will have the ability to link to various data sources relating to each individual, including CSO death registration information, Hospital In-Patient Enquiry (HIPE) data, autopsy reports and NPMR data. This is currently not possible due to the lack of a unique patient identifier. However, progress is being made since the enactment of the Health Identifiers Act in 2014, and the individual health identifier (IHI) project is now being rolled out across healthcare services in Ireland. The NPMR Child Death Notification form dataset will measure the timeliness of data collection and present how many death events are completed on the NPMR database within 24 hours and 5 days of occurrence, which is the new standard being implemented by the Department of Social Protection for notification of all deaths to the HSE. NPMR Child Death Notification form records will not be defined as complete until all validation checks have been fulfilled. The international standard used by the United Kingdom (UK), among other countries, for the official notification of deaths is 48 hours from the time of death. The suspected cause of death entered on the NPMR Child Death Notification form may not be the same as what the eventual certified cause of death is. Revised figures must be included in future reports.

CHAPTER 4
INFANT MORTALITY RATES

CONTENTS

CHAPTER 4: **INFANT MORTALITY RATES**

The data presented in this chapter are based on analysis of death registration information for the infant population aged under 1 year in Ireland and relate to data from the period 2019–2023. Estimates are provided of the age and sex distribution of infant mortality in Ireland, along with the main causes of infant death for the period 2019–2023.

BACKGROUND

Infant mortality rates (IMRs) are an important indicator of the overall health of a society because they reflect the social, environmental and economic conditions in which children live. Factors that can have an effect on IMRs include maternal health, quality of and access to medical care, socioeconomic conditions, and public health practices. Globally, the IMR decreased from an estimated rate of 65 deaths per 1,000 live births in 1990 to 29 deaths per 1,000 live births in 2018, and the annual number of infant deaths decreased from 8.7 million in 1990 to 4.0 million in 2018 (WHO, 2023).

The WHO defines the IMR as "the probability of a child born in a specific year or period dying before reaching the age of one, if subject to age-specific mortality rates of that period" (WHO, 2023), and it expresses the percentage as the number of deaths per 1,000 live births annually. This is most often calculated using official birth and death registration systems.

ANNUAL TRENDS IN INFANT MORTALITY IN IRELAND

The IMR in Ireland has demonstrated a gradual downward trend over time, decreasing from 8.2 deaths per 1,000 live births in 1990 to a low of 2.8 deaths per 1,000 live births in 2019 (see Figure 4.1, Table 4.1). This rate is one-half of the average rate recorded for the late 1990s and early 2000s.

There has been no further decrease in the IMR since 2019, however, and the data indicate an increase to 3.3 deaths per 1,000 live births in 2022 (an increase of 18% on 2019) and 3.1 deaths per 1,000 live births in 2023. Provisional data from the CSO indicate an IMR of 3.3 deaths per 1,000 live births for Q1 2024 (CSO, 2024).

The decrease in overall IMRs is reflected in a similar pattern of decline in both neonatal and postneonatal mortality rates, although mortality rates in the neonatal age group are consistently higher than those in the postneonatal age group. The postneonatal mortality rate (PNMR) has seen a greater reduction than the neonatal mortality rate, largely due to the decline in the incidence of SIDS deaths. The PNMR recorded for 2022 is the highest recorded since 2014. The data behind most figures are provided in corresponding frequency tables in Appendix 3.

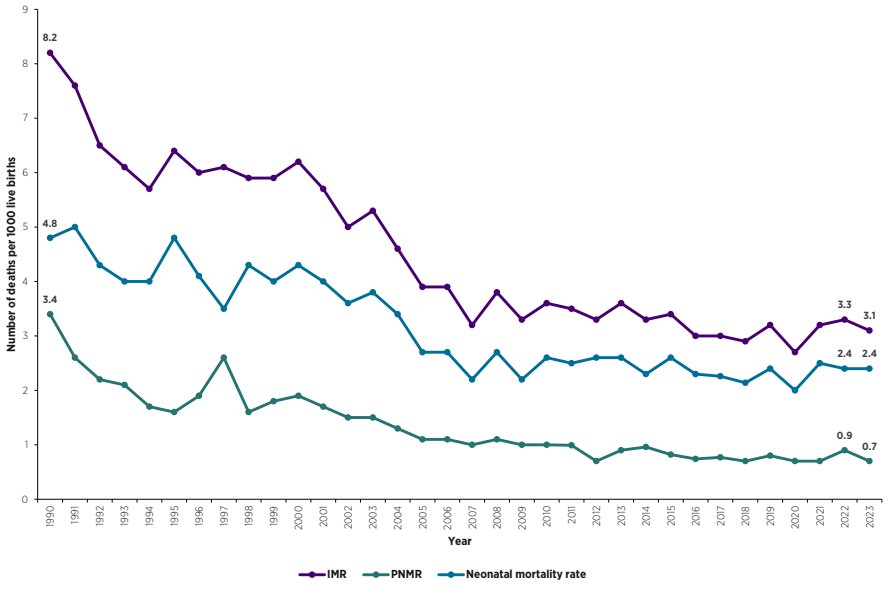


FIGURE 4.1: ANNUAL TRENDS IN INFANT, POSTNEONATAL AND NEONATAL MORTALITY RATES IN IRELAND, 1990–2023

Note: Data are based on year of registration. These data are distinct from data published by the National Perinatal Epidemiology Centre (NPEC) which reports on early and late neonatal deaths.

COMPARISON WITH INTERNATIONAL RATES

The most recent available IMRs reported for various European countries and the UK (for the year 2022) are outlined in Figure 4.2. Infant mortality has sharply declined over the past three decades (Eurostat, 2021). At 3.3 deaths per 1,000 live births, the IMR in Ireland is the same as the EU average rate for 2022, but it is higher than those in many other European countries, including Sweden and Estonia (2.2 deaths per 1,000 live births), Finland (2.0 deaths per 1,000 live births), Norway (1.9 deaths per 1,000 live births) and Iceland (1.4 deaths per 1,000 live births). Data on EU IMRs were obtained online from the Eurostat Data Browser, available at http://ec.europa.eu. The UK figure was retrieved from the Office for National Statistics (Office for National Statistics, 2023). Overall, there has been a sharp decline in infant mortality in the EU since 2009, when there were 4.3 infant deaths per 1,000 live births (Eurostat, 2021; Onambele *et al*., 2019).

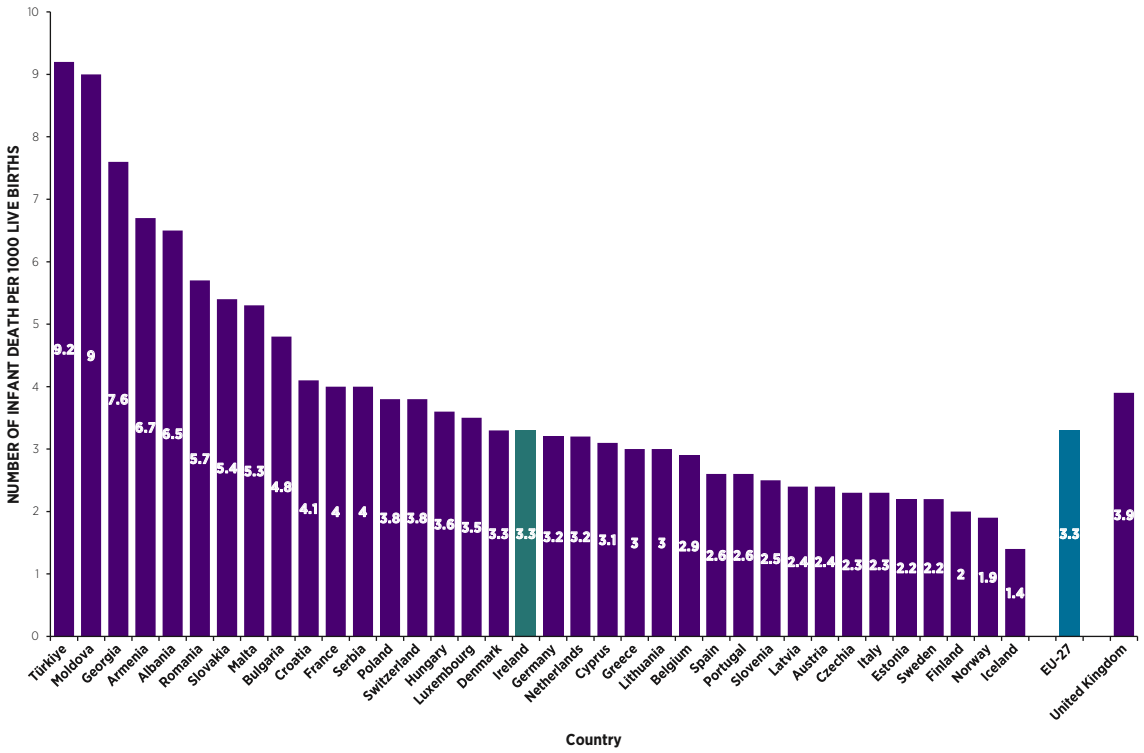


FIGURE 4.2: INFANT MORTALITY RATES IN SELECTED EUROPEAN COUNTRIES AND THE UNITED KINGDOM, 2022

INFANT, POSTNEONATAL AND NEONATAL MORTALITY RATES IN IRELAND, 2019–2023

Table 4.1 provides the number of infant, postneonatal and neonatal deaths registered with the GRO in Ireland for the period 2019–2023, alongside adjusted figures based on the year in which the deaths occurred as reported by the CSO. Year of occurrence data are used in order to calculate accurate infant, neonatal and postneonatal mortality rates per 1,000 live births during the same period. These data indicate increases in both the overall number of deaths and in the infant, neonatal and postneonatal mortality rates in 2022 in comparison with the previous 3 years. This increase was not sustained in 2023.

Data based on year of death are not available for the analysis of factors such as sex, place of death and cause of death. For this reason, data averages for the 2-year registration period for 2022 and 2023 are used in order to provide estimates of those variables.

TABLE 4.1: NUMBER AND RATE OF INFANT, POSTNEONATAL AND NEONATAL DEATHS IN IRELAND, BY YEAR OF DEATH AND YEAR OF REGISTRATION, 2019–2023

Data based on the year in which the deaths were registered with the GRO							
Year	**Number of live births**	**Total number of infant deaths (aged <1 year)**	**Number of neonatal deaths (aged ≤28 days)**	**Number of postneonatal deaths (aged 29–364 days)**	**IMR (number of infant deaths per 1000 live births)**	**Neonatal mortality rate (number of neonatal deaths per 1000 live births)**	**PNMR (number of postneonatal deaths per 1000 live births)**
2019	59 294	190	142	48	3.2	2.4	0.76
2020	56 812	153	112	41	2.7	2.0	0.72
2021	60 575	192	151	41	3.2	2.5	0.68
2019–2021	**176 681**	**535**	**405**	**130**	**3.0**	**2.3**	**0.74**
2022	57 540	191	140	51	3.3	2.4	0.88
2023	54 678	172	132	40	3.1	2.3	0.69
2022–2023	**112 218**	**363**	**272**	**91**	**3.2**	**2.4**	**0.81**

Data based on the year in which the deaths occurred							
Year	**Number of live births**	**Total number of infant deaths (aged <1 year)**	**Number of neonatal deaths (aged ≤28 days)**	**Number of postneonatal deaths (aged 29–364 days)**	**IMR (number of infant deaths per 1000 live births)**	**Neonatal mortality rate (number of neonatal deaths per 1000 live births)**	**PNMR (number of postneonatal deaths per 1000 live births)**
2019	59 294	167	128	39	2.8	2.2	0.66
2020	56 812	178	134	44	3.1	2.4	0.77
2021	60575	199	152	47	3.3	2.5	0.78
2019–2021	**176 681**	**544**	**414**	**130**	**3.1**	**2.3**	**0.73**

Note: Data for 2022 and 2023 are provisional and based on year of registration. Birth figures for 2022 and 2023 are provisional. Quarterly and yearly Vital Statistics Summary reports from the CSO provide figures on the number of births and deaths registered in a calendar year. Not all life events that are registered in a given year actually occur in that particular year (e.g. of the 54,678 births that were registered in 2023, 91.1% occurred in 2023, with the remainder occurring in 2022). These data are distinct from data published by the NPEC, which reports on early and late neonatal deaths.

Source: CSO (year of occurrence data), retrieved from the CSO infant mortality data file at http://data.cso.ie/.

AGE AND SEX DISTRIBUTION OF INFANT DEATHS, 2019–2023

The age and sex distribution of all deaths in children aged under 1 year in Ireland during the period 2022–2023 are outlined in Figures 4.3 and 4.4. Every year, the majority of infant deaths occur during the neonatal period, neonatal deaths accounted for 75% of all infant deaths during the period 2022–2023. A similar percentage was also reported for the previous 3-year period (2019–2021).

As in previous years, the sex distribution of infant deaths in 2022 and 2023 showed a slight male predominance. This higher death rate for male infants has been evident each year during the reporting period for all age groups (Figures 4.4 and 4.5).

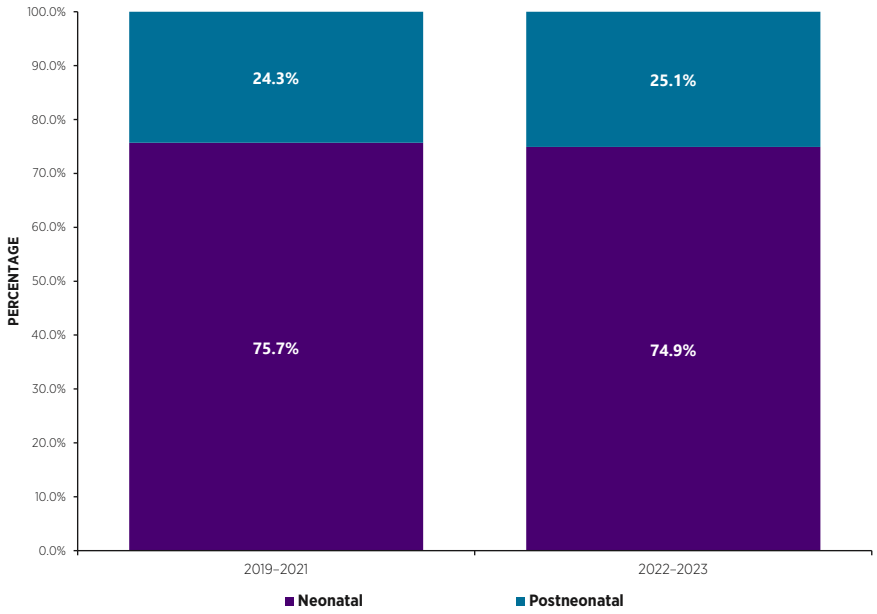


FIGURE 4.3: AGE DISTRIBUTION OF INFANT DEATHS REGISTERED IN IRELAND, 2019–2023 (n=898)

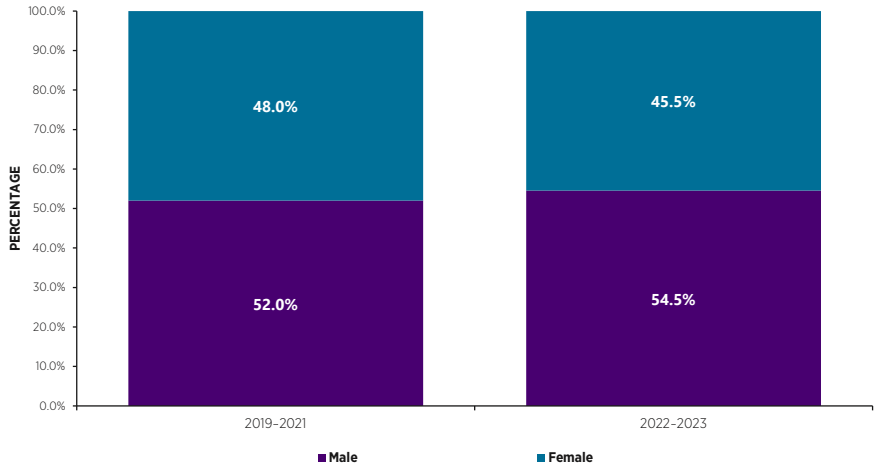


FIGURE 4.4: SEX DISTRIBUTION OF INFANT DEATHS REGISTERED IN IRELAND, 2019–2023 (n=898)

FIGURE 4.5: SEX DISTRIBUTION OF INFANT DEATHS REGISTERED IN IRELAND, BY AGE GROUP, 2019–2023 (n=898)

PLACE OF DEATH, 2019-2023

The vast majority of infant deaths in the years 2019–2023 occurred in a hospital (see Figure 4.6). The place of death for the years 2022 and 2023 was similar to that observed in previous years. The highest proportion of infant deaths occurred in two CHI units (CHI at Temple Street and CHI at Crumlin) and this is due to both the higher population in the Dublin area than in the rest of Ireland, and to the transfer of cases requiring critical care to paediatric specialist units (NOCA, 2023b).

Most infant deaths (i.e. deaths among children aged under 1 year) that occurred at home were due to SIDS. In the period 2019–2023, 37% of SIDS cases occurred at home and 32% were registered as occurring in CHI units; the latter cases were likely pronounced in the emergency departments (EDs) of CHI hospitals, with the patients having been brought in deceased by ambulance (see Table 4.2).

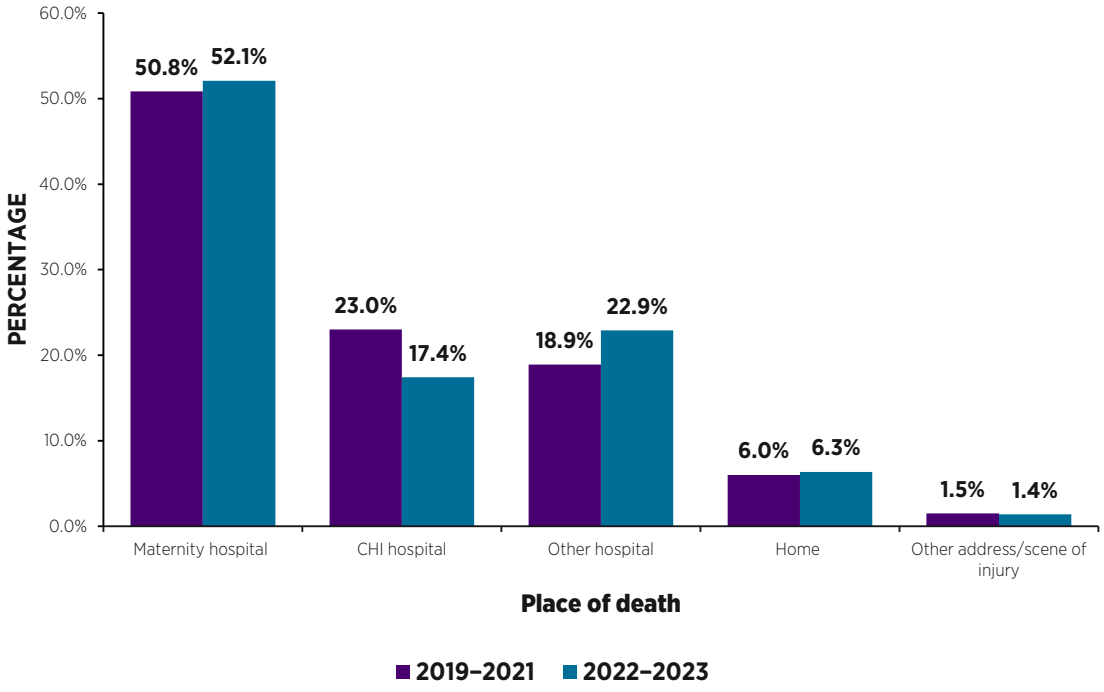


FIGURE 4.6: INFANT MORTALITY IN IRELAND BY PLACE OF DEATH, 2019–2021 v 2022–2023 (N=898)

TABLE 4.2: PLACE OF DEATH FOR INFANTS, 2019–2023: SUDDEN INFANT DEATH SYNDROME VERSUS ALL OTHER CAUSES

Place of death	SIDS		All other causes	
	n	%	n	%
CHI hospital	24	32.4	162	19.7
General hospital	19	20.7	165	20.0
Maternity hospital	~	~	460	55.8
At home	27	36.5	28	3.4
Hospice	~	~	~	~
Other	~	~	~	~
Total	39	100%	824	

~ denotes count <5

OCCURRENCE OF DEATHS BY YEARLY QUARTER

Figure 4.7 depicts the proportion of infant deaths in Ireland by quarter during the period 2022–2023 compared with the corresponding quarter in the period 2019–2021. For both periods, the fewest number of infant deaths occurred in the warmest months of the year (i.e. in the third quarter).

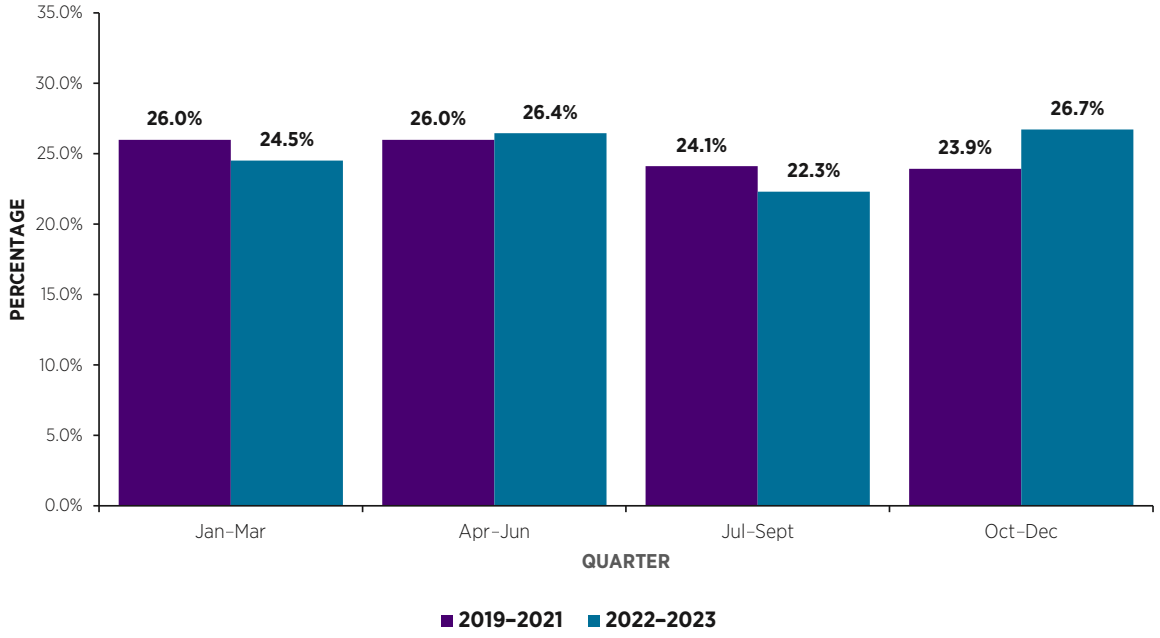


FIGURE 4.7: INFANT MORTALITY IN IRELAND BY YEARLY QUARTER, 2019–2021 VERSUS 2022–2023 (N=898)

PRINCIPAL CAUSES OF INFANT MORTALITY IN IRELAND, 2019–2023

The principal causes of infant mortality in Ireland during the years 2019–2023 (grouped according to ICD-10 classification) are provided for both the neonatal and postneonatal age groups in Table 4.3. Providing data for a period of 5 years combined makes it possible to report on a higher number of cause of death categories while avoiding disclosure issues due to small numbers of deaths. The considerable difference between the number of neonatal and postneonatal deaths (there were three times the number of neonatal deaths as postneonatal deaths) is due to the large number of babies with congenital malformations/chromosomal abnormalities and with perinatal conditions who die during the first 4 weeks of life.

During the 5-year period from 2019 to 2023, the greatest percentage of neonatal deaths was attributable to conditions arising in the perinatal period (56.3%; n=381). The majority of these conditions were due to extreme prematurity, but causes of death within this category also included necrotising enterocolitis, sepsis, and hypoxic ischaemic encephalopathy. After perinatal conditions, the second most common cause of death category for neonatal deaths was congenital malformations and chromosomal abnormalities, which accounted for 38.3% of deaths (n=259). These two categories accounted for 95% of all neonatal deaths registered during the period 2019–2023.

Of the remaining neonatal deaths that occurred during the period 2019–2023, 1.3% were registered as being due to SIDS or an undetermined/unexplained cause. Conversely, SIDS accounts for a much greater proportion of deaths in the postneonatal age group, and prior to 2005, it was the single leading cause of death in the postneonatal age group (McGarvey *et al*., 2016).

Congenital malformations and chromosomal abnormalities accounted for 37% of postneonatal deaths (n=81) during the period 2019–2023. The second largest category of deaths in the postneonatal age group was deaths due to SIDS (with ICD-10 codes R95 or R95.9) or an undetermined/unexplained cause. SIDS and undetermined/unexplained causes of death accounted for 29% of all postneonatal deaths registered in 2019–2023, with another 16% of deaths in this age group being due to perinatal conditions. Together, these three cause of death categories accounted for 82.4% of all postneonatal deaths registered in Ireland during this time period. Disorders of the nervous system accounted for 4.5% of postneonatal deaths, while infant deaths due to certain infectious and parasitic diseases and to diseases of the circulatory system each accounted for 3.2% of postneonatal deaths; all other causes combined accounted for the remaining 6.8% of postneonatal deaths in 2019–2023. These data are outlined in Table 4.3. Annual trends in the main cause of death categories for postneonatal deaths are outlined in Appendix 4.

As the percentage of postneonatal deaths attributed to SIDS has declined over time, congenital malformations and chromosomal abnormalities have accounted for the greatest proportion of postneonatal deaths in recent years. (Appendix 4). However data for 2022 and 2023 indicate a change in this trend with SIDS once again ranking as the leading cause of postneonatal deaths, at 37%. This is reflected in an increase in both the number and rate of SIDS cases (Tables 4.4 and 4.5).

TABLE 4.3: CAUSE OF DEATH CATEGORISATION OF NEONATAL AND POSTNEONATAL DEATHS REGISTERED IN IRELAND, 2019–2023 (N=898)

NEONATAL AGE GROUP			
Rank	**Cause of death category**	**n**	**%**
1	Perinatal conditions	381	56.3%
2	Congenital malformations and chromosomal abnormalities	259	38.3%
3	SIDS and undetermined/unexplained causes of death	9	1.3%
4	Diseases of the blood and blood-forming organs	6	0.9%
5	All other causes	22	3.3%
	Total	**677**	**100.0%**
POSTNEONATAL AGE GROUP			
Rank	**Cause of death category**	**n**	**%**
1	Congenital malformations and chromosomal abnormalities	81	36.7%
2	SIDS and undetermined/unexplained causes of death	65	29.4%
3	Perinatal conditions	36	16.3%
4	Disorders of the nervous system	10	4.5%
5	Certain infectious and parasitic diseases	7	3.2%
5	Diseases of the circulatory system	7	3.2%
	All other causes	15	6.8
	Total	**221**	**100.0%**

These data are distinct from data published by the National Perinatal Epidemiology Centre (NPEC) who report on early and late neonatal deaths.

TABLE 4.4: RANKING OF MAIN CAUSES OF POSTNEONATAL DEATHS IN IRELAND, 2019–2021 VERSUS 2022–2023

2019–2021 (n=130)		
Rank	**Cause of death category**	**%**
1	Congenital malformations and chromosomal abnormalities	41%
2	SIDS (R95)	24%
3	Perinatal conditions	19%
4	Diseases of the circulatory system	5%
5	Diseases of the nervous system	5%
	All other causes	6%
2022–2023 (n=91)		
Rank	**Cause of death category**	**%**
1	SIDS (R95)	37%
2	Congenital malformations and chromosomal abnormalities	31%
3	Perinatal conditions	13%
	All other causes	19%

DEATHS CERTIFIED AS SIDS

A summary of SIDS deaths registered during 2022–2023 in comparison with those registered during 2019–2021 is provided in Table 4.5. Both the number and percentage of SIDS deaths registered during 2022 and 2023 increased from those registered in previous years, indicating that the increase in proportionate mortality due to SIDS is not due to a reduction in the overall number of infant deaths (the average annual number of infant deaths registered in 2019–2021 was 178, compared with 182 in 2022–2023). The average rate of deaths due to SIDS was 0.35 per 1,000 live births in 2022–2023 versus 0.24 per 1,000 live births for the previous 3-year period (2019–2021), which is an increase of 45.8%.

An important consideration is whether the increased rate of deaths due to SIDS is a result of a higher than usual cluster of late registrations due to the COVID-19 pandemic. The delay in the registration of deaths impacts significantly on apparent SIDS rates. All cases of sudden unexplained deaths in infancy undergo a post-mortem examination, and because SIDS is a diagnosis of exclusion, this includes many investigative tests that take time to complete, extending the time required for completion of the post-mortem report. Review of the timeliness of registration of SIDS deaths during the period 2019–2023 shows that the proportion of late registration of SIDS deaths in 2022–2023 was lower than in the previous 3 years, suggesting that the increase in the number of SIDS deaths in 2022–2023 cannot be solely due to an accumulation of late registrations during that period (Table 4.6). However, these data must be revised by year of occurrence before they can be accepted as final.

As in previous years, more SIDS cases in 2022–2023 were male than female (56% versus 44%) (Table 4.7). In keeping with the trend observed in previous years, the majority of SIDS cases registered during 2022 and 2023 were in the postneonatal age group and a small number were in the neonatal age group (Table 4.8). The annual trend in the SIDS rate (per 1,000 live births) from 1992 to 2023 is illustrated in an SPC chart in Figure 4.8C.

TABLE 4.5: SUMMARY OF DEATHS DUE TO SUDDEN INFANT DEATH SYNDROME IN IRELAND, 2019–2021 VERSUS 2022–2023

Year	Total number of SIDS deaths registered	Percentage of postneonatal deaths	Percentage of all deaths aged <1 year	SIDS rate (number of infant deaths per 1000 live births)
2019-2021	35	23.8%	6.5%	0.24
2022-2023	39	37.4%	10.7%	0.35

TABLE 4.6: PROPORTION OF LATE SUDDEN INFANT DEATH SYNDROME DEATH REGISTRATIONS BY PERIOD IN IRELAND, 2019–2021 VERSUS 2022–2023

Year	Total SIDS deaths registered	Late registrations*	
	n	n	%
2019-2021	35	20	57%
2022-2023	39	18	46%

*Year of registration later than year of death.

TABLE 4.7: SEX DISTRIBUTION OF SUDDEN INFANT DEATH SYNDROME CASES REGISTERED IN IRELAND, 2019–2021 VERSUS 2022–2023

Year	Male		Female		Total
	n	%	n	%	N
2019-2021	21	60%	14	40%	35
2022-2023	22	56%	17	44%	39

TABLE 4.8: AGE DISTRIBUTION OF SUDDEN INFANT DEATH SYNDROME CASES REGISTERED IN IRELAND, 2019–2021 VERSUS 2022–2023

Year	Neonatal		Postneonatal		Total
	n	%	n	%	N
2019-2021	4	11%	31	89%	35
2022-2023	5	13%	34	87%	39

ANNUAL TRENDS IN MAIN CAUSE OF INFANT DEATH CATEGORIES

Annual trends in the main causes of infant death were examined using SPC charts and findings were summarised as follows:

PERINATAL CONDITIONS

This SPC chart (Figure 4.8A) indicates that the mortality rate due to perinatal conditions is relatively stable, staying within the expected limits throughout the observed period, despite some variability (Figure 4.8A).

CONGENITAL MALFORMATION AND CHROMOSOMAL ABNORMALITIES

Figure 4.8B illustrates a recent shift of improvement in mortality rates due to congenital malformations and chromosomal abnormalities from 2016 to 2023 (eight consecutive data points were below the mean). Future monitoring of these data will be important in order to determine if the current positive trend is maintained.

SIDS

Figure 4.8C shows that while mortality rates due to SIDS fluctuated between 2008 and 2018, they remained within the control limits, indicating no significant improvement or decline during this period. However, in 2019 and 2020, the data points were close to the lower control limit and triggered the '2 out of 3' rule, signalling a significant reduction in mortality rates. After 2020, the mortality rates returned closer to the mean, suggesting that the improvements were not sustained. Furthermore, mortality rates in 2022 and 2023 have risen above the mean, with 2023 marking the highest rate since 2013. Ongoing monitoring will be important in order to assess whether any signs of improvement or deterioration emerge in the coming years.

DISEASES OF THE NERVOUS SYSTEM

Figure 4.8D indicates that there was a significant improvement in mortality rates due to diseases of the nervous system from 2018-2023, as six consecutive data points appeared below the mean. It will be important to monitor these data in order to determine if this improvement continues and what the underlying reasons for such improvements might be.

CERTAIN INFECTIOUS AND PARASITIC DISEASES

Figure 4.8E indicates that the mortality rate due to certain infectious and parasitic diseases is relatively stable, staying within expected limits throughout the observed period, despite some variability.

DISEASES OF THE CIRCULATORY SYSTEM

Mortality rates due to diseases of the circulatory system have remained relatively stable from 2008 to 2023, staying within the expected limits throughout the observed period, despite some variability (Figure 4.8F).

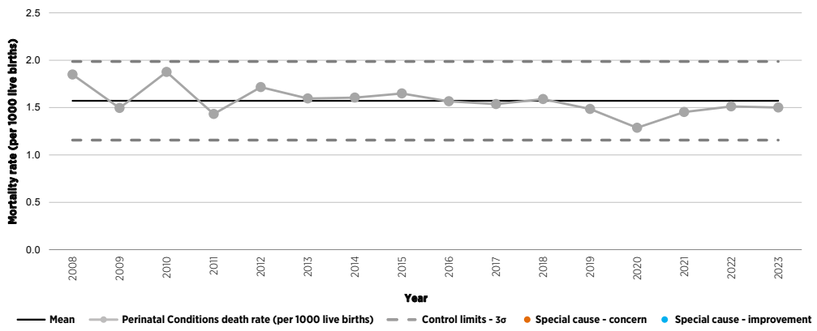
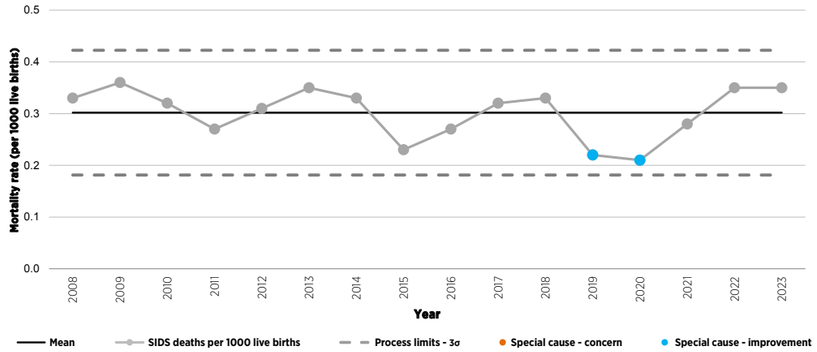


FIGURE 4.8A: CRUDE MORTALITY RATE DUE TO PERINATAL CONDITIONS IN INFANTS IN IRELAND, 2008–2023



Note: Data for year 2019-2023 are based on year of registration. All other figures based on year of occurrence.

FIGURE 4.8C: CRUDE MORTALITY RATE DUE TO SUDDEN INFANT DEATH SYNDROME IN INFANTS IN IRELAND, 2008–2023

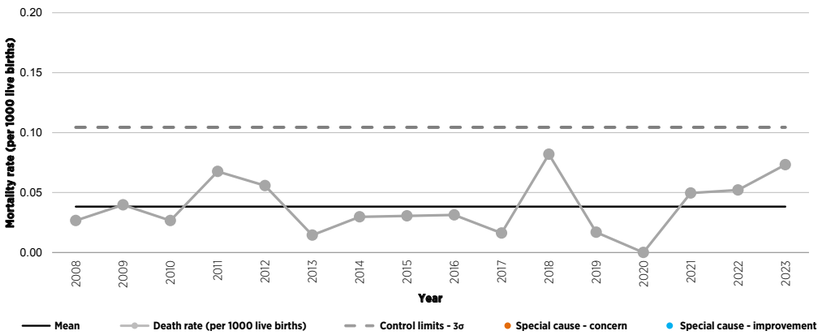


FIGURE 4.8E: CRUDE MORTALITY RATE DUE TO CERTAIN INFECTIOUS AND PARASITIC DISEASES IN INFANTS IN IRELAND, 2008–2023

SPC Chart Rules:

- A ***Shift*** occurs when **6 or more** consecutive points appear on the **same side of the mean** (centreline).
- A ***Trend*** occurs when there are **6 or more** consecutive points that move in the same direction (up or down) A Trend can cross the mean centreline.
- The ***2 out of 3*** rule highlights when 2 of 3 data points are close to the upper or lower control limits.
- Extreme values **(Special Cause)**: any value that falls outside the control limits (upper or lower).
- **Common cause** (grey data points) variation refers to the natural, inherent variability present in a process over time.

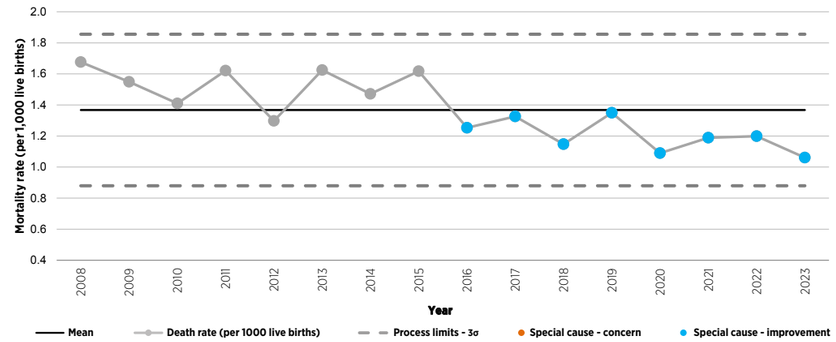


FIGURE 4.8B: CRUDE MORTALITY RATE DUE TO CONGENITAL MALFORMATION AND CHROMOSOMAL ABNORMALITIES IN INFANTS IN IRELAND, 2008–2023

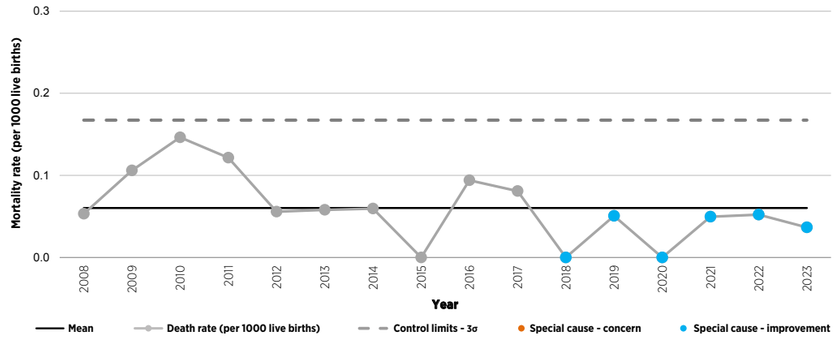


FIGURE 4.8D: CRUDE MORTALITY RATE DUE TO DISEASES OF THE NERVOUS SYSTEM IN INFANTS IN IRELAND, 2008–2023

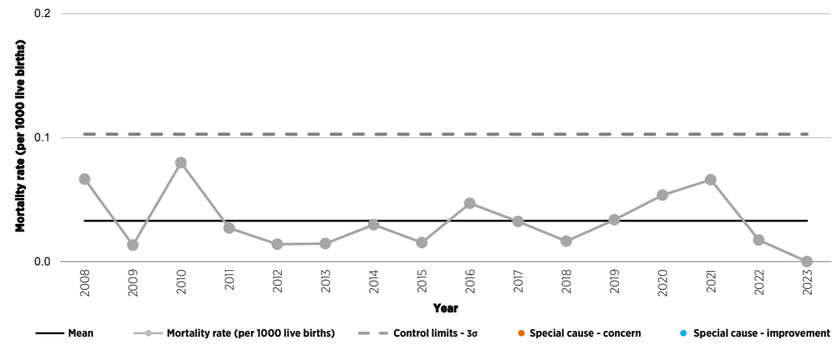


FIGURE 4.8F: CRUDE MORTALITY RATE DUE TO DISEASES OF THE CIRCULATORY SYSTEM IN INFANTS IN IRELAND, 2008–2023

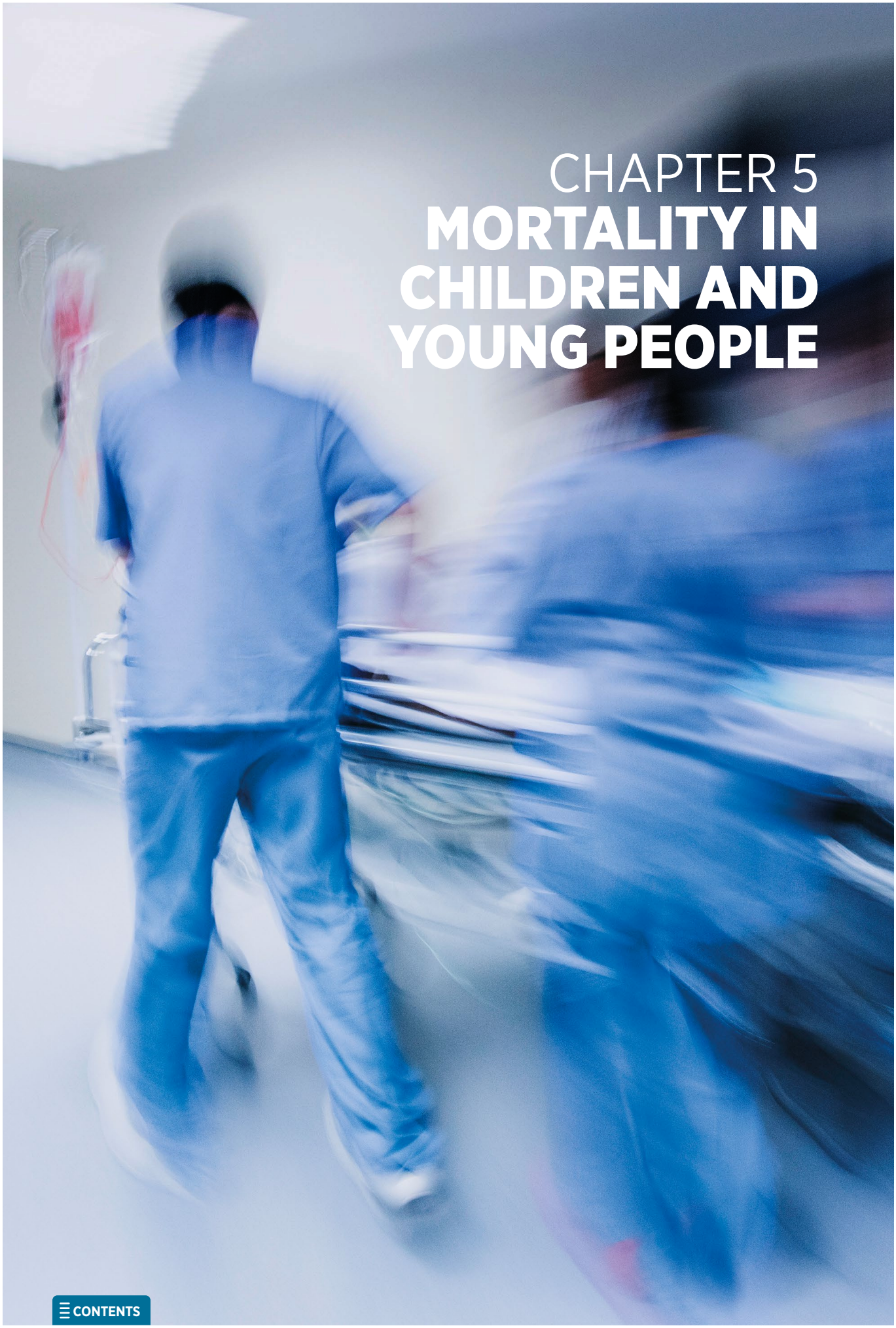
There are limitations to the available data presented in this chapter, mainly an inability to report accurate mortality estimates based on year of occurrence for 2022 and 2023 and a lack of detail to permit detailed descriptions of the main causes of death. Hence we cannot currently provide an overview of the characteristics of the various categories of infant death; for example an account of the sleeping position and location for SIDS deaths, or an accurate assessment of the impact of factors such as social deprivation, or the COVID-19 pandemic on the various categories of infant mortality

KEY FINDINGS FROM CHAPTER 4

- Timely and more detailed information is required in order to provide an accurate account and review of infant mortality and to inform policy aimed at reducing the number of infant deaths. Direct notification of deaths to the NPMR will permit the review of annual trends based on timely year of occurrence data, which is necessary in order to validate the observed variation in the main causes of CYP deaths in 2022 and 2023.
- The average IMR in Ireland for the period 2022–2023 is slightly higher than in 2019–2021 and is no longer below the EU average.
- Deaths due to perinatal conditions and due to congenital malformations and chromosomal abnormalities accounted for 95% of all neonatal deaths registered during the period 2019–2023.
- The distribution of the main causes of postneonatal deaths varied in 2022–2023 compared with previous years; the number and rate of registered deaths that were certified as SIDS deaths were higher in 2022 and 2023 than in 2019–2021, indicating that SIDS is once again the leading cause of death in the postneonatal period. These data must be revised for year of occurrence before they can be accepted as final.
- Due to limitations of the data, it is not currently possible to provide a description of the characteristics of SIDS deaths in Ireland, including the presence/absence of known risk factors or an accurate assessment of the impact of factors such as social deprivation or the COVID-19 pandemic.
- Mortality rates for the cause of death categories 'certain infectious and parasitic diseases', 'diseases of the circulatory system' and 'perinatal conditions' have not changed significantly over time, while mortality rates for deaths due to congenital malformations and chromosomal abnormalities and due to diseases of the nervous system have improved.
- Despite a decline in fatalities from two leading causes of infant death, 'congenital malformations and chromosomal abnormalities' and 'diseases of the nervous system', the overall infant mortality rate in Ireland has not decreased since 2019, and is higher than in many other European countries.

QUALITY IMPROVEMENT OPPORTUNITIES

The current knowledge gap on the epidemiology of SIDS can be closed through access to information from all post-mortem examination reports being made available to NPMR. In the latter half of 2024, the HSE commissioned a retrospective and more granular review of SIDS deaths.



CHAPTER 5
MORTALITY IN CHILDREN AND YOUNG PEOPLE

CONTENTS

CHAPTER 5: MORTALITY IN CHILDREN AND YOUNG PEOPLE

BACKGROUND

Death registration information provided by the CSO is currently the only dataset available that can provide population-based information on mortality in children and young people (CYP). Crude numbers and rates for child mortality are presented in the following age categories, in keeping with international convention:

- aged 1–4 years: pre-schoolers
- aged 5–9 years: younger children
- aged 10–14 years: older children
- aged 15–18 years: adolescents.

References to 'infant' or 'infancy' throughout this report relate to children aged under 1 year. Data on variables relating to sex and to the place and cause of death are reported as a combined age group of 1–14 years where necessary in order to avoid disclosure of small numbers, alongside separate data on older adolescents (aged 15–18 years) due to the varying patterns of mortality among this older age group.

As with data on infant deaths, these data must be interpreted with caution, as they are based on year of registration and may differ from final figures for each year in which the deaths actually occurred.

CHILD AND YOUNG PERSON MORTALITY IN IRELAND DURING THE PERIOD 2019–2023: AGE AND SEX DISTRIBUTION

The age distribution of child deaths registered in 2022–2023 and 2019–2021 is outlined in Table 5.1. The average estimates for this 2022–2023 period showed a pattern similar to that observed in previous years. The total number of child deaths (excluding children aged under 1 year) registered in Ireland during the period 2019–2023 was 592. Figures for infant deaths are included in Table 5.1 for ease of comparison and to provide a complete picture of all child deaths during this period.

Child mortality rates follow a U-shaped distribution; the largest number of deaths occurs during infancy and the second largest aged 15-18 years. Numbers of deaths drop substantially for children aged 1–14 years. This pattern was evident for each of the years examined.

The average annual number of deaths registered for older children increased in 2022–2023 in comparison with the previous three years, from an average of 67 deaths registered per year in 2019–2021 to 73 deaths registered per year in 2022–2023 for children aged 1–14years, and from an average of 47 deaths registered per year in 2019–2021 to 52 deaths registered per year for adolescents aged 15–18years.

The distribution of deaths in children aged 1–18 years by age group and sex is shown in Figure 5.1. The larger proportion of deaths among males is more evident in these older age groups than for infant deaths (those aged under 1 year). The higher number of male deaths becomes even more evident with increasing age (Figure 5.1); this is a consequence of the higher proportion of deaths attributable to external causes in older groups. The male preponderance of deaths was more pronounced in the cohort of deaths registered in 2019–2021 than for those registered in 2022-2023, and was not apparent for the younger age group 1–4 years and 5-–9 years during this period (2019–2023). This data however is subject to change following revision by year of occurrence.

TABLE 5.1: NUMBER AND PERCENTAGE OF CHILD DEATHS REGISTERED IN IRELAND, 2019–2023 (N=1490)

Year	Number of deaths registered											
	Aged <1 year		Aged 1–4 years		Aged 5–9 years		Aged 10–14 years		Aged 15–18 years		Total	
	N	%	n	%	n	%	n	%	n	%	n	%
2019	190	61.1%	29	9.3%	24	7.7%	21	6.8%	47	15.1%	311	100.0%
2020	153	57.0%	27	10.1%	24	9.0%	23	8.6%	41	15.3%	268	100.0%
2021	192	63.5%	15	5.0%	18	6.0%	21	7.0%	53	17.7%	299	100.0%
2019-2021	**535**	**60.9%**	**71**	**8.1%**	**66**	**7.3%**	**65**	**7.4%**	**141**	**16.1%**	**878**	**100.0%**
2022	191	63.9%	19	6.4%	16	5.4%	26	8.7%	47	15.7%	299	100.0%
2023	172	55.0%	25	8.0%	19	6.1%	40	12.8%	57	18.2%	313	100.0%
2022-2023	**363**	**59.3%**	**44**	**7.2%**	**35**	**5.7%**	**66**	**10.8%**	**104**	**17.0%**	**612**	**100.0%**

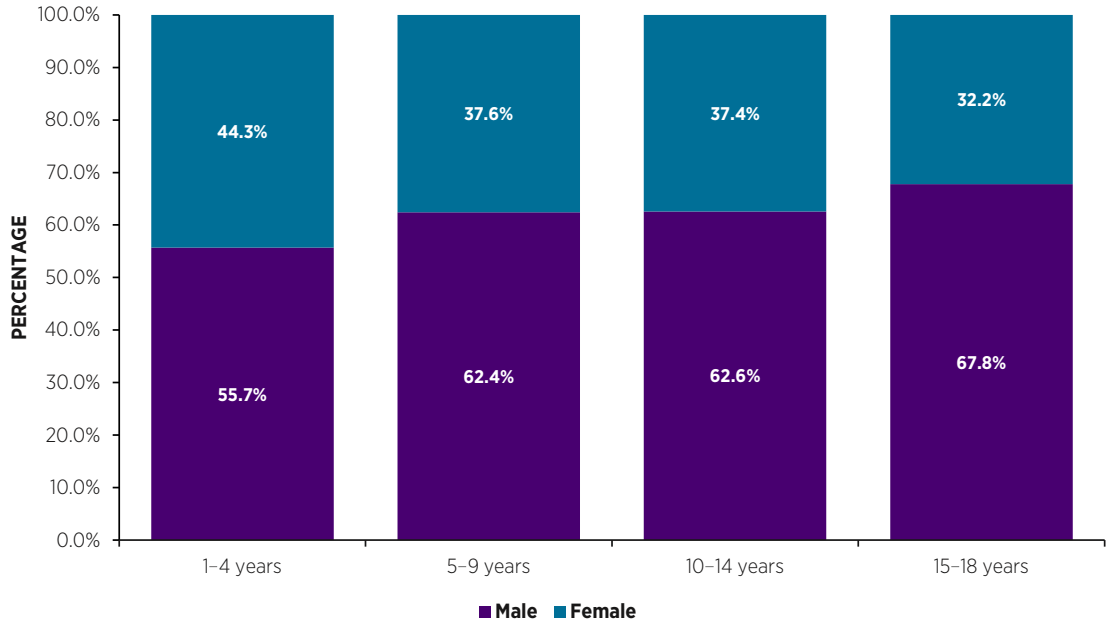


FIGURE 5.1: SEX DISTRIBUTION OF CHILD AND YOUNG PERSON DEATHS BASED ON YEAR OF REGISTRATION, BY AGE GROUP, 2019–2023 (n=592)

PLACE OF DEATH, 2019–2023

Data on place of death is provided as an aggregate figure for the five years 2019–2023 in order to allow reporting on as many subcategories as possible without the risk of disclosure. As with infant deaths (i.e. those aged under 1 year), the greatest proportion (63%) of child deaths (i.e. those aged 1–14 years) occurred in hospital; however this figure was much lower than the 92% of deaths occurring in hospital reported for the infant population. Thirty-one percent of deaths registered for this age group occurred at home, in comparison with just 6% of infant deaths. This proportion increased even further in the 15–18 years age group, in which almost one-half (45.5%) of all deaths occurred at home.

The higher proportion of deaths occurring outside of a hospital setting in the older age groups is a reflection of the large proportion of deaths occurring outside of infancy that are attributable to accident and injury. An additional 2.6% of deaths in children aged 1–14 years and 9.8% of deaths in adolescents aged 15–18 years occurred at the scene of an injury during the period 2019–2023 (Figure 5.2). A small number of deaths in both age groups occurred in hospices and care homes, although the exact proportion in the 1–14yr age category is not reported due to small numbers and the associated disclosure risk.

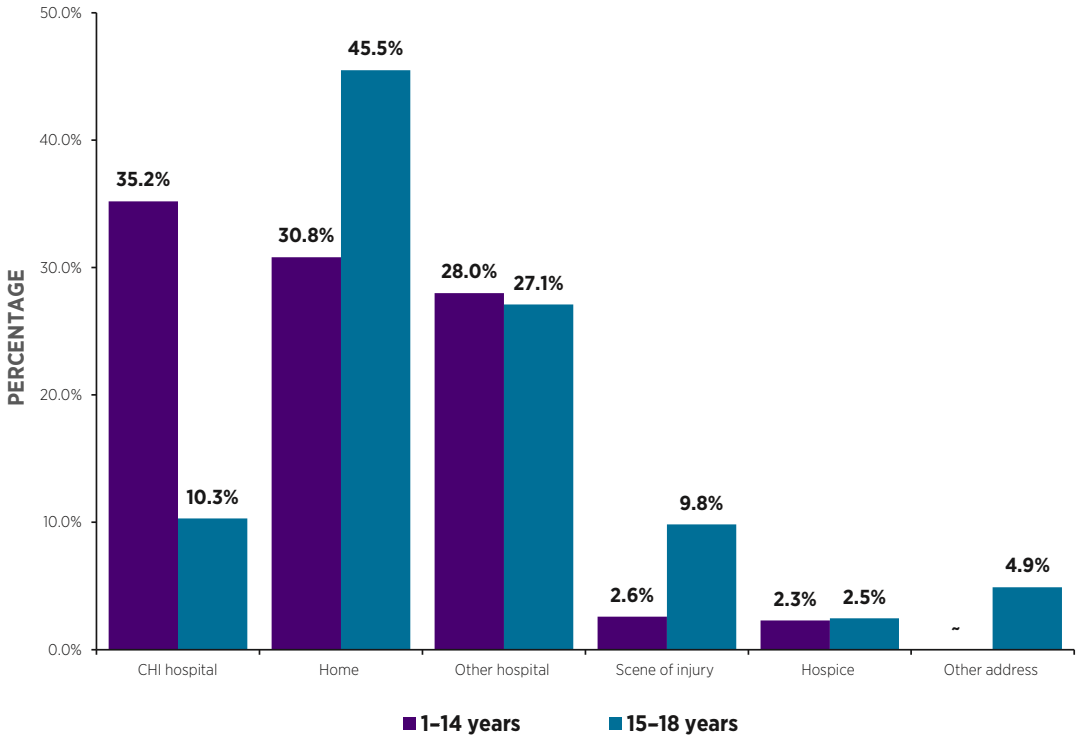


FIGURE 5.2: PLACE OF DEATH OF CHILD AND YOUNG PERSON DEATHS BASED ON YEAR OF REGISTRATION, BY AGE GROUP, 2019–2023

~ denotes fewer than 5 cases

CYP DEATHS BY MONTH OF DEATH

The distribution of CYP deaths by annual quarter demonstrated a similar pattern for both age groups (i.e. those aged 1–14 years and those aged 15–18 years). For children aged 1–14 years, the highest number of deaths occurred in the first quarter of the year, and the remainder were distributed equally across quarters 2–4. Among older children aged 15–18 years, a smaller proportion of deaths occurred in the fourth quarter of the year than in the first three quarters of the year.

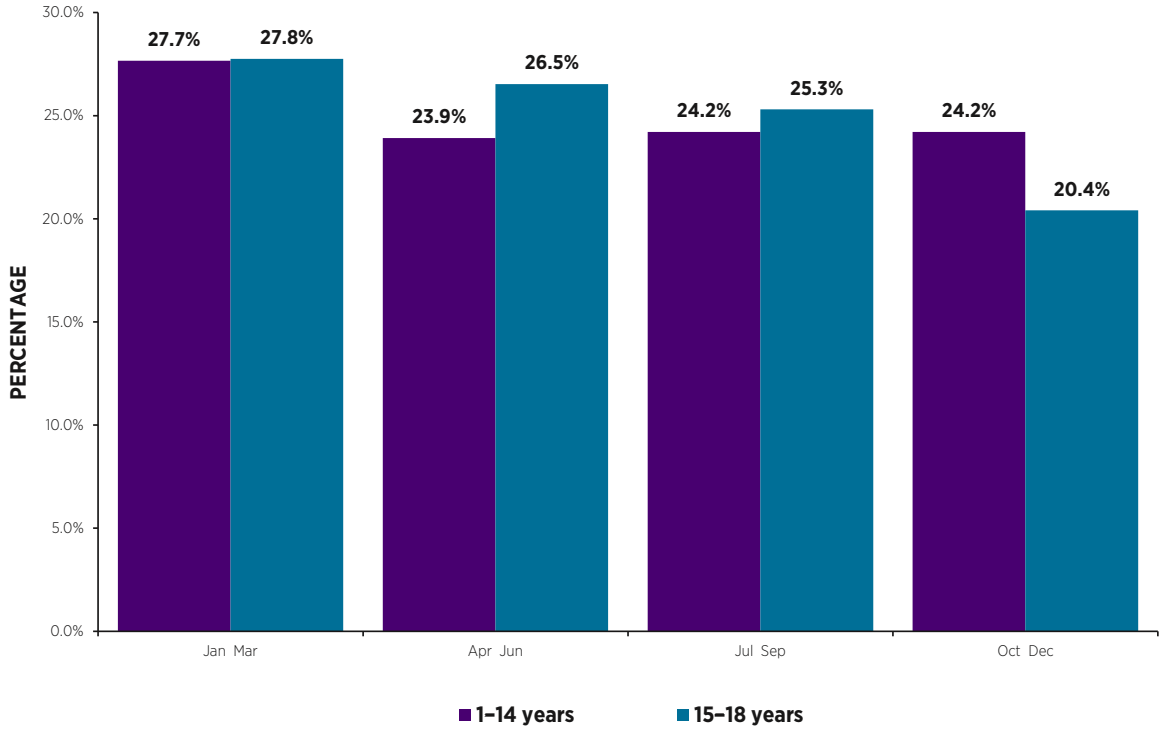


FIGURE 5.3: OCCURRENCE OF CHILD AND YOUNG PERSON DEATHS BY ANNUAL QUARTER, BY AGE GROUP, 2019–2023 (n=592)

ANNUAL TRENDS IN CYP MORTALITY RATES IN IRELAND

The annual trends in Ireland's child mortality rates for the period 2007–2023 are illustrated in Figure 5.4. These CSO data are presented in the format of 3-year average rates in order to eliminate random variation. The analysis is based on final year of occurrence figures for deaths published by the CSO and expressed as the number of deaths per 100 000 population. The data demonstrate a welcome decline by more than 40% in mortality rates in all age groups since 2007, with the exception of children aged 5–9 years. While mortality rates in children aged 1–4 years and 5–9 years have continued to decline gradually over time, there has been little change in older children aged 10–14 years and a steady increase in mortality rates among adolescents aged 15–18 years since 2017. A recent review and comparison of CYP mortality rates in Ireland with those in other EU countries reports that Ireland had rates lower than the EU average in all age groups except for infants aged under 1 year in 2021 (Department of Children, Equality, Disability, Integration and Youth, 2024).

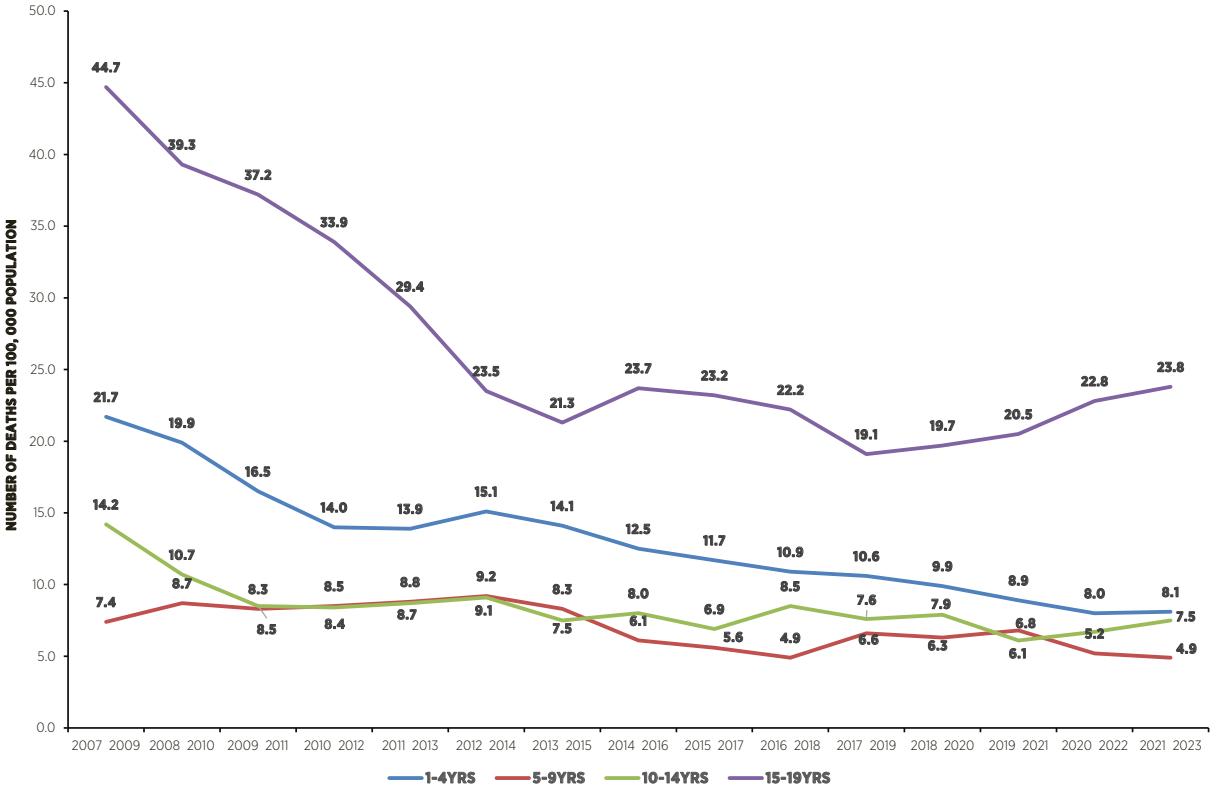


FIGURE 5.4: ANNUAL TRENDS IN CHILD AND YOUNG PERSON MORTALITY RATES IN IRELAND, BY AGE GROUP, 2007–2023 (3-YEAR MOVING AVERAGE RATES)

Note: This figure is based on year of occurrence data retrieved from the CSO online database and updated for revised occurrence figures on 08.08.2024 (Central Statistics Office, n.d.). Datapoints included for 2022 and 2023 are provisional. Data are presented using age groupings as derived from the CSO database which specifies adolescents aged 15–19 years.

PRINCIPAL CAUSES OF DEATH IN CHILDREN 1–14 YEARS FOR THE PERIOD 2019–2023, AS CATEGORISED BY ICD-10 CODING

The main contributory causes of childhood deaths as classified by the CSO according to ICD-10 classifications are outlined in Table 5.2 and in Figures 5.5A–5.6B. As these data are based on date of registration, they are presented as 5-year aggregate figures in order to provide a more accurate representation.

Historically, the leading cause of childhood death post-infancy has been external causes of accident and injury (also referred to as trauma deaths), which during 2019–2023 accounted for one-fifth of deaths in children aged 1–14 years and more than one-half of all deaths in adolescents aged 15–18 years (Figures 5.5A and 5.6A). However, the data for 2019–2023 showed some variation when compared with data reported in previous years (2007–2018). A decline in the number of external-cause deaths in 2022–2023 has led to an increase in the overall proportion of deaths due to other causes (Figures 5.5A and 5.5B); neoplasms accounted for the greatest proportion (24.5%) of deaths in younger children aged 1–14 years for the first time in 2019–2023, followed by external causes of injury, which accounted for 19.6% of deaths in this age group. The annual average number of neoplasm deaths in children aged 1–14 years was 13.3 in 2019–2021 compared with 22.5 in 2022–2023. The proportion of deaths in this age group due to infection also increased, accounting for 6.1% of deaths during 2019–2023 compared with 4.1% prior to 2019 (Table 5.2 and Figure 5.5B). A review of annual trends in rates of the main cause of death categories for children aged 1–14 years since 2008 is provided in Figures 5.7A–5.7F.

Other important causes of death among children aged 1–14 years were congenital malformations and chromosomal abnormalities (16.1%), diseases of the nervous system (9.2%), diseases of the respiratory system (4.6%) and endocrine, nutritional and metabolic diseases (4.3%). A small proportion (2.3%) of deaths in this age group were certified as SIDS or sudden unexplained deaths in childhood (SUDC) which is a slight decline from previous years (2.9%)

External causes remained the overwhelming leading cause of death among older children aged 15–18 years during the period 2019–2023, although the overall proportion decreased slightly from 59% of deaths in 2012–2018 to 51% in 2019–2023 (Table 5.3). Neoplasms were the second leading cause of death in older adolescents aged 15–18 years in 2019–2023, accounting for 16.3% of deaths, which was an increase from 11.5% reported in 2012–2018. Other causes of mortality among adolescents aged 15–18 years in 2019–2023 were diseases of the nervous system (7.8%), congenital malformations and chromosomal abnormalities (6.5%), and diseases of the circulatory system (6.1%). Certain infectious and parasitic diseases; endocrine, nutritional and metabolic diseases; and diseases of the respiratory system each accounted for 2.5% of deaths in this age group in 2019–2023 (Figure 5.6A).

TABLE 5.2: CAUSE OF DEATH CATEGORISATION OF DEATHS OF CHILDREN AGED 1–14 YEARS REGISTERED IN IRELAND, 2019–2023 (n=347)

Rank	Cause of death category	2019–2023		2019–2021			2022–2023		
		N	%	Rank	n	%	Rank	n	%
1	Neoplasms	85	24.5%	2	40	19.8%	1	45	31.0%
2	External causes	68	19.6%	1	41	20.3%	2	27	18.6%
3	Congenital malformations and chromosomal abnormalities	56	16.1%	3	38	18.8%	3	18	12.4%
4	Diseases of the nervous system	32	9.2%	4	20	9.9%	4	12	8.3%
5	Diseases of the circulatory system	25	7.2%	5	16	7.9%	6	9	6.2%
6	Certain infectious and parasitic diseases	21	6.1%	6	11	5.5%	5	10	6.9%
7	Diseases of the respiratory system	16	4.6%	7	11	5.5%	8	5	3.5%
8	Endocrine, nutritional and metabolic diseases	15	4.3%	8	8	4.0%	7	7	4.8%
9	SIDS/SUDC	8	2.3%		~	~		~	~
10	Mental and behavioural disorders	5	1.4%		~	~		~	~
	Diseases of the blood and blood-forming organs	5	1.4%						
	All other causes	11	3.2%		17	8.4%		12	8.3%
	Total	347	100.0%		202	100.0%		145	100.0%

~ denotes n <5 and cases included in category of 'all other causes'.

TABLE 5.3: CAUSE OF DEATH CATEGORISATION OF DEATHS OF CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS REGISTERED IN IRELAND, 2019–2023 (n=245)

Rank	Cause of death category	2019–2023		2019–2021			2022–2023		
		N	%	Rank	n	%	Rank	n	%
1	External causes	125	51.0%	**1**	79	56.0%	**1**	46	44.2%
2	Neoplasms	40	16.3%	**2**	21	14.9%	**2**	19	18.3%
3	Diseases of the nervous system	19	7.8%	**4**	8	5.7%	**3**	11	10.6%
4	Congenital malformations and chromosomal abnormalities	16	6.5%	**3**	9	6.4%	**4**	7	6.7%
5	Diseases of the circulatory system	15	6.1%	**4**	8	5.7%	**4**	7	6.7%
6	Certain infectious and parasitic diseases	6	2.5%		~	~		~	~
6	Endocrine, nutritional and metabolic diseases	6	2.5%		~	~		~	~
6	Diseases of the respiratory system	6	2.5%		~	~		~	~
	All other causes	12	4.9%		16	11.3%		14	13.5%
	Total	245	100.0%		141	100.0%		104	100.0%

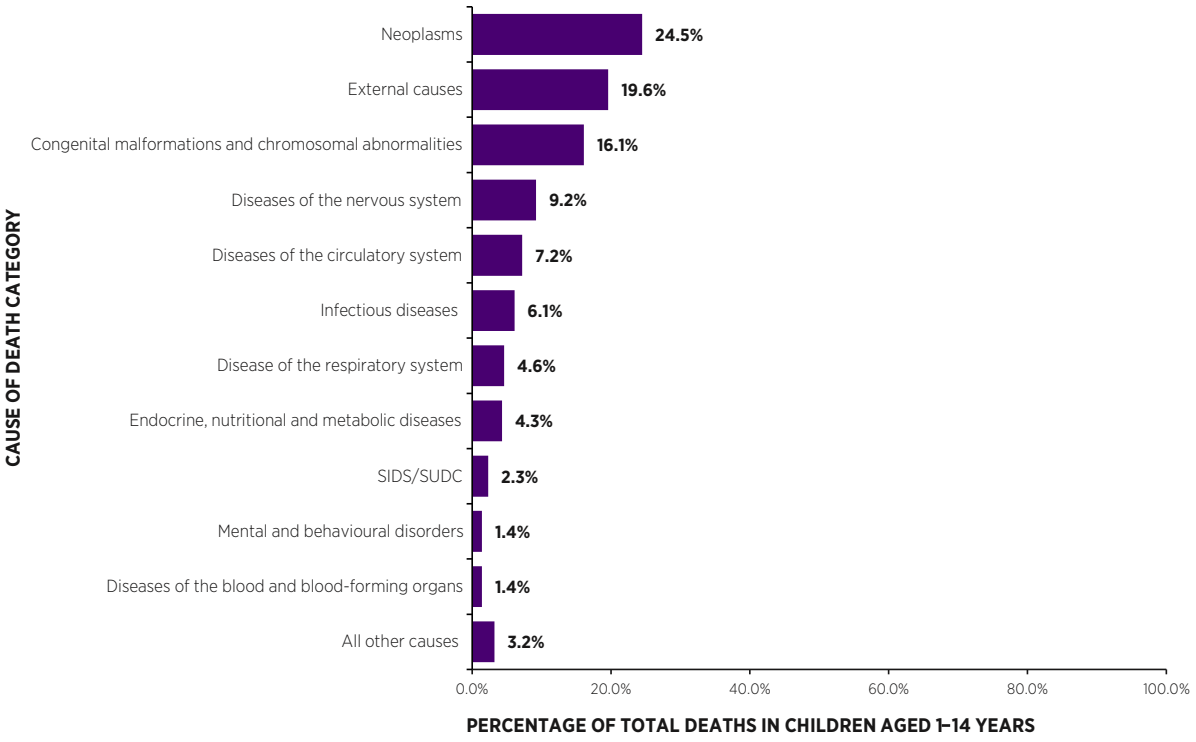


FIGURE 5.5A: PRINCIPAL CAUSE OF DEATH CATEGORIES IN CHILDREN AGED 1–14 YEARS BASED ON YEAR OF REGISTRATION, 2019–2023 (n=347)

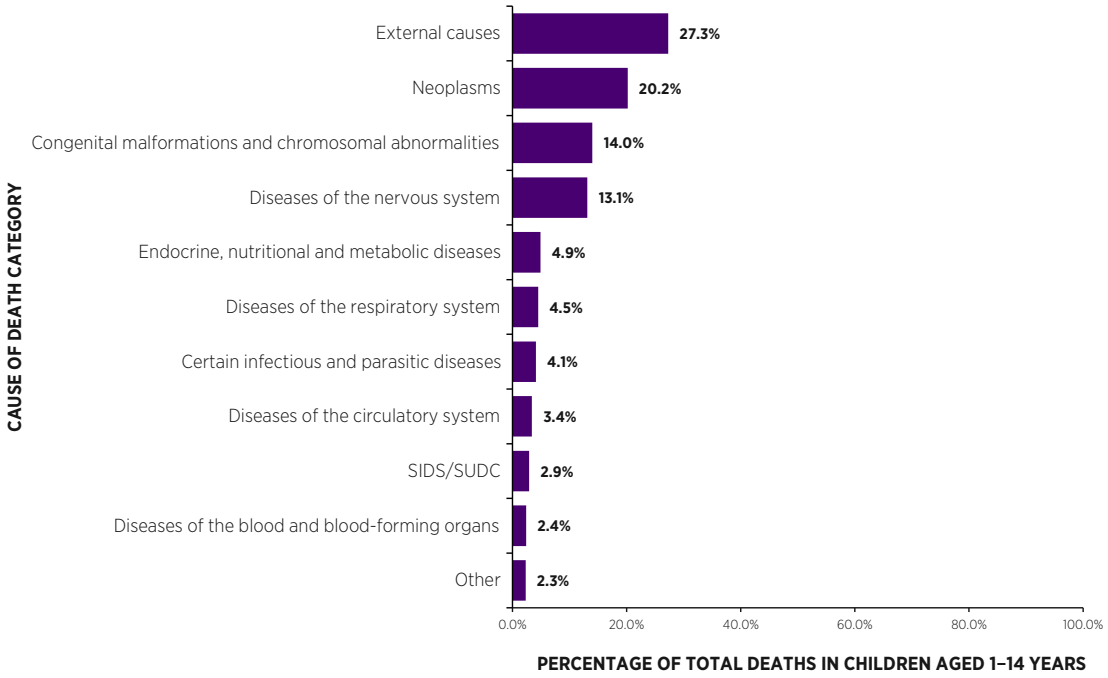


FIGURE 5.5B: PRINCIPAL CAUSE OF DEATH CATEGORIES IN CHILDREN AGED 1–14 YEARS BASED ON YEAR OF REGISTRATION, 2007–2018 (n=1124)

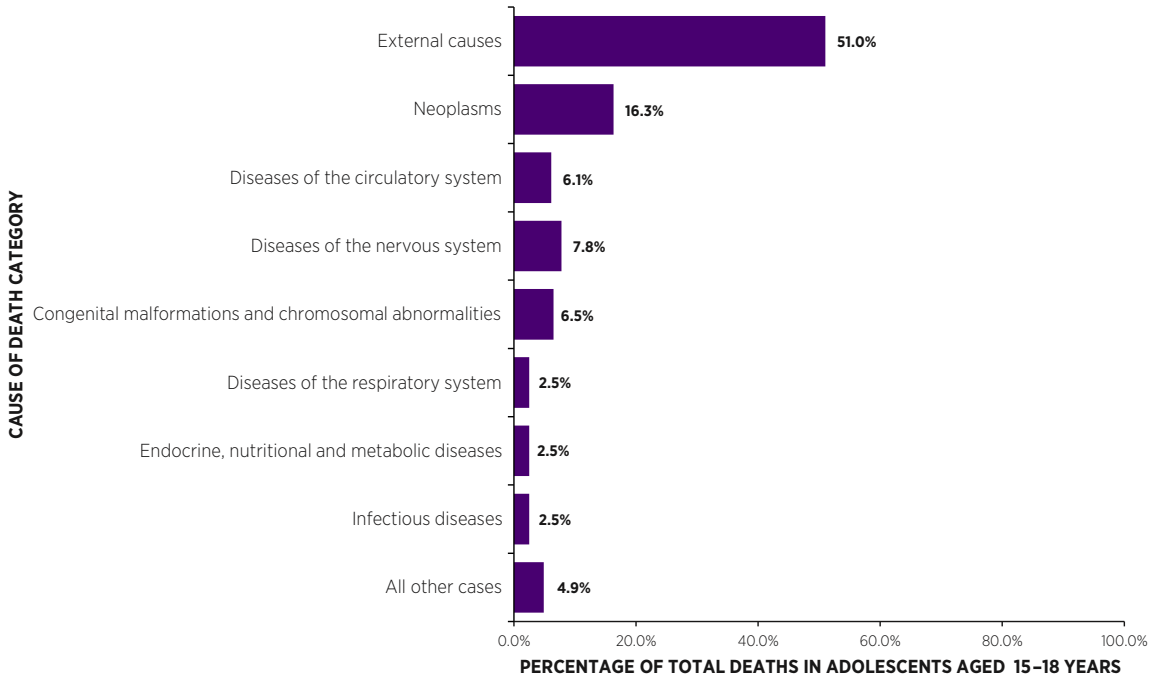


FIGURE 5.6A: PRINCIPAL CAUSE OF DEATH CATEGORIES IN ADOLESCENTS AGED 15–18 YEARS, 2019–2023 (n=245) BASED ON YEAR OF REGISTRATION

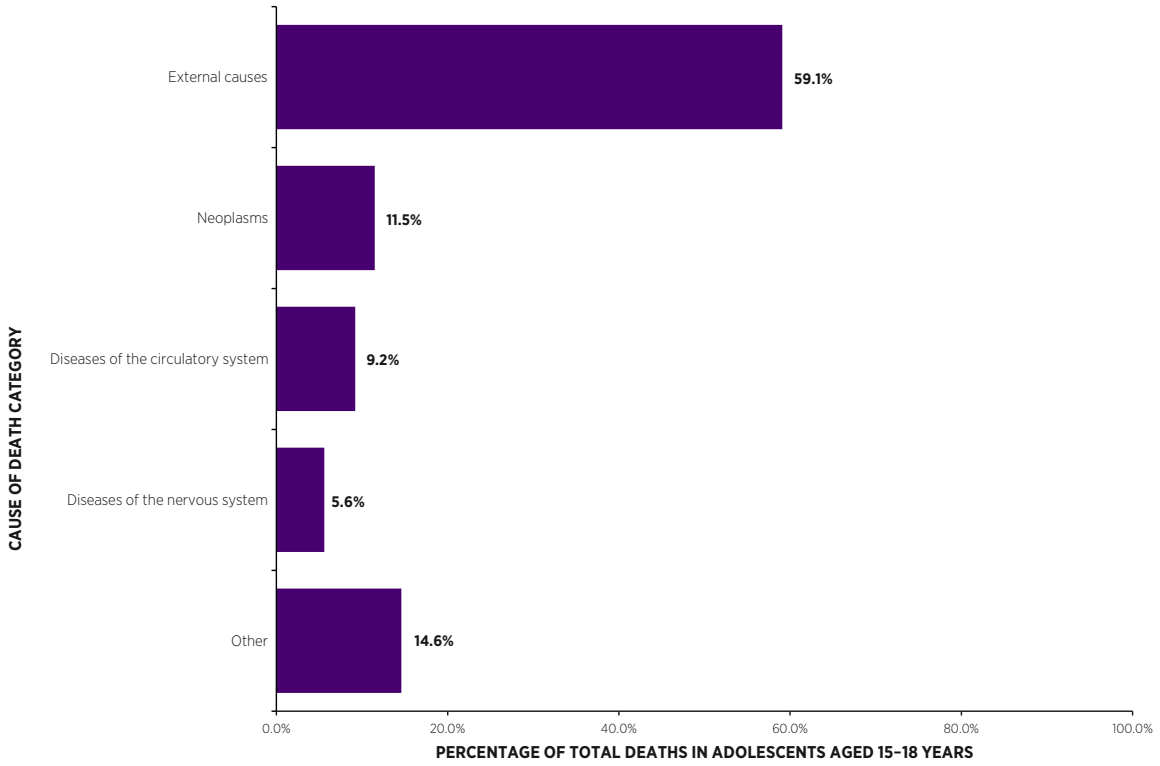


FIGURE 5.6B: PRINCIPAL CAUSE OF DEATH CATEGORIES IN ADOLESCENTS AGED 15–18 YEARS BASED ON YEAR OF REGISTRATION, 2012–2018 (n=425)

ANNUAL TRENDS IN MAIN CAUSE OF DEATH CATEGORIES FOR CHILDREN AGED 1-14 YEARS

Annual trends in the main causes of CYP deaths in children aged 1–14 years are provided in SPC charts in Figures 5.7A–5.7F. The findings from our analysis of data on children aged 1–14 years are summarised as follows:

EXTERNAL CAUSES

The mortality rates due to external causes for 2008 and 2009 exceed the upper control limits on the SPC chart presented in Figure 5.7A. However, these years mark the beginning of a statistically significant improvement trend that continued from 2008 to 2014, which takes precedence over the extreme values rule, explaining why the 2008 and 2009 data points are marked in blue. From 2015 to 2021, the data show common cause variation, indicating stability. In 2022 and 2023, mortality rates due to external causes approach or fall near the lower control limit, indicating a significant improvement. Continued statistical monitoring is recommended in order to assess whether this positive trend is sustained.

NEOPLASMS

The data in Figure 5.7B show a significant shift in neoplasm mortality rates, with nine consecutive data points falling below the mean between 2014 and 2022, indicating improvement. However, this trend ended in 2023, when mortality rates due to neoplasms rose above the mean, increasing from 1.99 in 2022 to 2.72 in 2023. While this is currently considered common cause variation, it is important to monitor this upward trend in order to determine if it continues and becomes a potential cause for concern in the future.

CONGENITAL MALFORMATIONS AND CHROMOSOMAL ABNORMALITIES

The mortality rate from congenital malformations and chromosomal abnormalities exhibits common cause variation between 2008 and 2023, indicating no significant improvement or emerging cause for concern (Figure 5.7C).

DISEASES OF THE NERVOUS SYSTEM

The SPC chart in Figure 5.7D highlights a significant improvement in mortality rates due to diseases of the nervous system between 2020 and 2022. However, in 2023, the data show no further improvement, with mortality rates returning to common cause variation, suggesting that the positive trend has not continued.

CERTAIN INFECTIOUS AND PARASITIC DISEASES

The mortality rates due to certain infectious and parasitic diseases show common cause variation between 2008 and 2023, indicating no significant improvement or cause for concern (Figure 5.7E). However, there was a notable increase in mortality rates between 2022 and 2023, when they rose from 0.10 to 0.73. It will be important to monitor this trend in the coming years in order to assess whether it becomes a cause for concern. It is also important to note that this cause of death category does not include infection-related deaths categorised under other conditions, such as respiratory or nervous system diseases.

DISEASES OF THE CIRCULATORY SYSTEM

The SPC chart in Figure 5.7F shows that death rates from diseases of the circulatory system have remained within the range of common cause variation between 2008 and 2023, indicating no significant improvement or cause for concern. However, there appears to be a downward trend from 2021 to 2023, which may signal a significant improvement if it continues in the coming years.

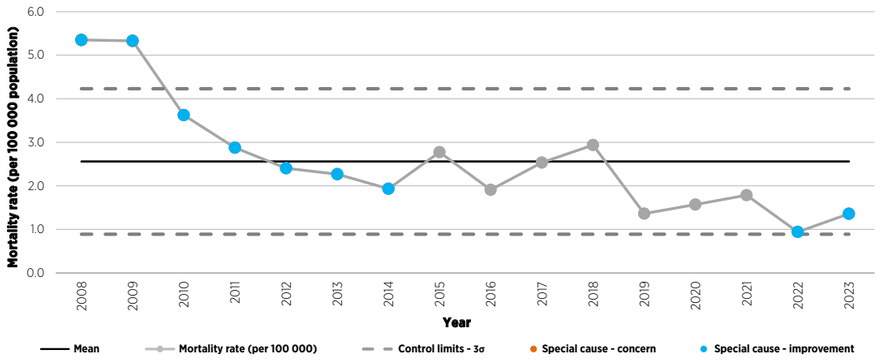


FIGURE 5.7A: CRUDE MORTALITY RATE DUE TO EXTERNAL CAUSES (INJURY) IN CHILDREN AGED 1–14 YEARS, 2008–2023

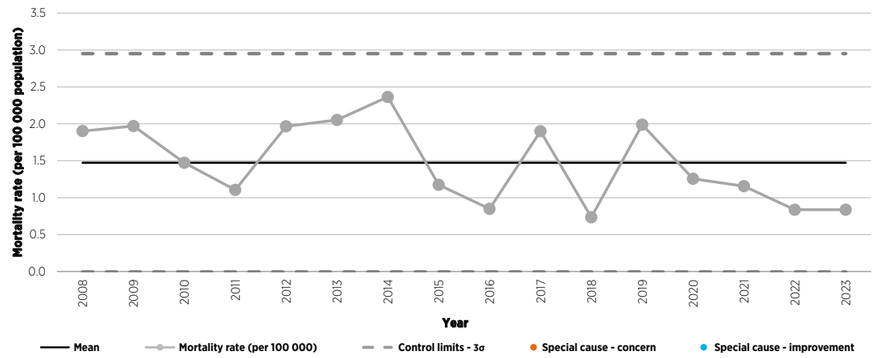


FIGURE 5.7C: CRUDE MORTALITY RATE DUE TO CONGENITAL MALFORMATIONS AND CHROMOSOMAL ABNORMALITIES IN CHILDREN AGED 1–14 YEARS, 2008–2023

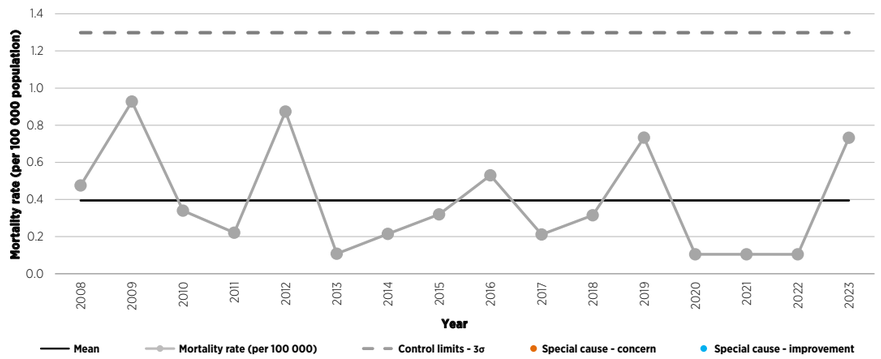


FIGURE 5.7E: CRUDE MORTALITY RATE DUE TO CERTAIN INFECTIOUS AND PARASITIC DISEASES IN CHILDREN AGED 1–14 YEARS, 2008–2023

SPC Chart Rules:

- A ***Shift*** occurs when **6 or more** consecutive points appear on the **same side of the mean** (centreline).
- A ***Trend*** occurs when there are **6 or more** consecutive points that move in the same direction (up or down) A Trend can cross the mean centreline.
- The ***2 out of 3*** rule highlights when 2 of 3 data points are close to the upper or lower control limits.
- Extreme values **(Special Cause)**: any value that falls outside the control limits (upper or lower).
- **Common cause** (grey data points) variation refers to the natural, inherent variability present in a process over time.

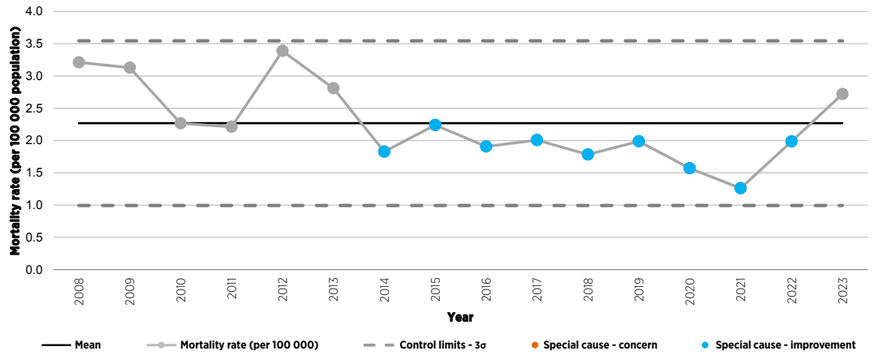


FIGURE 5.7B: CRUDE MORTALITY RATE DUE TO NEOPLASMS IN CHILDREN AGED 1–14 YEARS, 2008–2023

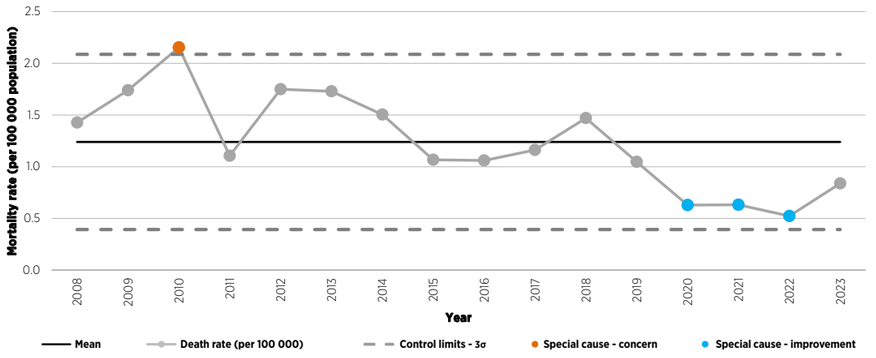


FIGURE 5.7D: CRUDE MORTALITY RATE DUE TO DISEASES OF THE NERVOUS SYSTEM IN CHILDREN AGED 1–14 YEARS, 2008–2023

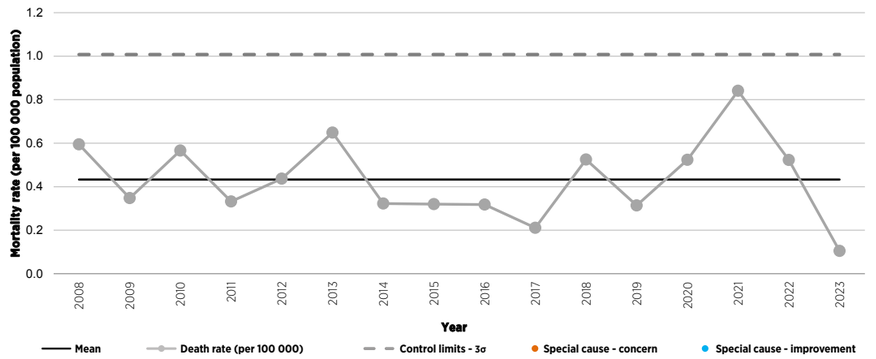


FIGURE 5.7F: CRUDE MORTALITY RATE DUE TO DISEASES OF THE CIRCULATORY SYSTEM IN CHILDREN AGED 1–14 YEARS, 2008–2023

ANNUAL TRENDS IN MAIN CAUSE OF DEATH CATEGORIES FOR CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS

As data on older children and young people aged 15–18 years are only available from 2012 onwards, there was an insufficient number of data points from which to create SPC charts for this age group. Annual mortality rates for the years 2012–2023 are instead provided in the form of run charts in Figures 5.8A–5.8E. The data show a decline in the rate of external-cause deaths from 2018 to 2020. The mortality rate due to diseases of the circulatory system has also declined in recent years following a slight increase between 2020 and 2021. Mortality rates due to neoplasms increased between 2021 and 2022 but have decreased most recently in 2023. The mortality rates due to diseases of the nervous system has showed some variability over time, increasing gradually between 2014 and 2018 before declining in 2019 and 2020 and increasing again between 2021 and 2023. It is possible that lower than usual death registrations during 2020 may account for some of this variability. Similarly, mortality rates due to certain infectious and parasitic diseases have fluctuated between 2008 to 2023, with a slight decrease most recently between 2022 and 2023.

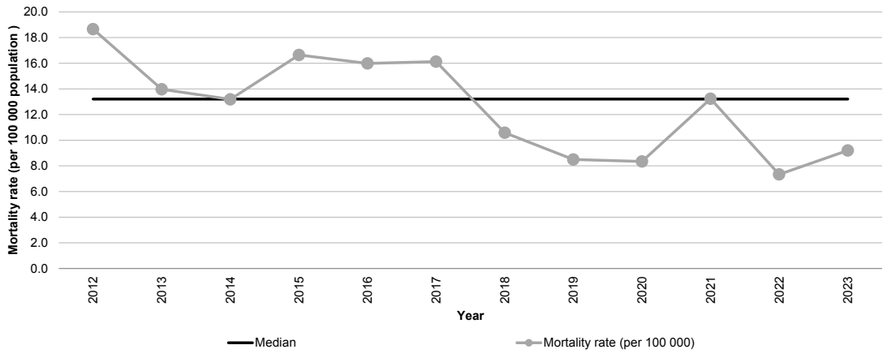


FIGURE 5.8A: CRUDE MORTALITY RATE DUE TO EXTERNAL CAUSES (INJURY) IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS, 2012–2023

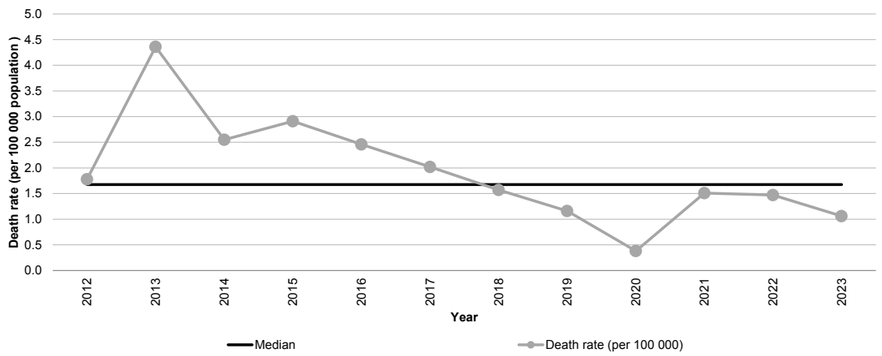


FIGURE 5.8C: CRUDE MORTALITY RATE DUE TO DISEASES OF THE CIRCULATORY SYSTEM IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS, 2012–2023

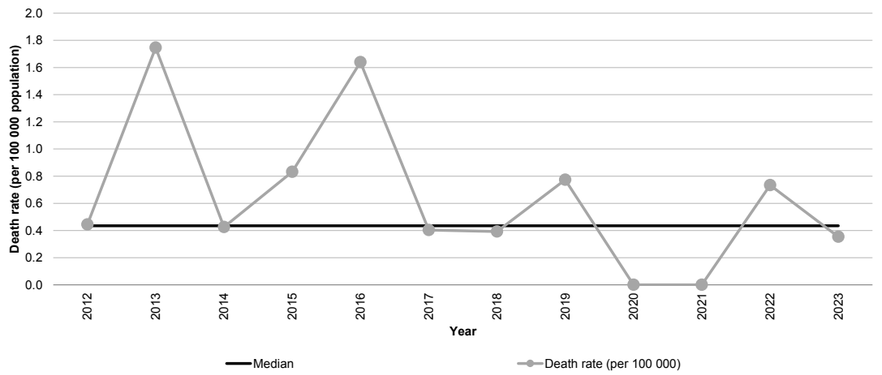


FIGURE 5.8E: CRUDE MORTALITY RATE DUE TO CERTAIN INFECTIOUS AND PARASITIC DISEASES IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS, 2012–2023

Run Chart Rules:

- A ***Shift*** occurs when **6 or more** consecutive points appear on the **same side of the median** (centreline).
- A ***Trend*** occurs when there are **5 or more** consecutive points that move in the same direction (up or down) A Trend can cross the median centreline.
- An **Astronomical data point**: An obviously unusual/different value. Note this is based upon judgement instead of predefined rules.

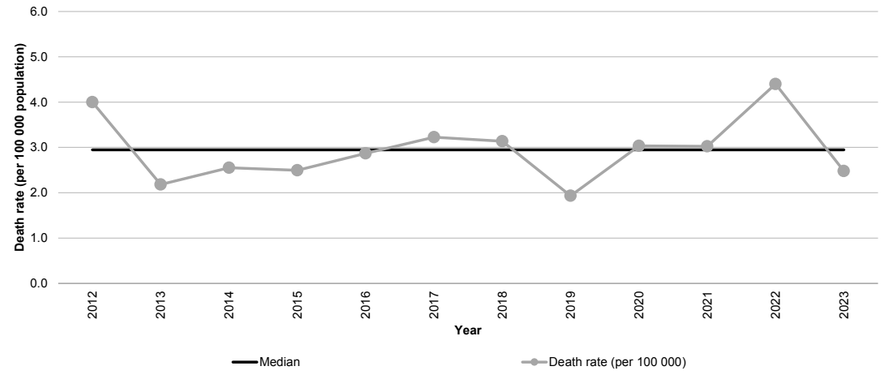


FIGURE 5.8B: CRUDE MORTALITY RATE DUE TO NEOPLASMS IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS, 2012–2023

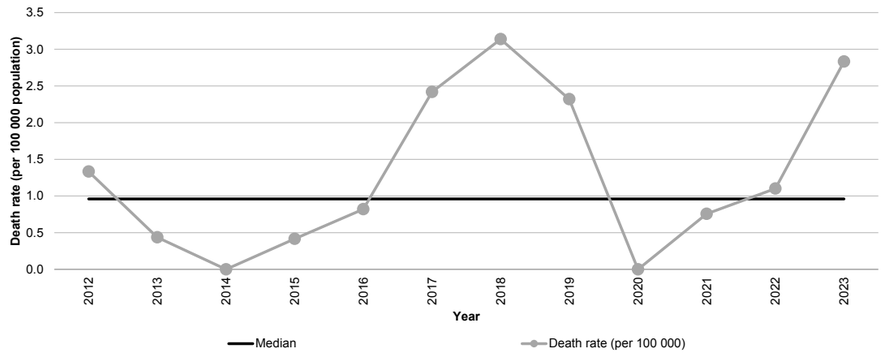


FIGURE 5.8D: CRUDE MORTALITY RATE DUE TO DISEASES OF THE NERVOUS SYSTEM IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS, 2012–2023

SUMMARY OF FINDINGS

Mortality in children post-infancy has declined by more than 40% across all age groups since 2007, with the exception of children aged 5–9 years, although this age group had a lower baseline mortality rate than the other age groups. While mortality in children aged 1–4 years and 5–9 years has continued to decrease gradually over time, there has been no overall decrease in the mortality rates of older children (aged 10–14 years and 15–18 years) since 2013.

Data on the main contributory cause of death categories among children in Ireland are consistent with international data, which report that external causes of injury are the main cause of CYP death (Eurostat, 2024; World Health Organization, 2022). For young people aged 16–29 years in the EU, most deaths (53%) in 2021 were related to external causes, such as accidents or intentional self-harm (Eurostat, 2024).

Trauma remains the leading cause of death among older adolescents aged 15–18 years, accounting for more than one-half (51%) of all deaths registered for this age group during 2019–2023. Neoplasms accounted for 16% of all deaths in this age group registered during the same 5-year period.

Among younger children aged 1–14 years, the decrease in trauma-related deaths has led to an increase in the overall proportion of deaths due to other causes, and neoplasms ranked as the leading cause of death in this age group for the first time in 2019–2023. The number and proportion of deaths due to neoplasms in older children aged 15–18 years increased in 2022–2023 relative to the previous 3 years.

Confirmation of these data is required, with year of occurrence data and additional detail required in order to determine the reason(s) for the decrease in external-cause deaths among CYP aged 1–18 years.

The larger proportion of CYP deaths among males becomes more evident with increasing age. This is a consequence of the higher proportion of deaths that are attributable to external causes in older age groups, the majority of which have been shown to be the result of RTCs (McGarvey *et al*., 2019).

The greatest proportion of child deaths among those aged 1–14 years occurred in hospital, while the greatest proportion of deaths in adolescents (i.e. those aged 15–18 years) occurred at home, which is a reflection of the high number of injury deaths in this age group. Thirty-one percent of deaths in children aged 1–14 years occurred at home, increasing to almost one-half (46%) of all deaths in those aged 15–18 years.

There is a need for more detailed classification data in order to allow a more granular analysis of cause of death and in order to explore the reasons for the changes observed in the main contributing causes of death in the 1–14 years age group, which cannot be fully explained by a reduction in the overall number of deaths. A more informative analysis of the causes of CYP death would consider details relating to underlying conditions and existing comorbidities alongside final cause of death. This would be most efficiently and accurately facilitated by linking existing datasets using the individual health identifier (IHI).

KEY FINDINGS FROM CHAPTER 5

- The average annual number of deaths registered for children increased in 2022–2023 in comparison with the previous 3 years, from an average of 47 deaths registered per year in 2019–2021 to 52 deaths registered per year in 2022–2023 for adolescents aged 15–18 years, and from an average of 67 deaths registered per year in 2019–2021 to 73 deaths registered per year in 2022–2023 for children aged 1–14 years.
- Review of annual mortality rates in Ireland from 2007 to 2023 shows that while mortality rates in children aged 1–4 years and 5–9 years have continued to decrease gradually over time, there has been no overall decrease in the mortality rates of older children (aged 10–14 years and 15–18 years) since 2013.
- Trauma remains the leading cause of death in adolescents aged 15–18 years, accounting for just over one-half of all deaths in this age group. However, the proportion of deaths due to neoplasms has increased in this age group in recent years, from 11.5% in 2012–2018 to 16.3% during 2019–2023.
- The ranking of causes of mortality in children aged 1–14 years during 2019–2023 varies from previous years; neoplasms are now the leading cause of death in this age group, accounting for 25% of all deaths, followed by external causes of injury, which accounted for 20%.
- Neoplasms, certain infectious and parasitic diseases, congenital malformations and chromosomal abnormalities and diseases of the circulatory system account for a greater proportion of deaths in children aged 1–14 years during 2019–2023 than in previous years. Accurate year of occurrence analysis is required in order to confirm these data.
- Timely and more detailed information is required in order to provide an accurate account and review of CYP mortality and to inform policy aimed at reducing the number of deaths.

QUALITY IMPROVEMENT OPPORTUNITIES

Current ICD-10 coding does not provide for the reporting of all infection-related deaths in one broad category, as many cases are incorporated into other system-based disease categories, such as diseases of the respiratory, nervous or circulatory system. Review of individual-level data using relevant four-digit coding is required in order to establish accurate infection-related mortality rates in children. This can be accomplished through interrogation of the death registration dataset available through the CSO with clinical input required in order to identify relevant cases for inclusion in the review.

CHAPTER 6

TRAUMA MORTALITY IN CHILDREN AND YOUNG PEOPLE

CONTENTS

CHAPTER 6: TRAUMA MORTALITY IN CHILDREN AND YOUNG PEOPLE

INTRODUCTION

The *World report on child injury prevention*, which was published by the World Health Organization (WHO) in 2008, acknowledges that childhood injury is the main paediatric public health issue in the world. It estimates that there are approximately 950,000 childhood deaths from injury worldwide every year (Peden *et al*., 2008). Paediatric trauma accounts for up to 48% of all paediatric deaths in children and adolescents aged 1–18 years in the UK (Royal College of Paediatrics and Child Health 2013). The main causes of paediatric mortality internationally are RTCs, followed by accidents/poisoning, including, but not limited to, asphyxia and drowning (Sethi *et al*., 2008).

Fortunately, the majority of cases of paediatric trauma result from preventable mechanisms and can be reduced by overall healthcare system development and improved infrastructure (McAleese *et al*., 2021; Peden *et al*., 2008; Sethi *et al*., 2008).

TRAUMA-RELATED MORTALITY IN CHILDREN AGED 1–14 YEARS

A breakdown of the main causes of trauma-related deaths (also referred to as external-cause deaths) among children aged 1–14 years and adolescents aged 15–18 years is outlined in Figures 6.1A and 6.2A respectively. Comparative data for previous years are provided in Figures 6.1B and 6.2B, and in Table 6.1. , These data are based on year of registration and must therefore be interpreted with caution as they may differ from final figures for each year in which the deaths actually occurred.

Data for the 5-year period from 2019 to 2023 are combined to allow as many subcategories of injury as possible to be described. A more detailed description of trauma-related deaths by narrower age groups and type is not possible due to the disclosure risk associated with low case numbers; hence, the number of deaths attributable to some external causes cannot be reported. These include postural asphyxia, poisoning, farm accidents, high falls, and accidental strangulation. Specific causes with an incidence of fewer than five cases are combined in the 'other' category.

At 26.5% of cases, the overall greatest proportion of trauma-related deaths in children aged 1–14 years were due to RTCs, with 18 deaths registered during the period 2019–2023. This is the equivalent of 3.6 deaths per year and is a reduction from the proportion of RTCs registered in this age group in previous years (2007–2018), when RTCs accounted for 33.6% of all external-cause deaths, and equated to an annual average of 10 RTC deaths per year in this age group. This is probably a reflection of the impact of the lockdown during the COVID-19 pandemic, when the numbers of cars and pedestrians on the road were reduced and children were not attending schools in person (Gilmartin *et al*., 2022; McDonnell *et al*., 2020).

Deaths registered as being due to 'hanging' or 'suspension by ligature' accounted for 19% of fatalities, and this was the second leading cause of trauma death in children aged 1–14 years during 2019–2023 (n=13). Deaths due to homicide/unlawful killing accounted for 13.2% (n=9) and deaths due to drowning accounted for 11.8% (n=8). Together those four categories accounted for 71% of trauma fatalities among children 1–14 years in 2019–2023. There were fewer homicide deaths registered in 2022 and 2023 then in the previous three year period. These figures do not include deaths registered as undetermined or 'open verdict' in young children, and may therefore be a slight underestimation of the true number of children who were unlawfully killed in Ireland during 2019–2023. The vast majority of these deaths occurred in the child's own home and were committed by a family member or someone known to the child. Data from previous years report drowning as the third leading cause of injury-related death in children aged 1–14 years. This statistic is in keeping with that observed internationally (World Health Organization, 2014).

A breakdown of the annual number of external-cause deaths registered for all age groups during the period 2007–2023 is outlined in Table 6.1.

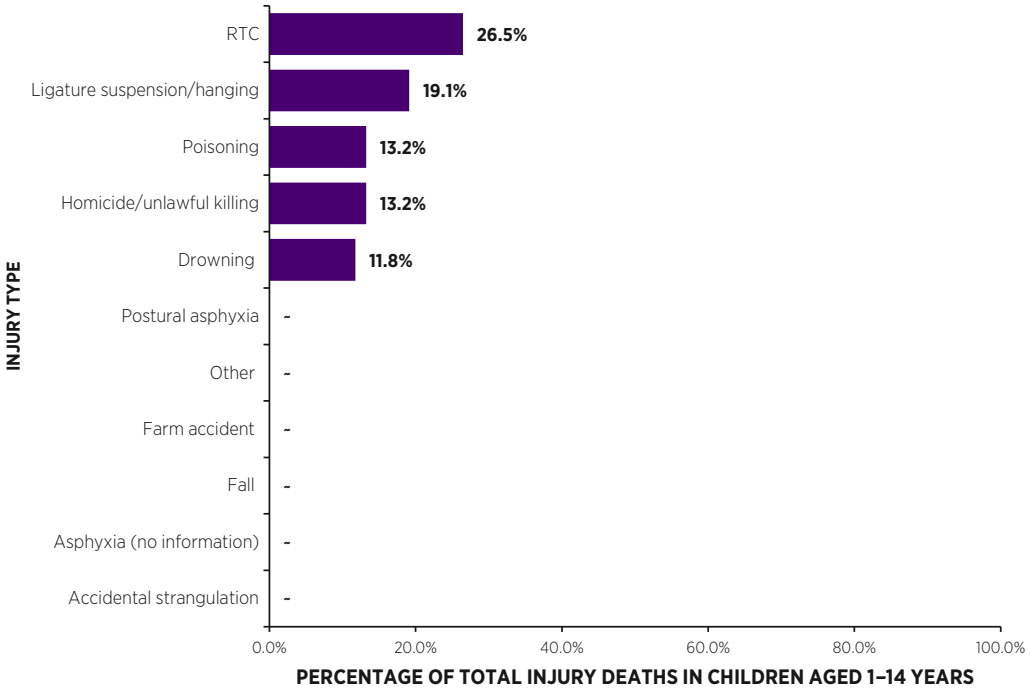


FIGURE 6.1A: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN CHILDREN AGED 1–14 YEARS BASED ON YEAR OF REGISTRATION, BY INJURY TYPE, 2019–2023 (N=68)

-Denotes fewer than 5 cases.

Deaths categorised according to detail entered on death registration i.e. ligature strangulation reported separately to ligature suspension/hanging and accidental strangulation.

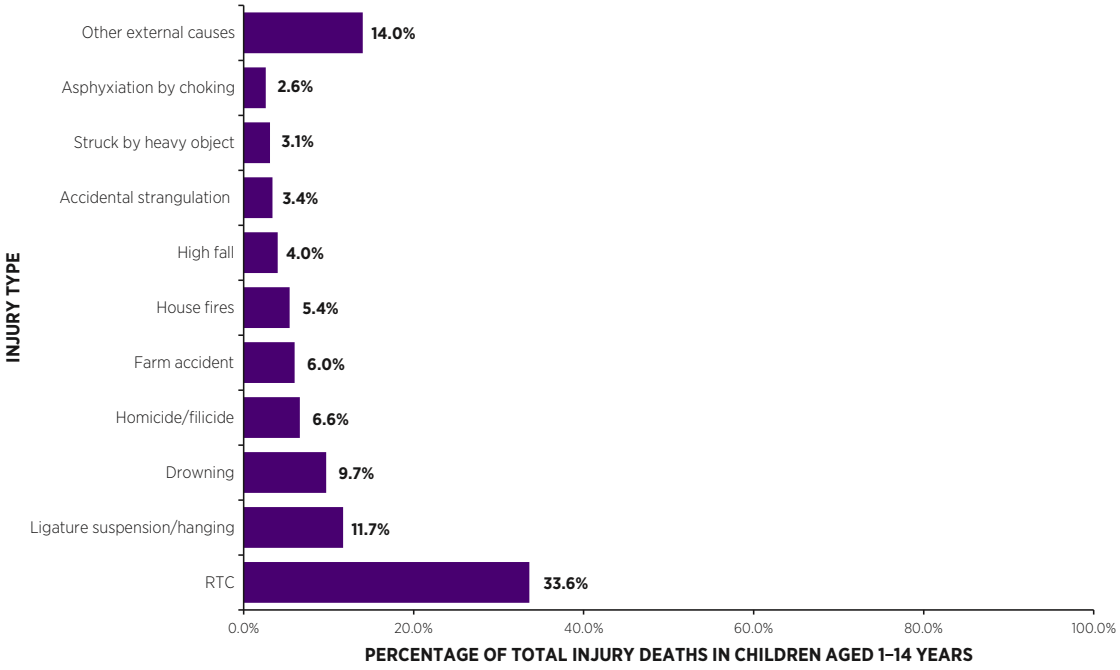


FIGURE 6.1B: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN CHILDREN AGED 1–14 YEARS BASED ON YEAR OF REGISTRATION, BY INJURY TYPE, 2007–2018 (n=351)

Note: "Other external causes" denotes the collective representation of various other injuries of small number that cannot be presented individually due to potential disclosure concerns. Deaths categorised according to detail entered on death registration i.e. ligature strangulation reported separately to ligature suspension/hanging and accidental strangulation.

TRAUMA MORTALITY IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS

In the older adolescent age group (aged 15–18 years), the leading cause of trauma-related deaths in 2019–2023 was ligature suspension or 'hanging' (54.0%) followed by RTCs (13.5%), drowning (5.6%) and toxicity related to drugs and/or alcohol (4.8%). Together, these four categories accounted for 78% of trauma-related fatalities in this age group during the period 2019–2023. The proportion of deaths from RTCs declined from 26.3% (or 9.4 deaths per year) during the period 2012–2018 to 13.5% (or 3.4 deaths per year) during the period 2019–2023. The available death registration data were insufficient to provide additional detail on road user type. However, the Road Safety Authority's *Child Casualties Report 2014–2022* revealed that approximately two in three child casualties from 2014 to 2022 were either a pedestrian or a cyclist (Road Safety Authority, 2023a). A dedicated National Child Safety Day during Irish Road Safety Week in 2024 focused on educating parents and children on the importance of a number of measures for safe road use by all road users, especially drivers.

The data also show that the proportion of deaths due to ligature suspension or hanging increased from 47.8% during the period 2012–2018 to 54.0% during the period 2019–2023. However this does not equate to an increase in the number of these deaths and is due, at least in part to the decline in the overall number of trauma deaths in this age group in 2019–2023 (Table 6.1). There was an average of 13.6 deaths per year due to ligature suspension or hanging during the period 2019–2023 compared with 17.1 deaths per year during the period 2012–2018.

Regrettably, there was insufficient detail in death registration information in order to accurately confirm intent in many cases of injury-related fatalities among adolescents aged 15–18 years; hence, these figures should not be interpreted as accurate estimates for suicide deaths. Additional information obtained from autopsy reports and other sources is required in order to provide accurate estimates of suicide rates among this age group. The proportion of drug- and/or alcohol-related deaths varied only slightly over the two time periods that were analysed and remains fairly constant at an annual average of two deaths per year.

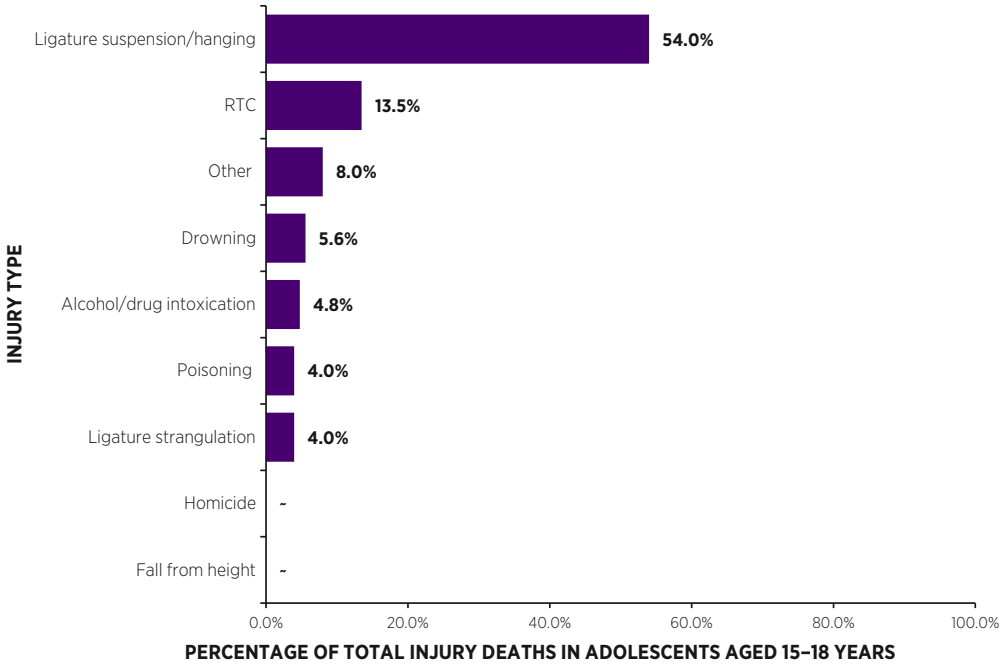


FIGURE 6.2A: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN ADOLESCENTS AGED 15–18 YEARS BASED ON YEAR OF REGISTRATION, BY INJURY TYPE, 2019–2023 (n=125)

Deaths categorised according to detail entered on death registration i.e. ligature strangulation reported separately to ligature suspension/hanging and accidental strangulation.

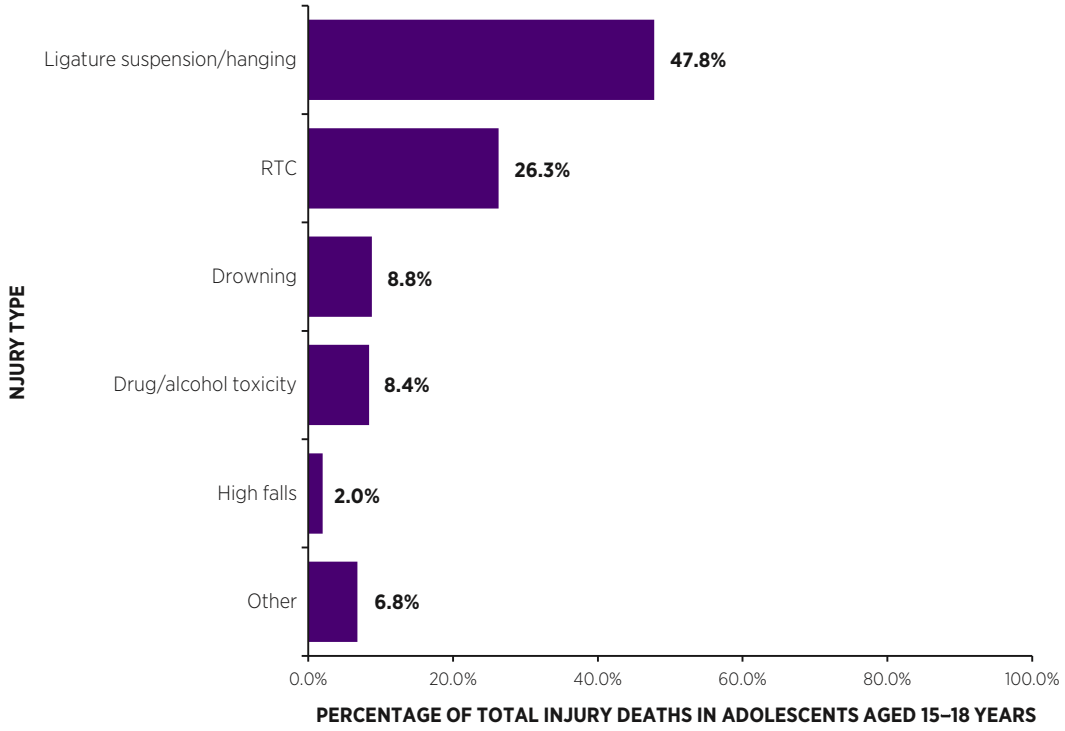


FIGURE 6.2B: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN ADOLESCENTS AGED 15–18 YEARS BASED ON YEAR OF REGISTRATION, BY INJURY TYPE, 2012–2018 (n=251)

Deaths categorised according to detail entered on death registration i.e. ligature strangulation reported separately to ligature suspension/hanging and accidental strangulation.

TABLE 6.1 ANNUAL NUMBER AND PERCENTAGE OF EXTERNAL-CAUSE DEATHS AMONG CHILDREN AND YOUNG PEOPLE AGED 1–14 YEARS AND 15–18 YEARS, 2008–2023

Year	1–14 years		15–18 years	
	Number of external-cause deaths	External-cause deaths as a percentage of all deaths	Number of external-cause deaths	External-cause deaths as a percentage of all deaths
2008	45	35.2%	na	na
2009	46	35.1%	na	na
2010	32	27.8%	na	na
2011	26	27.7%	na	na
2012	22	20.2%	42	59.2%
2013	21	18.3%	32	57.1%
2014	18	27.7%	31	62.0%
2015	26	26.8%	40	65.6%
2016	18	23.7%	39	59.1%
2017	24	27.0%	40	58.8%
2018	28	27.2%	27	50.9%
2019	14	18.9%	22	46.8%
2020	15	20.3%	22	53.7%
2021	12	22.2%	35	66.0%
2022	9	14.8%	20	42.6%
2023	18	21.4%	26	45.6%

Note: Data for the period 2008–2011 are unavailable for adolescents aged 15–18 years.

ANNUAL TRENDS IN TRAUMA-RELATED MORTALITY RATES IN CHILDREN AGED 1–14 YEARS

Statistical analyses of data on annual trends in the rate of trauma deaths per 100,000 population for children aged 1–14 years are provided in the form of SPC charts in Figures 6.3A–6.3C.

The decline in trauma-related deaths for children aged 1–14 years is clearly evident in Figure 5.7A.(Chapter 5); from a peak of 5.4 deaths per 100,000 population in 2008 to 1.4 deaths per 100,000 population during the 2019–2023 period, which is a reduction of 74%. The fatality rate reported in 2022 is the lowest injury fatality rate reported for this age group as of 2024.

The findings from analysis of data on children aged 1–14 years is summarised as follow

RTCS

The decline in trauma mortality rates is reflected in a similar pattern of decline in RTC fatalities for this age group: the mortality rate due to RTCs decreased by 92% from a peak rate of 2.6 deaths per 100,000 population in 2008 to 0.2 deaths per 100,000 population in 2022 (Figure 6.3A). In 2008 and 2009, there was significant cause for concern because the RTC death rates rose above the upper control limit to 2.6 deaths per 100,000 population in 2008 and 2.3 deaths per 100,000 population in 2009. There has been a steady decline in the mortality rate due to RTCs since then, however, with a significant improvement observed between 2016 and 2023. Figures on long-term trends published by the Road Safety Authority show a similar pattern of decline in the overall number of RTC fatalities among children, with further decline evident during the COVID-19 pandemic years (Road Safety Authority, 2023b). However, preliminary figures for 2023 and 2024 show that the number of RTC fatalities has started to increase again (Road Safety Authority, 2024b).

LIGATURE SUSPENSION/HANGING

The SPC chart in Figure 6.3B indicates a significant improvement in mortality rates due to ligature suspension/hanging between 2011 and 2016. Since then, the data have shown common cause variation, with no further improvement in mortality rates since 2016. However, there was a notable increase in death rates between 2022 and 2023, and it will be important to monitor this trend in order to determine whether it will become a cause for concern in the coming years.

HOMICIDE

Homicide: The SPC chart in Figure 6.3C shows that mortality rates from homicide have exhibited common cause variation between 2008 and 2023, indicating a steady process with no significant changes or cause for concern.

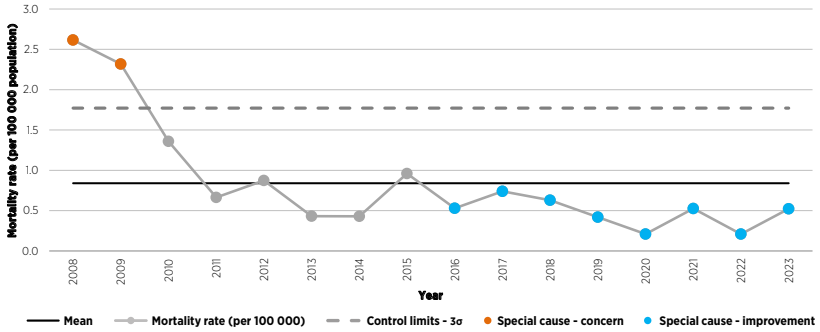


FIGURE 6.3A: CRUDE MORTALITY RATE DUE TO ROAD TRAFFIC COLLISIONS IN CHILDREN AGED 1–14 YEARS, 2008–2023

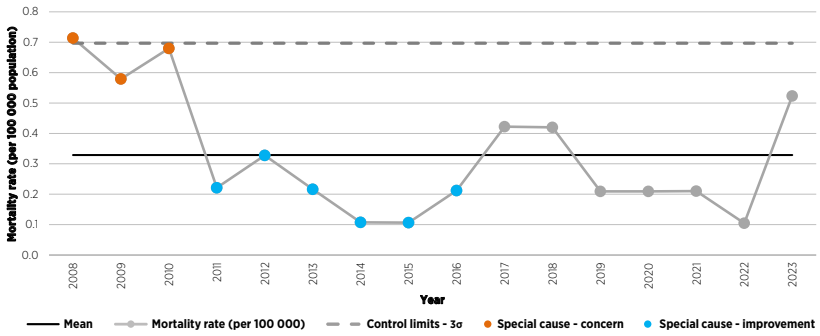


FIGURE 6.3B: CRUDE MORTALITY RATE DUE TO LIGATURE SUSPENSION/HANGING IN CHILDREN AGED 1–14 YEARS, 2008–2023

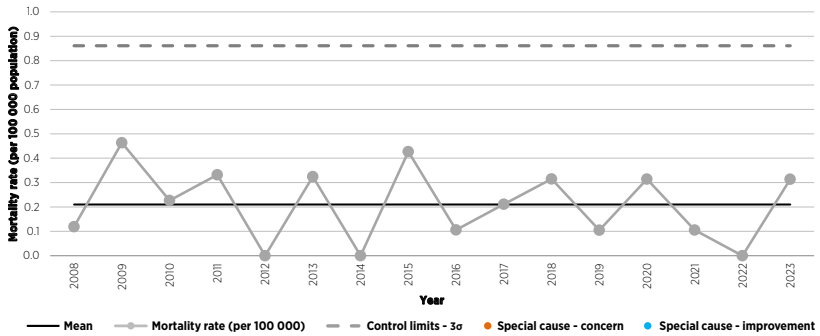


FIGURE 6.3C: CRUDE MORTALITY RATE DUE TO HOMICIDE IN CHILDREN AGED 1–14 YEARS, 2008–2023

SPC Chart Rules:

- A ***Shift*** occurs when **6 or more** consecutive points appear on the **same side of the mean** (centreline).
- A ***Trend*** occurs when there are **6 or more** consecutive points that move in the same direction (up or down) A Trend can cross the mean centreline.
- The ***2 out of 3*** rule highlights when 2 of 3 data points are close to the upper or lower control limits.
- Extreme values **(Special Cause)**: any value that falls outside the control limits (upper or lower).
- **Common cause** (grey data points) variation refers to the natural, inherent variability present in a process over time.

ANNUAL TRENDS IN TRAUMA-RELATED MORTALITY IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS

The construction of SPC charts requires a minimum number of data points. As data for adolescents aged 15–18 years are only available from 2012 onwards, it was not possible to conduct statistical analysis, and these data are presented as run charts rather than as SPC charts (Figures 6.4A and 6.4B).

The reduction in the rate of overall injury-related fatalities was less pronounced in older adolescents aged 15–18 years than in children aged 1-14. Despite a decline in rates of RTC fatalities among adolescents aged 15–18 years, the overall trauma fatality rate in this age group remained high until 2018 due to a gradual increase in the number of deaths due to ligature suspension/hanging. The Road Safety Authority's preliminary figures for 2023 and 2024 show that the number of RTC fatalities has started to increase again, particularly among young people aged 16–25 years (Road Safety Authority, 2024b).

The rate of deaths due to ligature suspension/hanging among adolescents aged 15–18 years should not be interpreted as the rate of suicide in this age group, as it is likely to be an underestimate. This figure will be impacted by delayed death registrations occurring as a result of such deaths being subject to a coroner's review and/or inquest, which may result in them being registered later than the 22-month deadline adopted by the CSO for annual publications. Adjusted figures will be provided in subsequent reports.

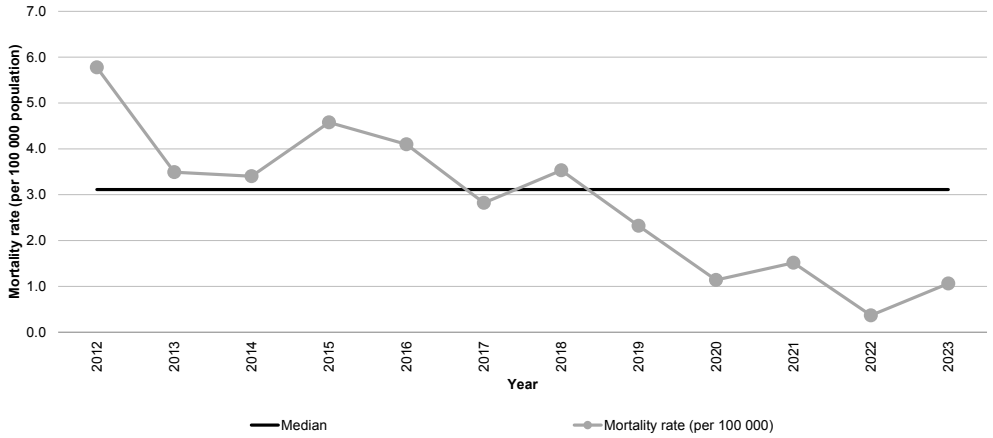


FIGURE 6.4A: CRUDE MORTALITY RATE DUE TO ROAD TRAFFIC COLLISIONS IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS, 2012–2023

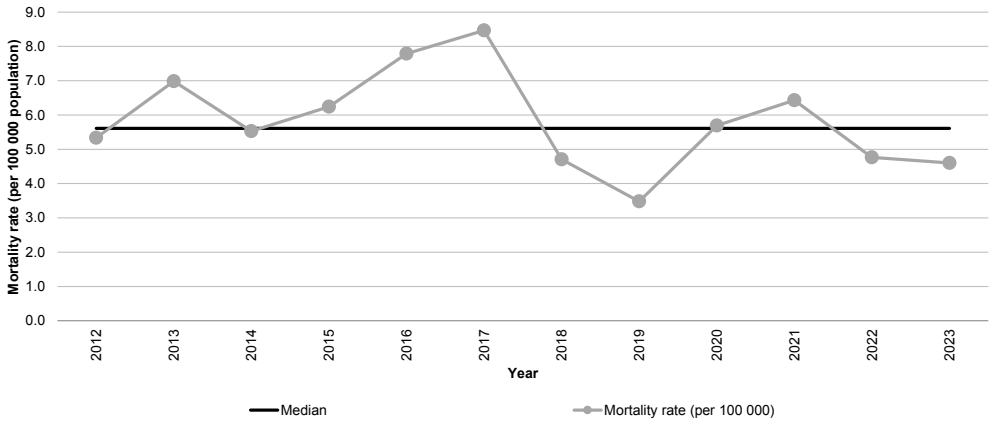


FIGURE 6.4B: CRUDE MORTALITY RATE DUE TO LIGATURE SUSPENSION/HANGING IN CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS, 2012–2023

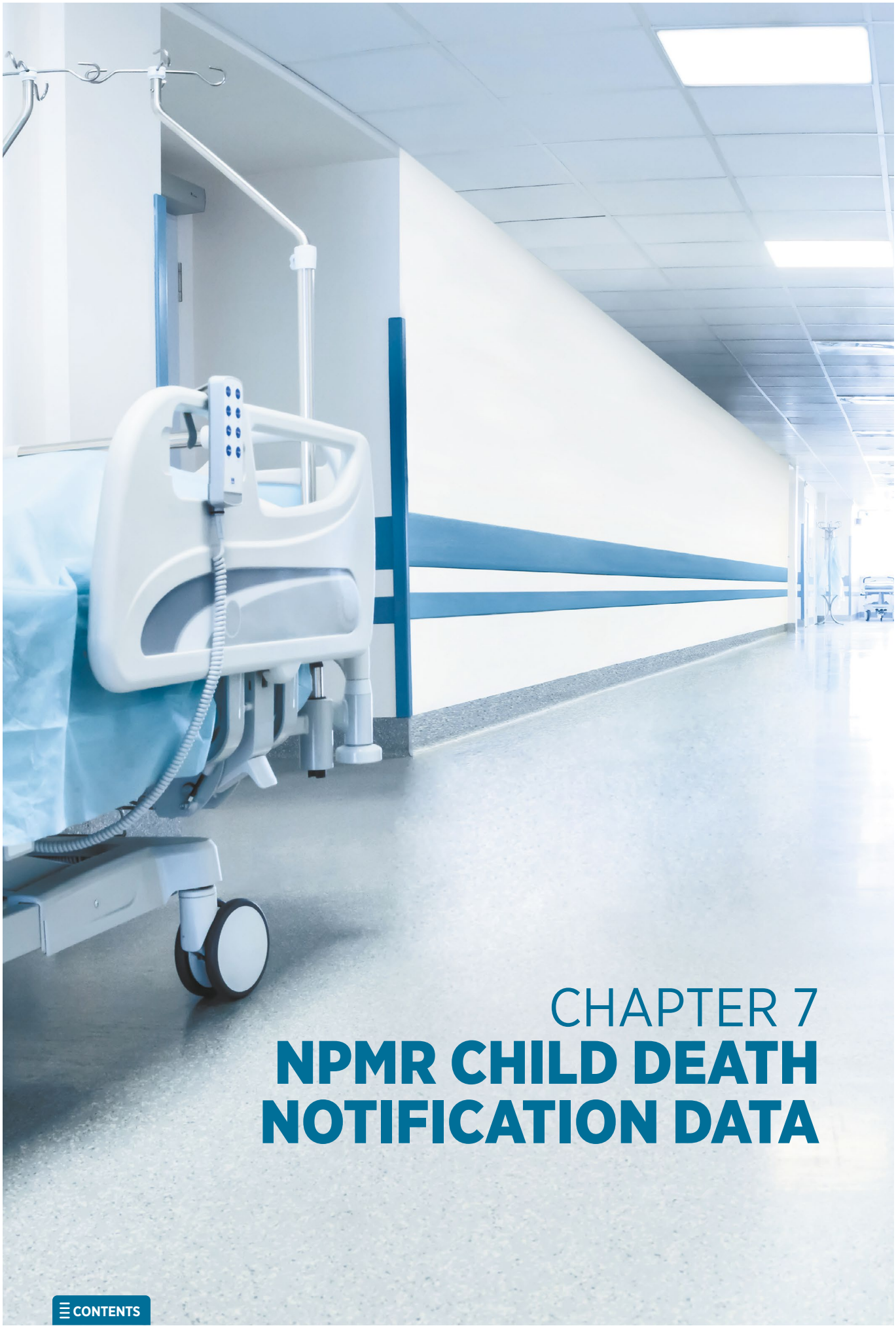
KEY FINDINGS FROM CHAPTER 6

- There has been a decrease in the overall number and rate of trauma-related deaths registered during the period 2019–2023 among children aged 1–14 years and adolescents aged 15–18 years.
- The greatest proportions of trauma-related deaths among children aged 1–14 years registered during 2019–2023 were due to RTCs (26.5%) and ligature suspension/hanging (19.1%).
- The proportion of registered deaths due to RTCs has declined among children of all ages from 9.8 deaths per year in 2007–2018 to 3.6 deaths per year in 2019–2023 among children aged 1–14 years, and from 9.4 deaths per year in 2012–2018 to 3.4 deaths per year in 2019–2023 among adolescents aged 15–18 years.
- The decline in the number of RTC and other external-cause deaths during the period 2019–2023 compared with previous years is likely related to changes in activity and exposure to certain risk factors during the COVID-19 pandemic.
- Ligature suspension/hanging remains the leading cause of death among adolescents aged 15-18 years, accounting for more than one-half (54%) of all trauma deaths and almost one-third (28%) of all registered deaths in this age group during 2019-2023.
- Once again, there is a need for more detailed classification data in order to allow a more granular analysis of cause of death, and confirmation of annual occurrence figures is required. Additional data collections are required in order to provide a more detailed description of trauma-related deaths among CYP, including deaths due to RTCs and suicide. This will help increase public awareness of these causes of death.

QUALITY IMPROVEMENT OPPORTUNITIES

Despite the high burden of mental health conditions among adolescents, services to address these are currently lacking. Available mortality data that are based on death registration information cannot be used to report timely self-harm mortality rates. This is due to difficulties with to the documentation of intent in relation to injury fatalities. Consequently, the data presented in this report relate to mortality rates based on injury type and are an underestimate of true self-harm rates. Furthermore, there is an increasing problem with the late registration of self-harm deaths, and this is having an effect on the comparability of statistics across years (CSO, 2023). Additional data must be collected on CYP mortality in order to accurately establish the burden of both intentional and unintentional injury in the Irish CYP population and to aid in the identification of contributory and modifiable risk factors. These data should be used in order to increase awareness of the high incidence of such deaths among the Irish CYP population and support the development of mental health services and preventative initiatives.

The NPMR can assist with the improvement of available statistics on intentional and unintentional injury mortality through the review of the data available in post-mortem examination reports. This information can be used in order to help guide policy aimed at addressing the high number of injury-related CYP deaths. Future data collection by the NPMR will include health equity stratifiers in its minimum core dataset, and this will inform the appropriate targeting of prevention strategies to the most vulnerable groups.



CHAPTER 7
NPMR CHILD DEATH NOTIFICATION DATA

CONTENTS

CHAPTER 7: **NPMR CHILD DEATH NOTIFICATION DATA**

BACKGROUND

The NPMR Child Death Notification form was designed to capture standardised and prompt notifications of child deaths in a central unit for analysis and reporting. The form aimed to capture a minimum core dataset of information on child deaths in Children's Health Ireland (CHI) at Temple Street, the objective of which is to enable accurate, standardised and timely reports on which children die, where these children die and from what causes. The form was introduced into hospital policy in December 2018, and is included on a checklist of tasks that staff must complete in the event of the death of a child in the hospital. The form is completed by the consultant in charge of the child's care at the time of death, or by a team member. The data discussed in this chapter were collected for the full years from 2019 to 2023 and for Q1–Q3 2024.

The aim of the NPMR Child Death Notification form is to establish the feasibility of capturing a minimum core dataset of information on all deaths occurring in CHI at Temple Street.

METHODOLOGY

A detailed description of the methodology and data quality statement of the piloting of this form is provided in Chapters 2 and 3 of this report. The completion rate of NPMR Child Death Notification forms during the period 2019–2021 was impacted by the COVID-19 pandemic, and consequently, the presentation of these data was restricted due to the small number of cases recorded. This chapter supplements the data collected during 2019–2021 with data for 2022, 2023 and the first three quarters of 2024, allowing a more comprehensive description of deaths in CHI at Temple Street.

RESULTS

Completion rate of NPMR Child Death Notification forms in CHI at Temple Street, 2019 to Q3 2024

The NPMR child death notification system captured the majority of deaths that occurred in CHI at Temple Street during the period between 1 January 2019 and 30 September 2024. Missed cases were identified via the hospital's internal alert messaging system, based on the information received by the integrated patient management system (iPMS). The number of deaths that occurred in CHI at Temple Street and the number captured by the NPMR Child Death Notification form are outlined in Table 7.1. Following an initial high NPMR Child Death Notification form completion rate of 83.3% in 2019, the percentage of deaths notified to the NPMR dropped to just 52.6% in 2020, but increased again to 72.7% in 2021. The decrease in notifications in 2020 was largely due to difficulties relating to changes and staffing issues that occurred during the COVID-19 pandemic. The capture rate dropped again in 2022 to 64%, but increased to 78% in 2023 and 96% in Q1–Q3 2024. The low capture rate in 2020 and 2022 means that the data for those years must be interpreted with caution. In order to supplement the dataset, forms were completed retrospectively where possible by a data collection coordinator (n=9).

Throughout the study period (2019 to Q3 2024), the NPMR was not notified of cases that involved the Office of the State Pathologist. Cross-checking of numbers with those recorded by the Hospital In-Patient Enquiry (HIPE) dataset revealed a discrepancy in the number of deaths captured by the various systems (i.e. HIPE, the iPMS and the NPMR Child Death Notification form). This is likely due to a number of patients who died at home appearing on the iPMS. It is also noteworthy that every year, place of death was not specified for a number of patients who were identified on the iPIMS as deceased, which limits the usefulness of the iPIMS as a data validation tool. The data for all three systems are outlined in Table 7.2.

TABLE 7.1: NUMBER AND COMPLETION RATE OF NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORMS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET (JANUARY 2019 TO SEPTEMBER 2024)

Year	Total deaths recorded in hospital	NPMR Child Death Notification forms completed		Deaths without completed NPMR Child Death Notification forms		Additional data collected retrospectively	Total number of cases in dataset
	N	n	%	n	%	n	n
2019	24	20	83.3%	4	16.7%	3	23
2020	19	10	52.6%	9	47.4%	9	19
2021	22	16	72.7%	6	27.3%	0	16
2019–2021	**65**	**46**	**70.8%**	**19**	**29.2%**	**12**	**58**
2022	36	23	63.8%	13	36.1%	0	23
2023	27	21	77.8%	6	22.2%	0	21
2024 (Q1–Q3)	23	22	95.8%	1	4.3%	0	22
2022 to Q3 2024	**86**	**66**	**76.7%**	**20**	**23.3%**	**0**	**66**

TABLE 7.2: COMPARISON OF DATA CAPTURED BY THE NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORM, THE HOSPITAL IN-PATIENT ENQUIRY DATASET AND THE INTEGRATED PATIENT MANAGEMENT SYSTEM IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET (JANUARY 2019 TO SEPTEMBER 2024)

Year	NPMR Child Death Notification form	HIPE dataset	iPMS
2019	20	16	24
2020	10	18	19
2021	16	24	22
2022	23	28	36
2023	21	21	28
2024 (Q1–Q3)	22	n/a	23

Note: HIPE data for 2024 were not available at the time of writing this report.

CHARACTERISTICS OF DEATHS OCCURRING IN CHI AT TEMPLE STREET, 2019 TO Q3 2024

The median age of death of children who died in CHI at Temple Street during the 3-year period from 2019 to 2021 was 1.1 years, compared with 2.4 years from 2022 to Q3 2024. Infants and young children aged under 5 years accounted for 69% of deaths in CHI at Temple Street during 2019–2021, and 58% of deaths from 2022 to Q3 2024 (Figure 7.1).

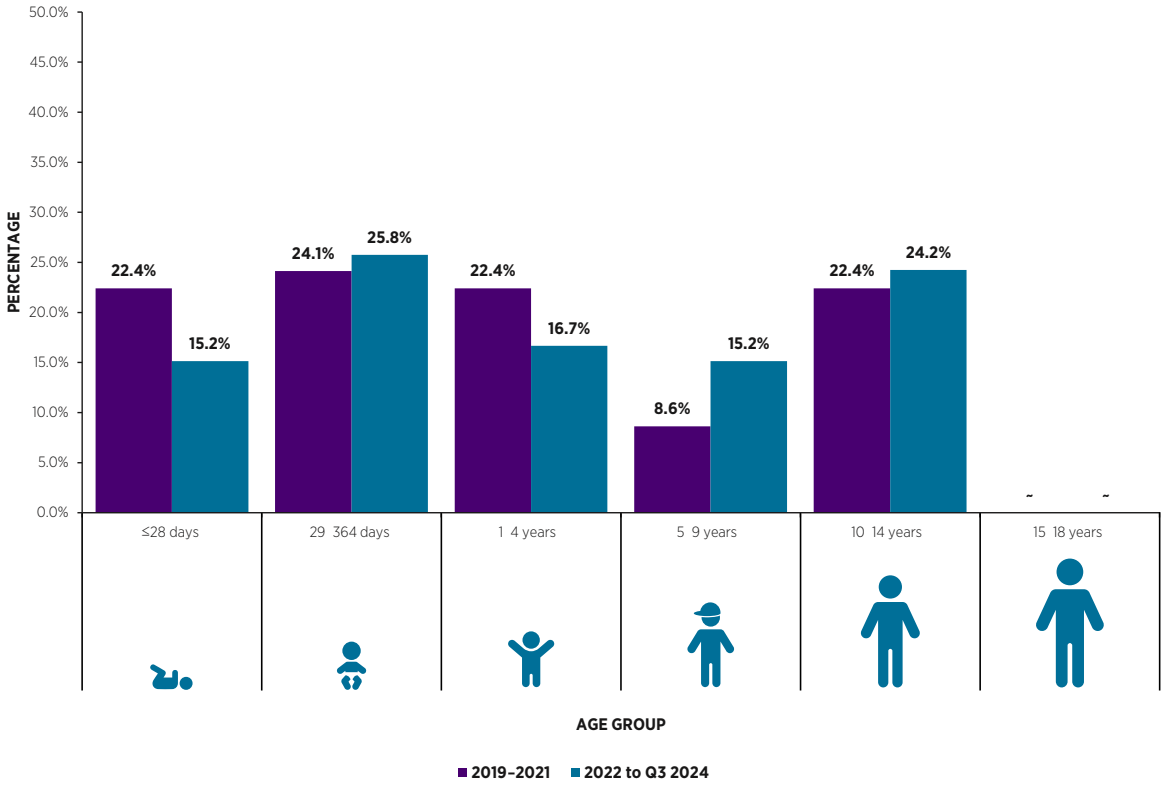


FIGURE 7.1: PROPORTION OF PAEDIATRIC INPATIENT DEATHS AMONG CHILDREN AGED UNDER 19 YEARS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET, BY AGE GROUP, 2019 TO Q3 2024 (n=124)

~ denotes fewer than 5 cases.

LOCATION AT TIME OF DEATH

Data on the location of death were captured for 90% (n=112/124) of all deaths in CHI at Temple Street during the period 2019 to Q3 2024, as illustrated in Figure 7.2. During this period, the majority of deaths (71%) were reported to have occurred in the intensive care unit (ICU). Other notifications included deaths that occurred in the emergency department (ED), in the hospital ward or hospital end-of-life suite, or at home. The proportion of deaths occurring in the ICU did not vary substantially between the two periods (2019–2021 and 2022 to Q3 2024) (see Appendix 3).

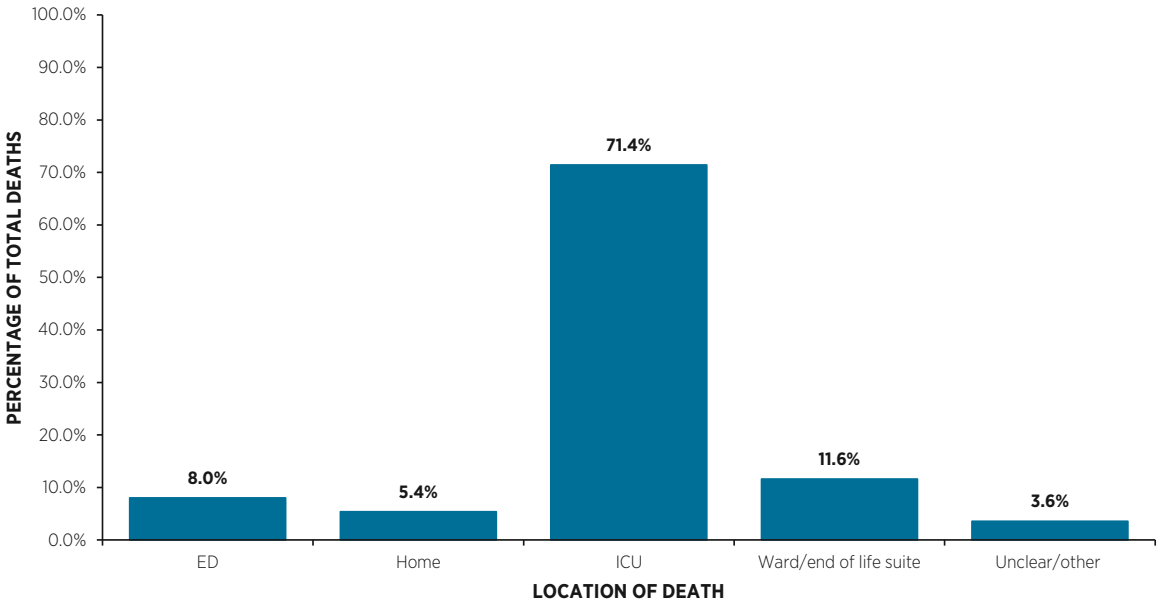


FIGURE 7.2: LOCATION OF DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET, 2019 TO Q3 2024 (n=112)

End of Life suite is a private room near the PCCU where parents can spend the last days with their terminally ill child.

PATIENT TRANSFERS

Sixty-four percent of the deaths in CHI at Temple Street reported to the NPMR during the period 2019 to Q3 2024 were patients who were transferred from other hospitals. Twenty hospitals transferred patients for treatment during this period (see Appendix 5). The greatest proportion of transfers were from the Dublin maternity hospitals and other CHI hospitals (38%), University Hospital Limerick (10%) and Cork University Maternity Hospital (8%).

SUSPECTED CAUSE OF DEATH

The suspected cause of death for each child who died in CHI at Temple Street during the period from 2019 to Q4 2024 is provided in Table 7.3 and Figure 7.3. Due to the small number of cases in some categories, it was not possible to examine annual trends, and data are presented as aggregate data for period 1 (2019–2021) and period 2 (2022 to Q3 2024) in Figure 7.3. Three main cause of death categories accounted for 57% of all deaths that occurred in CHI at Temple Street during this period: external causes (21%), infection and/or sepsis (19%) and life-limiting conditions (18%). Necrotising enterocolitis and various neonatal conditions accounted for 20% of deaths, all of which occurred in children aged under 1 year, while 7% were sudden unexplained deaths.

Review of cause of death data over the two time periods showed an increase in the proportion of deaths in each of the main cause of death categories during 2022 to Q3 2024 (Figure 7.3). This was particularly evident in the proportion of deaths due to infection and/or sepsis, which increased both in number and proportion, from 12.1% of deaths (2.3 deaths per year) in 2019–2021 to 24.2% of deaths (5.8 deaths per year) from 2022 to Q3 2024. Infection/sepsis accounted for the greatest proportion of deaths notified to the NPMR by CHI at Temple Street during the period from January 2022 to September 2024. The majority (65%) of infection/sepsis-related deaths during 2019 to Q3 2024 occurred in infants and children aged under 5 years (Figure 7.4). Review of the distribution of deaths by yearly quarter revealed that the majority (74%) of infection/sepsis-related deaths occurred during the colder months of the year (in Q1 and Q4) in contrast to other causes of death, which were more evenly spread throughout the year (Figure 7.5).

The number of sudden unexplained deaths in infancy (SUDI) (which encompasses SIDS) and sudden unexplained deaths in childhood (SUDC) cases presenting to CHI at Temple Street decreased during 2022 to Q3 2024 relative to 2019–2021, and this is most likely a consequence of the fact that such cases were being sent directly to CHI at Crumlin due to the lack of a pathologist in CHI at Temple Street. These data must be confirmed by CSO death registration information, as the necessary information is unavailable from either the HIPE or iPMS datasets.

The proportion of registered deaths due to neonatal conditions was also lower during 2022 to Q3 2024 than in 2019–2021, while the proportion of registered deaths due to life-limiting conditions increased from 15.5% (3.0 deaths per year) in 2019–2021 to 19.7% (4.7 deaths per year) in 2022 to Q3 2024.

TABLE 7.3: MAIN CAUSE OF DEATH CATEGORIES OF PAEDIATRIC DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET REPORTED TO THE NATIONAL PAEDIATRIC MORTALITY REGISTER, 2019 TO Q3 2024 (n=124)

Cause of death category	n	%
External causes	26	21.0%
Infection/sepsis	23	18.5%
Life-limiting conditions	22	17.7%
Other neonatal conditions	13	10.5%
Sudden unexplained death in infancy and childhood (SUDI/SUDC)	8	6.5%
Necrotising enterocolitis	12	9.7%
All other causes	13	10.5%
No cause of death specified	7	5.6%
Total	124	100.0%

Note: Deaths certified as being due to sepsis associated with necrotising enterocolitis are not included in the 'infection/sepsis' category.

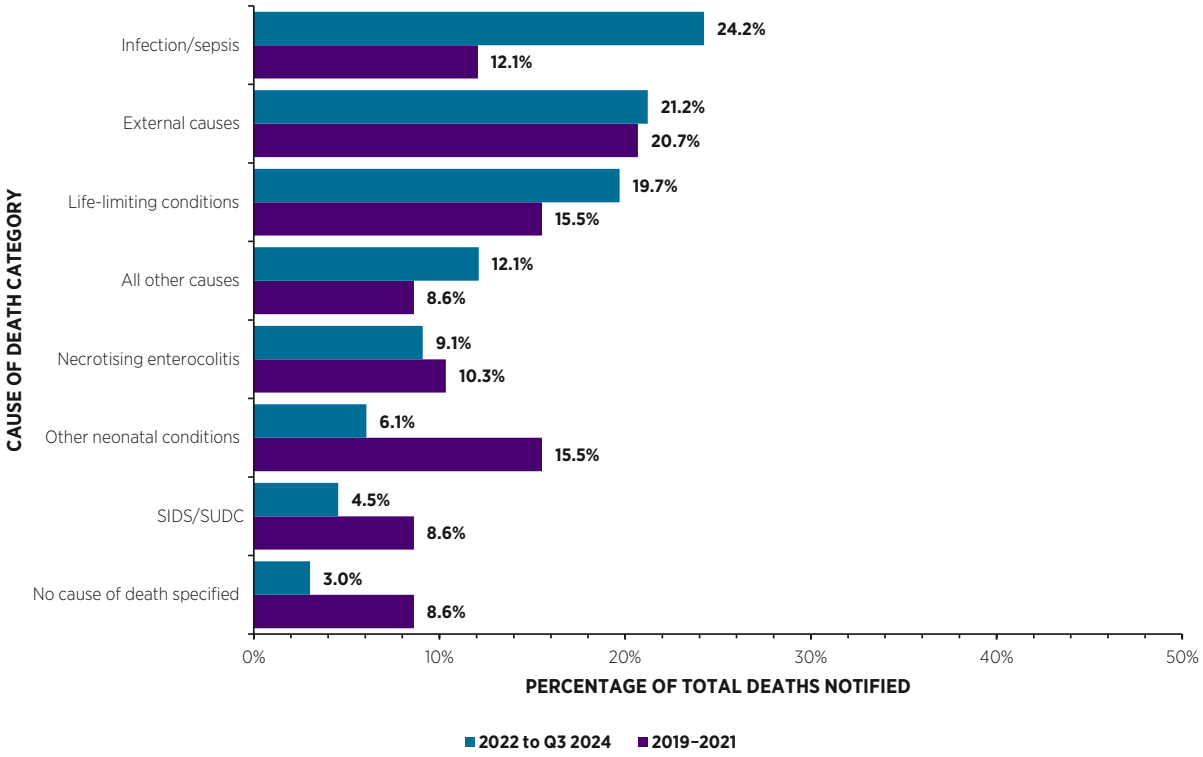


FIGURE 7.3: MAIN CAUSE OF DEATH CATEGORIES OF CYP DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET REPORTED TO THE NATIONAL PAEDIATRIC MORTALITY REGISTER, 2019–2021 COMPARED WITH 2022 TO Q3 2024 (n=124)

Note: Deaths certified as being due to sepsis associated with necrotising enterocolitis are not included in the 'infection/sepsis' category.

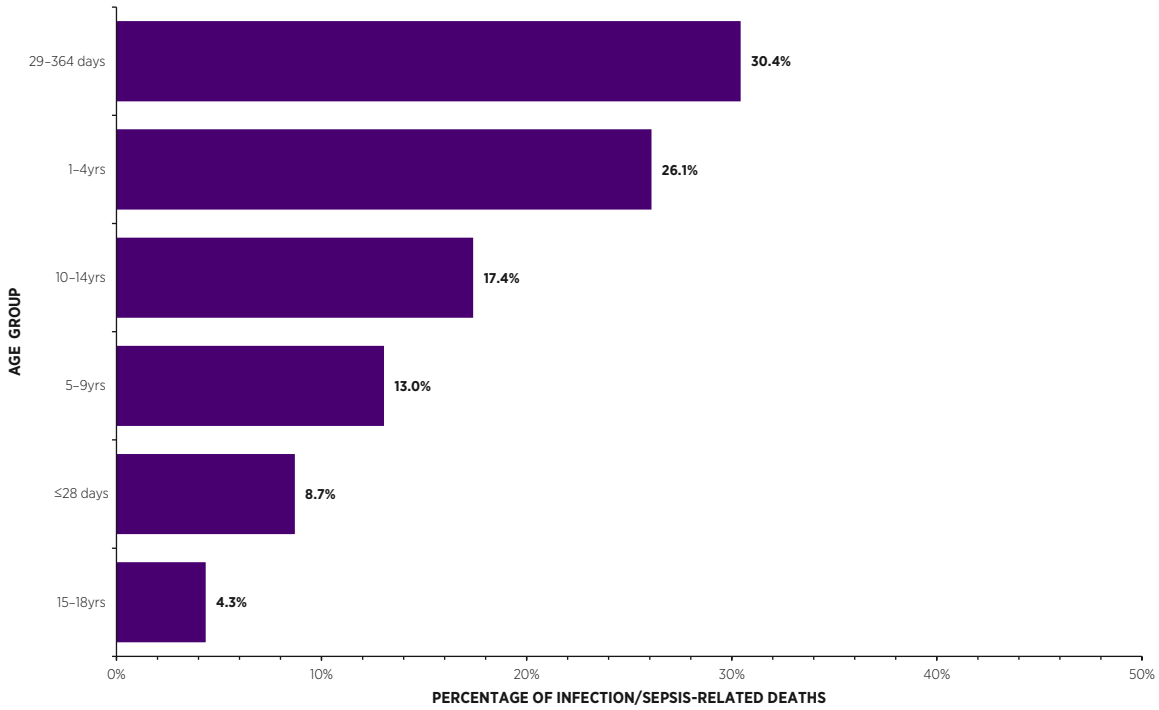


FIGURE 7.4: AGE DISTRIBUTION OF INFECTION/SEPSIS-RELATED DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET, 2019 TO Q3 2024 (n=23)

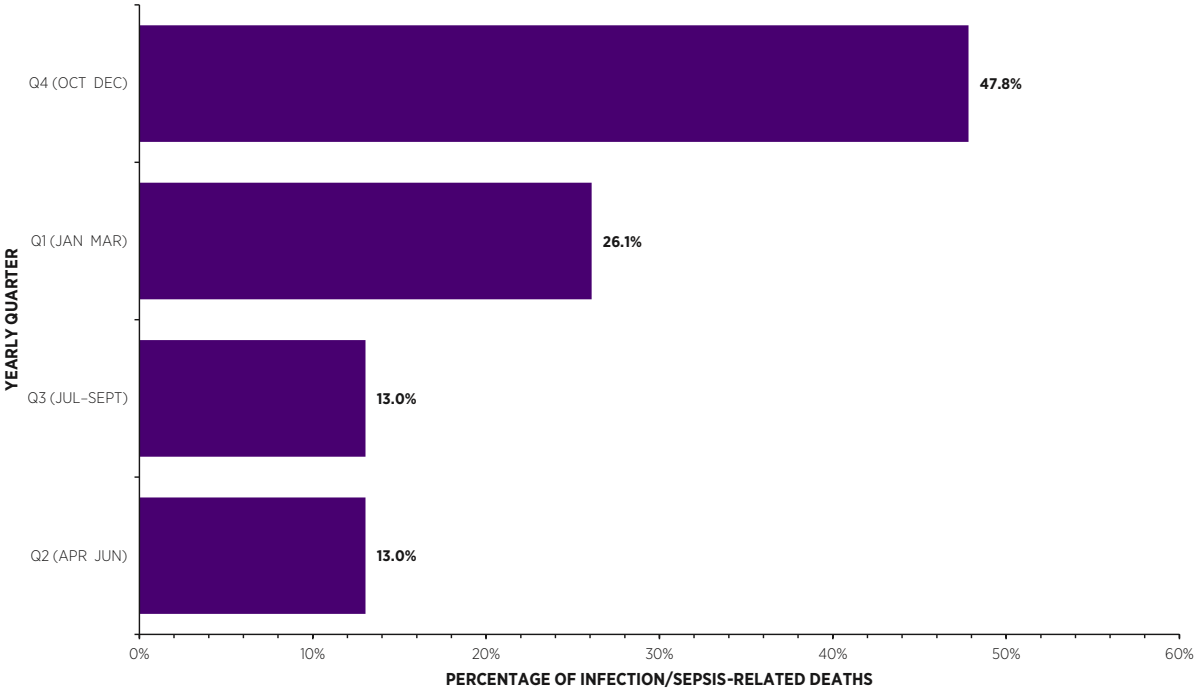


FIGURE 7.5: DISTRIBUTION OF INFECTION/SEPSIS-RELATED DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET BY YEARLY QUARTER, 2019 TO Q3 2024 (n=23)

MODE OF DEATH, ADVANCED CARE DIRECTIVES AND AUTOPSY RATE

A breakdown of data relating to variables for mode of death, autopsy rates, number of coroner's cases and patients with an advanced care directive in place is outlined in Table 7.4.

TABLE 7.4: SUMMARY OF MODE OF DEATH AND PROCESSES SURROUNDING DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET REPORTED TO THE NATIONAL PAEDIATRIC MORTALITY REGISTER, 2019 TO Q3 2024

VARIABLE	n	%
MODE OF DEATH		
Unexpected	57	54.2%
Expected/other	48	45.7%
Total	105	100.0%
ADVANCED CARE DIRECTIVE IN PLACE		
Yes	29	28.2%
No/other	74	71.8%
Total	103	100.0%
AUTOPSY CONDUCTED		
Yes	52	47.7%
No	49	45.0%
Decision pending/not known	8	7.4%
Total	109	100.0%
CORONER NOTIFIED		
Yes	91	85.0%
No	16	15.0%
Total	107	100.0%

Note: Unexpected death is defined as the death of a child that was not anticipated as a possibility 24 hours prior to death or where there was an unexpected collapse precipitating events that led to the death.

KEY LEARNINGS ON THE NPMR CHILD DEATH NOTIFICATION PROCESS

The data provided in this chapter demonstrate the feasibility of collecting timely notifications of in-hospital deaths using the pilot NPMR Child Death Notification form in a tertiary paediatric hospital. An account of the completeness, timeliness and accuracy of the data is provided in Chapter 3. Additional learnings from the implementation of the NPMR child death notification process in CHI at Temple Street will be used to inform the piloting of a new electronic-based system for data collection, and are outlined in Chapter 8.

KEY FINDINGS FROM CHAPTER 7

Analysis of the data on deaths in CHI at Temple Street that were reported to the NPMR revealed the following:

- The median age of death of children who died in CHI at Temple Street during the 3-year period from 2019 to 2021 was 1.1 years, compared with 2.4 years from January 2022 to September 2024.
- The majority (71%) of deaths in CHI at Temple Street over the period 2019 to Q3 2024 occurred in the ICU, and 64% of children who died in CHI at Temple Street during this period were transferred from other hospitals throughout the country.
- Fifty-four percent of deaths notified to the NPMR during the review period (2019 to Q3 2024) were considered to be unexpected, 85% were notifiable to the coroner and almost one-half required a post-mortem examination.
- Three main cause of death categories accounted for 57% of the deaths in CHI at Temple Street from 2019 to Q3 2024: external causes (21%), infection and/or sepsis (19%) and life-limiting conditions (18%).
- The number and proportion of notified deaths due to infection and/or sepsis increased from 2.3 deaths per year (12.1% of all notified deaths) during 2019–2021 to 5.8 deaths per year from 2022 to September 2024 (24.2% of all notified deaths). The majority of those deaths occurred in infants and children aged under 5 years (65%) and occurred during the colder months of the year (Q1 and Q4; 74%) in contrast to other causes of death, which were more evenly spread throughout the year. Further review of national data on infection/sepsis deaths in children is required to establish whether this observation is reflective of a change in the overall crude mortality rate from infectious diseases and findings included in a spotlight chapter in the next NPMR report.
- The NPMR Child Death Notification form collects data on the provisional cause of death as determined by the clinician in charge of the patient's care. This may not necessarily be the same as what is recorded during the death registration process. Revised figures, corrected for final registered cause of death, will be published in future NPMR reports.

CHAPTER 8
QUALITY IMPROVEMENT

CONTENTS

CHAPTER 8: **QUALITY IMPROVEMENT**

1. NATIONAL QUALITY IMPROVEMENT PROJECT: NPMR DEVELOPMENT

OBJECTIVE: Implement structures to facilitate the standardised reporting of child deaths across the healthcare system in order to improve the quality of CYP mortality data in Ireland.

ACTIONS TAKEN: A description of the NPMR development project and its progress is provided in Chapter 9 of this report.

OUTCOMES: An operational NPMR child death notification system will have the following benefits:

- Timely and reliable mortality estimates will be available, which will enable accurate comparison with international estimates and will in turn assist with benchmarking the overall quality of care provided to CYP in Ireland and inform the agenda for clinical audit in paediatrics.
- The NPMR will provide continuity of data to be included in future reports and inform new audit or quality improvement opportunities arising from future NPMR findings. This will include referencing specific report findings with the intention to stimulate responses from report users.
- The NPMR dataset will facilitate improvement in the accuracy of cause of death statistics in underserved populations, particularly sudden unexpected deaths and those due to causes with the greatest potential for misclassification. Additional information on underlying conditions and comorbidities associated with specific causes of death will be particularly valuable. This is because the current practice of categorising and reporting child deaths according to a single cause of death limits the information available and opportunities for improvement because broader factors affecting mortality, including underlying conditions and comorbidities, are not considered (Duke *et al*., 2019).
- The data would aim to describe the characteristics of those dying from various causes and highlight any differences between groups (i.e. vulnerability or socioeconomic status). The objective here is to help identify high-risk patients and use this information to drive improvements and promote better outcomes.

2. LEARNINGS FROM THE CHILD DEATH NOTIFICATION PROCESS IN CHI AT TEMPLE STREET

BACKGROUND: The data provided in Chapter 7 demonstrate the feasibility of collecting timely notifications of in-hospital deaths using the pilot NPMR Child Death Notification form in a tertiary paediatric hospital. An account of the completeness, timeliness and accuracy of the data is provided in Chapter 3. Additional learnings from the implementation of the process in CHI at Temple Street have been used to inform the piloting of a new electronic-based system for data collection and include the following:

- The completion rate of NPMR Child Death Notification forms from 2022 to Q3 2024 improved compared with 2019–2021, when completion of the forms was affected by staffing changes and absences due to the COVID-19 pandemic. Renewed engagement with unit staff contributed to the improvement in completion rates reported from 2022 to Q3 2024. A detailed breakdown of the capture rates is provided in Table 7.1.
- The timeliness of the notifications to the NPMR also improved from 2022 to Q3 2024; of the cases that were notified, 71% were notified within 24 hours, 80% were notified within 2 days, 85% were notified within 1 week and 100% were notified to the NPMR within 1 month (Appendix 7).
- All forms submitted from 2022 onwards were completed by the consultant or registrar in charge of the child's care at the time of their death. The presence of a data collection coordinator in the hospital was critical for data collection, and during 2019–2021 made the retrospective collection of missed cases a feasible option, which improved the completeness of the dataset. Awareness and promotion of the process among hospital staff is necessary in order to ensure optimal completion rates, and must include informing and training all new non-consultant hospital doctors of the need to complete the NPMR Child Death Notification form and how to do so.
- NPMR Child Death Notification forms were not completed for deaths which involved the Office of the State Pathologist. A process must be developed in order to ensure that there is follow-up on such cases and that they are included in annual figures in subsequent NPMR reports.
- An option for a separate dedicated room outside of the hospital's paediatric critical care unit for families and their child at the end of life is to be included as a separate option for the 'location of death' variable. This is to ensure that this location is distinct from 'ward'.
- The quality of the data collected was high, and issues/errors detected will be utilised in order to build additional validation checks into the data collection process. The capture rate for most variables for the period from 1 January 2022 to 30 September 2024 was ≥90% (see Appendix 6). This is an improvement from the period 2019–2021, when 70% of variables included in the dataset had a capture rate of ≥80%. The variables with the greatest number of omissions are under review as part of the audit development process in preparation for the piloting of the new electronic data collection tool (Chapter 9).
- The NPMR Child Death Notification form collects data on the provisional cause of death as determined by the clinician in charge of the patient's care. This may not necessarily be the same as what is recorded during the death registration process. Revised figures, corrected for the final registered cause of death, will be published in subsequent reports.

3. UPDATING A COMMON IRISH REFERENCE SET FOR SYSTEMATIZED NOMENCLATURE OF MEDICINE CLINICAL TERMS: STANDARDISATION OF CODING FOR DOCUMENTING CAUSE OF DEATH FOR CYP IN IRELAND

BACKGROUND: The Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) coding standard enables clinicians to record data with enhanced accuracy and consistency and is mapped to other international standards, such as the International Classification of Diseases, Tenth Revision (ICD-10) (eHealth Ireland, n.d.). The use of SNOMED CT terminology underpins the shared care record and ensures the future-proofing and interoperability of the dataset. Once entered into the system, a numeric code is assigned to every term that is fed into a central repository. These are common codes that can be used across jurisdictions.

IDENTIFYING AREAS FOR IMPROVEMENT: ICD-10 coding is a system used for the classification of deaths but is not linked to a standardised list of terms for use by clinicians. Furthermore, the ICD-10 system is not optimal for use when classifying CYP deaths. A common Irish reference set for use in paediatrics is being updated for codifying the cause of death in CYP. This exercise is being conducted with the NPMR Governance Committee and the Health Service Executive (HSE) Death Notification Project Team for the purpose of codifying the variable for cause of death and ensuring consistency in the terminology of variables used in these datasets. Clinical input from the members of the NPMR Governance Committee will ensure that terminology that is specific and relevant to CYP deaths is embedded in the application. Once finalised, the terminology listed in the reference set will be included in the electronic systems used to submit the death notification. Specific areas requiring expansion and consultation include:

- multiple genetic disorders
- congenital anomalies
- infections specific to the paediatric population.

ACTION TAKEN: Members of the NPMR Governance Committee are actively working with the HSE's eHealth Ireland SNOMED CT National Release Centre on developing a common reference set to be used nationally by NOCA for the NPMR and by the HSE/General Register Office (GRO) for the new death notification process. The reference set will be known as the National Death Register Ireland, which will be intended for use in Ireland but will also be shared with SNOMED International. Initial consultations have taken place with the eHealth Ireland SNOMED CT National Release Centre and a workshop is pending to coordinate and finalise the preparation of the list in order for it to be included in the next release, which is scheduled for February 2025.

CHAPTER 9
AUDIT UPDATE

CONTENTS

CHAPTER 9: **AUDIT UPDATE**

UPDATE ON RECOMMENDATIONS

The inaugural NPMR report published in October 2023 (NOCA, 2023b) included five recommendations aimed at the establishment of a national database on all CYP deaths in order to analyse data and report on trends in rates of, and factors impacting on, CYP mortality. Table 9.1 provides an update on the implementation of those recommendations.

TABLE 9.1: UPDATE ON IMPLEMENTATION OF RECOMMENDATIONS OF THE INAUGURAL REPORT OF THE NATIONAL PAEDIATRIC MORTALITY REGISTER, 2024

RECOMMENDATION	UPDATE
All deaths in children and young people in Ireland should be notified as part of death certification to a central national database. The Department of Social Protection has commenced drafting legislation pertaining to death notification. The National Office of Clinical Audit (NOCA) recommends the completion of publication and enactment of legislation to mandate timely reporting of all deaths.	**The Civil Registration (Electronic Registration) Act 2024 was passed in July 2024. This amendment to the Civil Registration Act 2004 makes provisions for the online notification and registration of deaths and for a process to ensure the availability of more timely data on deaths. The legislation mandates early notification of all deaths to the HSE and completion of the Medical Certificate of the Cause of Death by a medical practitioner within 5 days of the death occurring. The time afforded to the relatives of a deceased person to formally register a death has also been reduced from 3 months to 28 days from the date of death.**
NOCA should work with the Health Service Executive (HSE) Office of the National Director Operations and Integration to ensure that the implementation of the proposed changes to the death notification process is aligned with the NPMR. This partnership should support the NPMR objective of implementing a universal, standardised system for capturing data on all CYP deaths in a national CYP mortality database.	**A business case for the NPMR death notification process was submitted to the Death Notification Working Group of the HSE Health Identity Management Services, Technology and Transformation in November 2023. There is ongoing active engagement between NOCA NPMR and the HSE through monthly meetings of the Death Notification Working Group (the NPMR Audit Manager and NOCA's Information Manager are members of the working group). The HSE project team is tasked with implementing the electronic child death notification process across the health service in order to facilitate the early notification and registration of deaths, and the aim of NOCA's participation is to ensure the alignment of NPMR child death notification dataset and processes with the national death notification process . The NPMR Child Death Notification form and data dictionary have been revised in order to be consistent with the terminology used for the national death notification process. Relevant information gleaned from the NPMR audit development process, including process mapping in paediatric hospitals, will be fed back to the Death Notification Working Group in order to inform their processes. Once the HSE implements new processes for the official notification and registration of deaths, the NPMR system will adapt to use a unified notification approach. This will allow for a streamlined process where the NPMR receives data directly concerning the CYP subset of death notifications, ensuring efficiency and compliance with notification of CYP deaths to NPMR.**

RECOMMENDATION	UPDATE
The NPMR must have a universal and standardised death notification process that is designed to capture details of all deaths in children and young people nationally, including deaths occurring outside of hospital as well as in-hospital deaths. The dataset should be built in line with international best practice (e.g. including health equity stratifiers) and data must be received by NOCA in a timely fashion using electronic systems.	**An overview of progress on the development of the NPMR is provided in the audit development section of this chapter. This work encompasses the elements specified in this recommendation to implement structures for capturing standardised, timely information on all CYP deaths nationally, in line with international best practice, and using electronic systems for the collection of the data.**
The proposed individual health identifier (IHI) should be utilised for the purpose of the NPMR in order to facilitate the national linkage of datasets. This will allow for an accurate assessment of the causes of CYP deaths by making essential information relating to underlying conditions and pre-existing comorbidities universally accessible.	**A placeholder for the individual health identifier (IHI) has been included in the reviewed NPMR Child Death Notification form. NOCA will engage with the HSE Access to Information Health Identifiers (A2i HIDs) team to progress the embedding of the IHI in the relevant paediatric systems in order to support the NPMR.**

RECOMMENDATION	UPDATE
In line with international best practice, NOCA should engage with the Department of Health and the HSE in order to advocate for the establishment of a national child mortality review panel. The independent review panel would examine childhood deaths, write reports and make recommendations relating to local and system-wide improvements or interventions aimed at reducing the number of childhood deaths.	A mandatory child death review process is the gold standard approach in terms of learning from child deaths and offers the most in terms of identifying opportunities for system-wide improvement and interventions. Activities related to advocating for this recommendation to date include the following: **1. Stakeholder engagement:** • The NOCA and NPMR clinical leads met with the Department of Children, Equality, Disability, Integration and Youth on 28 May 2024. • The NPMR audit manager and clinical leads met with the Ombudsman for Children's Office on 5 September 2024. • Chair National Review Panel (29 August 2024). It is important to clarify that the National Review Panel does not investigate the causes and circumstances of child deaths, but is concerned with the quality of child protection and welfare services provided to the young person and their family during their contact with Tusla. National Review Panel reports endeavour to be systematic, highlight any missed opportunities, provide evidence-based learning points, and, where relevant, make policy recommendations. **2. Proposal to host a multi-agency symposium on the establishment of a national child death review process in Ireland:** • The objective is to plan and coordinate a multidisciplinary, cross-departmental symposium in order to discuss and gain national consensus on the merit of and requirements for establishing a national child death review process for all child deaths in Ireland. • The proposed approach involves the use of digital tools for real-time polling and feedback in order to gauge participant engagement and capture reactions for discussion. Outputs are to include a policy brief targeting decision-makers and summarising key findings and actionable recommendations; the publication of meeting proceedings; and the creation of an online resource hub that will serve as a reference point for ongoing dialogue. **3. Participation in the Child Death Review Working Group of the International Society for the Study and Prevention of Perinatal and Infant Death:** • The Chair of the NPMR Governance Committee participated in a survey on international practice on child death review (Dr Joanna Garstang, UK, Chair of the Child Death Review Working Group, 21 August 2024). The survey was also directed to the Department of Children, Equality, Disability, Integration and Youth and the Chair of the National Review Panel. **4. Submission to the Department of Justice's *Report of the Public Consultation on the Reform of the Coroner Service*:** • The recommendation to establish a national child death review process was included in a wider NPMR submission to the Department of Justice as part of the consultation on the reform of the Coroner Service in January 2024, and was included in the subsequent report (Department of Justice, 2024).

AUDIT DEVELOPMENT

NPMR development work in 2024 has focused on the following key objectives:

1. **Review of the NPMR child death notification process:** A two-step approach has been adopted for the collection of data. The first step is an initial early notification of the death with just a small number of key data points. The second step involves follow-up by NOCA staff with the referring hospital to collect the remaining data points on the form in order to complete the minimum core dataset of information on all deaths. The rationale for this two-step approach is to reduce the burden of effort on frontline clinical staff and to ensure that NPMR processes align with those of the HSE death notification process. In a later phase of development, additional data points will be collected on various cause of death categories.

2. **Development of an electronic system for the collection of data:** Information obtained from piloting the paper-based NPMR Child Death Notification form was used in order to inform the building and testing of an electronic web-based tool for the collection of child death notifications, a key requirement for the national implementation of this process. The specifications for this tool have been submitted to the technical team that will build the electronic tool and beginning in Q2 2024 will be piloted in four sites: CHI at Crumlin, CHI at Temple Street, CHI at Tallaght and University Hospital Limerick.

3. **Integration into hospital policy:** The NPMR Child Death Notification form must be seamlessly integrated into hospital policies and the clinical workflow for handling child deaths. This will ensure consistency and compliance across all healthcare settings. Requirements for this will be established via engagement with pilot sites and detailed process mapping.

4. **Stakeholder engagement and process mapping:** The NOCA NPMR audit Development team carried out an extensive consultation process with relevant stakeholders at CHI and University Hospital Limerick in order to conduct a detailed process mapping exercise. The aim of this exercise was to outline the data flow within each unit when a child dies in order to clarify the roles and responsibilities of those involved, ensuring accountability for the completion of the NPMR Child Death Notification form, the verification of details, and the final submission. The process was facilitated by a predefined set of guiding questions. The process comprised of initial stakeholder mapping, individual interviews followed by group workshops in each of the pilot sites to gain consensus on final process maps in each hospital. The insights gained enabled the efficient planning and execution of the pilot study.

5. **Pilot study schedule and objectives:** In order to ensure the effective implementation of the NPMR child death notification tool and process, a comprehensive pilot study is essential. Without this preliminary testing, it is not feasible to apply the tool and process recommendations universally. The process mapping exercise was completed across three pilot sites in November 2024, with the pilot of the notification system commencing in Q2 2025. The pilot will extend over 3 months. Subsequently, an analysis and a comprehensive report detailing the findings and recommendations for the tool's national roll-out will be published. This structured approach ensures that the pilot study not only tests the notification tool effectively but also sets the foundation for a standardised and efficient national implementation, enhancing the overall management of child mortality data.

6. **Alignment with national regulations:** See the update on Recommendation 2.

Implementation of the NPMR child death notification process will be carried out on a phased basis, starting with paediatric hospitals and followed by all hospitals nationally, before extending to capture deaths that occur in the community. A summary of the development plan and proposed data flow for an operational NPMR child death notification process is outlined in Figures 9.1 and 9.2.

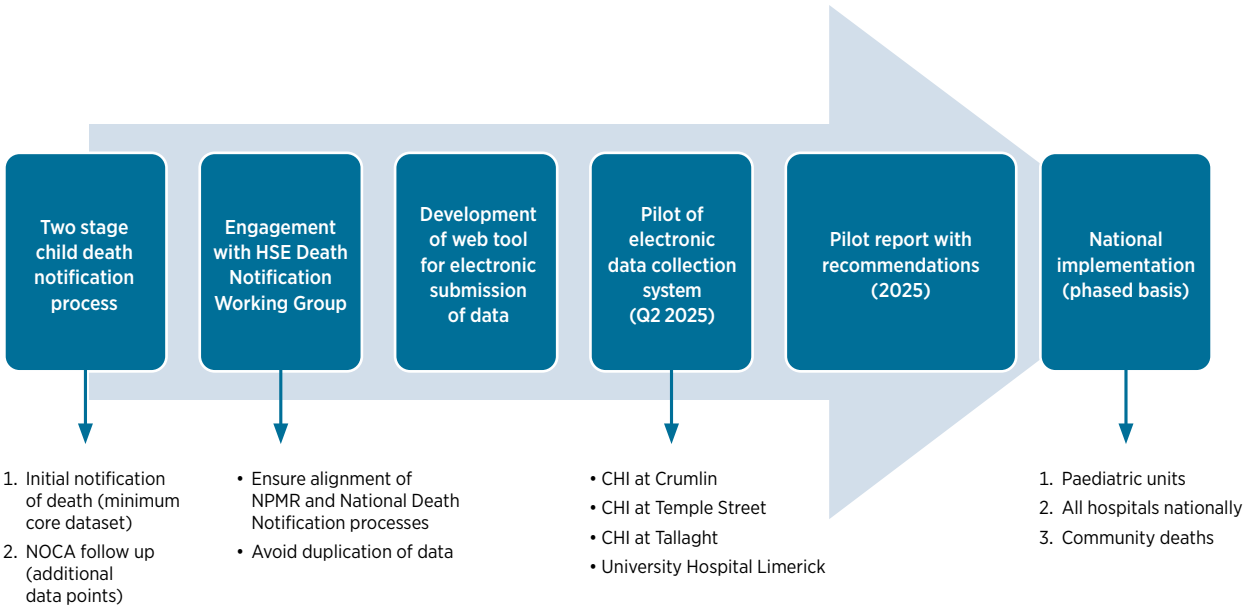


FIGURE 9.1: OVERVIEW OF NATIONAL PAEDIATRIC MORTALITY REGISTER DEVELOPMENT PLAN

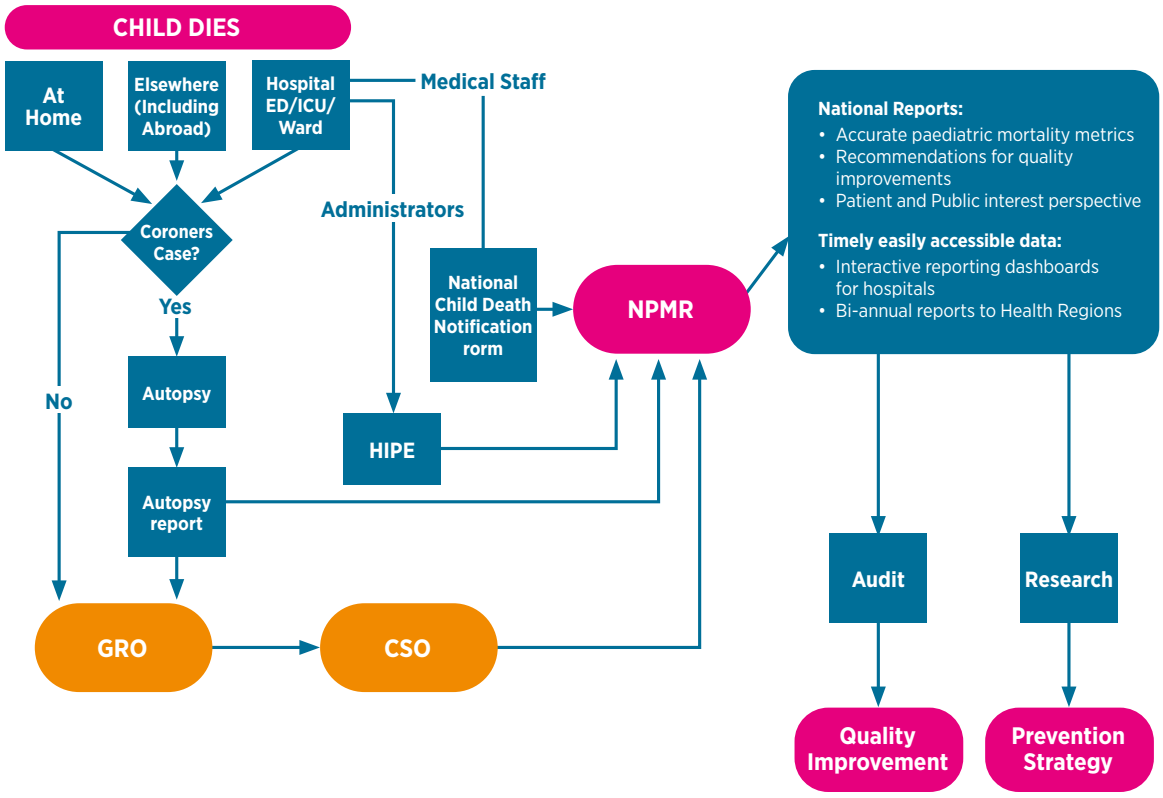


FIGURE 9.2: PROPOSED NATIONAL PAEDIATRIC MORTALITY REGISTER DATA FLOW

AUDIT ACTIVITY

The information and findings from the inaugural NPMR report have been presented at a number of conferences during 2024 and abstracts published in the scientific literature. Details of these presentation/abstracts are provided in tables 9.2 and 9.3

TABLE 9.2: CONFERENCE PRESENTATIONS

Meeting/conference name	Location	Date	Presentation title	Presented by
2nd Annual Conference of the Irish Paediatric Emergency Medicine Association	Tallaght University Hospital, Dublin	19–20 March 2024	Inaugural NOCA NPMR Report on Mortality In Children And Young People In Ireland: 2019-2021	Prof. Michael Barrett
Faculty of Public Health Medicine Summer Scientific Meeting 2024	No. 6 Kildare Street, Dublin	21–22 May 2024	1. A review of structures supporting mortality datasets for children and young people in Ireland	Dr Cliona McGarvey PhD
			2. The National Paediatric Mortality Register (NPMR): International approaches to child mortality databases.	Dr Niamh Beirne

TABLE 9.3: PUBLISHED ABSTRACTS

Journal	Title	Author
Irish Medical Journal, September 2024; Vol 117; No. 8; P1032	Inaugural NOCA NPMR Report on Mortality In Children And Young People In Ireland: 2019-2021	McGarvey, C., Beirne, N., Kelly, F., Hamilton, K., Healy, M., Barrett, M. and the NOCA NPMR Governance Committee
Irish Medical Journal, September 2024; Vol 117; No. 8; P1032	A review of structures supporting mortality datasets for children and young people in Ireland	McGarvey, C., Beirne, N., Kelly, F., Hamilton, K., Healy, M., Barrett, M. and the NOCA NPMR Governance Committee

RESEARCH COLLABORATIONS

RESEARCH PROJECT: Improving Children's Palliative Care in Ireland: using evidence to guide and enhance palliative care for children with life-limiting conditions and their families

Lead applicants: Dr Samantha Smith, Trinity College Dublin, and Dr Joanne Balfe, Consultant in Paediatric Palliative Medicine
Co-applicants include NPMR Governance Committee members Dr Mary Devins and Dr Fiona McElligott.

Funding: Health Research Board grant, co-financed by the Irish Hospice Foundation and by LauraLynn, Ireland's Children's Hospice

This research focuses on the substantial gaps in information relating to children in Ireland who have life-limiting conditions and their care. Although universal access to children's palliative care is a national policy objective, there are issues around inconsistent referral patterns, unmet needs, lengthy hospital stays, limited children's palliative care workforce planning and regional inequalities in children's palliative care supply. Substantial gaps in evidence impede policy development, as well as the planning and delivery of children's palliative care in Ireland. The NPMR will provide researchers with national data on the number, sex and geographical profile of all children with life-limiting conditions who die in Ireland, along with place of death (as per the CSO definition).

CHAPTER 10
RECOMMENDATIONS

CONTENTS

CHAPTER 10: **RECOMMENDATIONS**

RECOMMENDATION 1

The National Office of Clinical Audit (NOCA) must urgently progress the implementation of an electronic data collection system in order to allow for the timely submission of CYP mortality data to the NPMR, and engage with the Health Service Executive (HSE) Access to Information Health Identifiers (A2i HIDs) team to request the utilisation of the IHI in paediatric settings in order to support the NPMR.

Rationale
• The implementation of this data collection system is necessary in order to generate accurate and reliable information on CYP mortality that will permit the timely identification of emerging public health trends. A deeper understanding of the causes of death is essential for improving care delivery, services and end-of-life outcomes. Analysis of data based on the death registration information outlined in this report has indicated that there is variation in the pattern of the main causes of infant mortality and CYP mortality in the period from 2019 to 2023. However, accurate year of occurrence data are currently unavailable for 2022 and 2023, and the data presented must be reviewed in the coming years in order to confirm/refute these findings.
• Reviewing the data must include examining annual trends in overall CYP mortality, as well as assessing the various cause of death categories and considering whether a diagnostic shift may account for the observed increase or decrease in mortality rates in some categories. It will also allow an assessment of the impact, if any, of the COVID-19 pandemic on CYP mortality and determine whether additional delays in the registration of deaths during the pandemic may have had an impact on mortality statistics and account for the observed variation in recent years. The currently available data cannot be validated until 2026, when year of occurrence figures for 2023 will have been finalised. Thus, it is not currently possible to act on the findings of these data in a timely manner. The notification of deaths directly to the NPMR will make it possible to review annual trends based on timely year of occurrence data, which is necessary in order to validate the observed variation in the main causes of CYP death since 2019.
• The introduction of an electronic data collection system will maximise participation in the NPMR child death notification process, eliminate duplication and waste, and enhance accessibility, data security, and scalability. The NPMR child death notification process will synchronise with the work of the HSE Death Notification Working Group, which aims to implement electronic systems across all hospitals nationally in order to enable faster death notification and registration following enactment of the Civil Registration (Electronic Registration) Act 2024.
• Utilisation of the IHI would enable the linkage of existing data sources and permit efficient and more informative analysis of child mortality data by including important information relating to underlying conditions and pre-existing comorbidities.

Evidence base for implementation

- The capture of high-quality, standardised data requires uniform data collection across the healthcare system, which is necessary for accuracy and detail but is not currently in place. The inaugural NOCA NPMR report recommended establishing a national database to be used for analysing and reporting on trends and factors affecting CYP mortality rates (NOCA, 2023b).
- Review of international best practice (NOCA, 2023b) revealed that successful systems for reporting child deaths involve the mandatory and timely reporting of deaths to a centralised unit using electronic systems for the collection of data, and Ireland should seek to achieve those international best practice standards.
- The routine collection of population-based mortality data is essential for informing policy and evaluating the effectiveness of those policies, and it also aids in the generalisability of audit findings and is recommended by the World Health Organization (WHO) (WHO, 2018; Morrato *et al*., 2007).
- An electronic data collection system will enable the timely production of accurate mortality estimates for Ireland's CYP population that can be benchmarked against international data. It will also enable the early identification of emerging public health issues, gaps in information and opportunities for intervention, as well as informing the agenda and prioritisation of a CYP national audit.
- An electronic data collection system would align with the *eHealth Strategy for Ireland* (Department of Health, 2013).

Who benefits from this recommendation

- **Children and families:** Timely data collection will allow for the quicker identification of emerging health issues, ensuring that healthcare providers can respond proactively. Families will benefit from better-informed policies and services that target preventable deaths, thereby improving health outcomes and safety for children.
- **Healthcare providers:** Clinicians will gain access to real-time, accurate data, which will enable them to track mortality trends and implement interventions faster. This system will reduce administrative burden by eliminating duplicative paperwork and centralising data, thereby allowing providers to focus more on patient care.
- **Public health authorities and policy-makers:** Access to accurate and up-to-date data will enable policy-makers to identify public health trends early, devise targeted interventions and allocate resources more effectively. This will support the creation of evidence-based policies that directly address the causes of CYP mortality.
- **Researchers and academics:** The availability of reliable, standardised mortality data will serve as a foundation for research studies on child health trends, factors influencing mortality and potential preventative measures. This work will help to advance academic research and inform clinical guidelines.
- **Healthcare system administrators and auditors:** Streamlined electronic data collection will help facilitate audits and evaluations of health outcomes, thereby helping to identify gaps in service provision. This system will enhance accountability and quality control, and will optimise healthcare resources at the national level, thereby improving the overall healthcare framework for CYP.

Recommended actions for improvement and implementation

NOCA must progress the development of the NPMR child death notification system and the complete national implementation of this system. This includes progressing plans to:

- Complete the testing of the newly developed electronic data collection system in pilot sites: CHI at Crumlin, CHI at Temple Street, CHI at Tallaght and University Hospital Limerick.
- Report on the findings of the pilot study, including recommendations for national implementation.
- Develop a national implementation plan for the NPMR child death notification system, which is to be initiated in 2025. The system will be rolled out in phases, starting with CHI locations, then moving to regional paediatric units before being implemented in all hospitals. The final stage will involve developing a process for capturing deaths that occur in the community.
- Continue collaboration/partnership with the HSE Death Notification Working Group in order to ensure alignment of the NPMR and the national death notification/registration process. NOCA should share information generated during the process mapping of the data flow in paediatric units with the HSE Death Notification Working Group.

Action owners/leads

- The NOCA NPMR Audit Manager should work with the NPMR Governance Committee, clinical leads and the NOCA executive team to complete the audit development process for the NPMR, move the NPMR child death notification process to an electronic system, finalise a plan for national implementation, and initiate the phased implementation of the system in 2025.

Recommended prioritisation of actions

- Piloting of the electronic tool for data collection must be prioritised in order to inform and enable national implementation, which should begin in Q3 or Q4 of 2025. The pilot should run for a period of 3 months and scheduled to begin in January 2024.
- In agreement with the HSE Death Notification Working Group, NOCA's NPMR processes will be reviewed as required in order to align with future developments relating to the implementation of systems by the HSE, thereby facilitating the proposed changes to the national death registration process as they arise and avoiding the duplication of data.
- The system should be implemented on a phased basis commencing in paediatric units before moving to regional units and then all hospitals nationally. The final phase of this process will be capturing data on deaths occurring in the community.

Explicit statement on resources dependency

- The development and national implementation of the NPMR is dependent on the continued support of data analytics, audit development, operations, and information governance expertise within NOCA.

RECOMMENDATION 2

Detailed analysis of infection related deaths in children is warranted. Statutory and other appropriate data sources should be interrogated, and together with input from appropriate stakeholders, a review of infection related CYP deaths included as a spotlight report in the next NPMR report.

Rationale
• At present, all death registration data categorise deaths according to the WHO's ICD-10 coding system. This system does not provide for the reporting of all infection-related deaths in one broad category, as many cases are incorporated into other system-based disease categories, such as diseases of the respiratory, nervous, or circulatory systems. A review of individual level data using relevant four-digit coding is required in order to establish accurate infection-related mortality rates in children that can be monitored over time. Clinical input is required in order to identify relevant cases for inclusion in the analysis.
• The review should aim to provide accurate incidence rates for infection-related mortality among the CYP population, describe the characteristics of CYP infection-related deaths, and share any learnings derived from this work with policy-makers and service providers.
• This review will inform the data points that the NPMR should collect on infection-related deaths in the future.
• Analysis of data collected from one large paediatric referral hospital over a period of almost 6 years between 1 January 2019 and 30 September 2024 using the NPMR Child Death Notification form showed that there was an increase in the number of notifications of deaths due to infection during 2022 to Q3 2024 relative to the previous three years. Review of national data on incidence rates of various infectious diseases and crude mortality rates is required for accurate understanding and interpretation of this observation.
• The Health Protection Surveillance Centre monitor and report on a schedule of statutory notifiable infectious diseases. An increase in notified invasive Group A *Streptococcus* infections was reported in Ireland since October 2022, and there have been 12 deaths in children (10 in children aged under 10 years and 2 in children aged 10–17 years) and 13 in adults (ranging in age from 46 to 96 years) (Health Protection Surveillance Centre, 2023). Data from 2023 indicate that the number of invasive Group A *Streptococcus* cases continues to remain at higher levels than expected, with 305 cases notified in the first 5 months of 2023, compared with an average of 67 cases annually during the pre-pandemic years of 2017–2019.
• Infection remains the leading cause of child mortality globally (Liu, 2015).
• European research into life-threatening infections in children who were admitted to hospital with sepsis and severe infection has shown that the disease burden is mainly in children aged under 5 years, and that many cases are vaccine preventable and responsive to commonly available antibiotics (Martinón-Torres *et al*., 2018).
• Reliable timely data is required to examine trends in deaths due to infectious diseases and investigate the underlying reasons for any changes in incidence in order to identify factors associated with such deaths, assist with the identification of high-risk patients and adequately respond to future surges and inform preventative strategies.
• Increased mortality and morbidity from invasive bacterial disease in recent years has been reported in other European countries (Van Kempen et al., 2023, Holdstock et al., 2023).

Evidence base for implementation

- A similar review of infection-related deaths in children by the National Child Mortality Database (NCMD) in England produced valuable information on the nature of these deaths that enabled the provision of a series of recommendations to multiple organisations reflecting issues and gaps that had been identified in the analysis (Healthcare Quality Improvement partnership, 2023).
- The observed increase in the incidence of infection/sepsis-related deaths in CHI at Temple Street is in keeping with a recent report of invasive bacterial disease across all three CHI hospitals (Kyne *et al*., 2024). This study has sufficient detail to provide an informative report on the characteristics of these deaths, including a description of the pathogens involved, a comparison of Paediatric Overall Performance Category (POPC) scores and the presence of underlying conditions.

Who benefits from this recommendation

- **Children and families:** Enhanced data on infection-related deaths will lead to better-targeted healthcare interventions, which can reduce preventable deaths in children. Families will benefit from the improved understanding and prevention of life-threatening infections, especially among vulnerable age groups such as infants and toddlers.
- **Healthcare providers and hospitals:** Accurate data will enable healthcare professionals to identify high-risk factors and implement early interventions. Hospitals in particular will be able to adapt their infection prevention protocols and treatment guidelines in order to respond effectively to current infection trends and surges.
- **Public health authorities and policy-makers:** The insights that are derived from this analysis will equip policy-makers and public health officials with actionable data, helping them to shape policies on infection prevention, vaccination and resource allocation.
- **Medical researchers and epidemiologists:** The detailed data will support research into the underlying causes of infection-related deaths in children, especially in the wake of the COVID-19 pandemic.
- **The healthcare system and communities:** A reduction in paediatric infection-related deaths will ease the overall burden on the healthcare system, reducing costs associated with hospital admissions, emergency interventions and long-term care. Communities will also benefit from healthier children, lower transmission rates and a more resilient healthcare system, particularly during infectious disease outbreaks.

Recommended actions for improvement and implementation

- Until these data are available through the NPMR child death notification system, NOCA should resume the collection and review of post-mortem examination reports provided by coroners nationally and other available data sources in order to provide additional detail on the characteristics of these deaths. Potential data sources include the Health Protection Surveillance Centre, HIPE, post-mortem examination reports and NPMR death notification data (where they are available), and hospital ICU and ED datasets.
- NOCA should link with the HSE's sepsis programme and the Department of Public Health in order to determine how the information made available via the NPMR can be used to support the evidence base for informing intervention policy.
- Further information on factors such as causative pathogens should be collected for further review of this category of deaths and included in future NPMR reports. This should include the examination of deaths that are directly due to infection, along with data on deaths of children with other underlying conditions where infection may have been a contributory factor.
- Death registration in its current format does not include one broad category that captures all infection-related deaths; NOCA should liaise with the CSO in order to ensure that there is additional access for clinical experts to examine the database and identify all relevant cases for inclusion in a review of infection-related deaths.
- NOCA should link with the national clinical lead for Child Health Public Health to leverage support in securing access for an appropriate clinical colleague to the CSO dataset to review the death registrations relating to infections and sepsis.
- These deaths should be monitored over time in order to inform quality improvement strategies (e.g. the identification of barriers to following sepsis guidelines or accessing appropriate services).

Action owners/leads

- NOCA and the NPMR Governance Committee should engage with the following:
  - **coroners:** to resume the collection of post-mortem reports
  - **the Department of Public Health:** to leverage support for the provision of access to relevant data sources
  - **the CSO:** to add an identified clinical researcher to the NPMR project in order to access individual level data and identify relevant cases for inclusion in reviews
  - **the Sepsis Programme:** to inform data points for questionnaire used by the NPMR in future data collections.

Recommended prioritisation of actions

- Engagement with all organisations will be initiated early in 2025 in order to avoid delays in accessing relevant datasets and at the report planning stage.

Explicit statement on resource dependency

- Clinical protected time must be available in order to allow review of the CSO death registration dataset and identify all relevant cases for retrospective review.

RECOMMENDATION 3

NOCA should contribute to the evidence base required to inform policy around suicide prevention by reviewing the available data related to the circumstances of potential suicide deaths among children and young people, to support stakeholders e.g. the HSE National Office of Suicide Prevention in their work.

Rationale
• Improving the evidence base for prevention of suicide deaths. These data should be used in order to increase awareness of the high incidence of such deaths among the Irish CYP population and support the development of prevention services and initiatives.
• Available mortality data that are based on death registration information cannot be used to report timely suicide mortality rates. This is due to difficulties with the documentation of intent in relation to injury fatalities. Consequently, data presented in this report relate to mortality rates based on injury type and are an underestimate of true self-harm rates. Furthermore, problems with the late registration of suicide deaths are growing, and this has an effect on the comparability of statistics across years (CSO, 2023).
• Without information on intent, it is not possible to provide accurate estimates of the number self-harm deaths among Irish children. However ligature suspension/hanging is the leading cause of death in children aged 15–18 years in Ireland, accounting for 28% of total deaths registered for this age group during the period 2019–2023.
• While CYP mortality due to other causes of injury death has declined, the number and rate of deaths due to ligature suspension have remained high.
• Eurostat data reports Ireland as having the ninth highest suicide rate among the age group 15–19 years in the EU. (Eurostat, 2024).
Evidence base for implementation
• The Department of Health and the HSE's *Connecting for Life: Ireland's National Strategy to Reduce Suicide 2015-2020* is a cross-sectoral strategy with seven strategic goals, the seventh of which is better data and research. NPMR data can contribute to Goal 7 by providing timely data on possible/probable suicide deaths among CYP. These data will help to improve understanding of the demographics and other characteristics of suicide deaths among CYP.
• Children living in disadvantaged areas are more than four times as likely to develop severe mental health challenges as those from wealthier communities, and up to 250,000 families that include a child aged under 5 years are currently living below the poverty line (Roantree *et al.*, 2024).
• Enhanced surveillance and analysis of data on CYP suicide deaths in England by the NCMD led to a number of recommendations being made for everyone involved in the provision of services for CYP (Healthcare Quality Improvement Partnership, 2021).
• The COVID-19 pandemic may have contributed to an increase in the rates of suicide among people of all ages (Lantos and Nyári, 2024; HSE, 2020).

Who benefits from this recommendation

- **Adolescents and young people:** Better-targeted suicide prevention efforts and mental health support will help at-risk young people by providing early intervention, support services and resources to reduce the risk of suicide.
- **Families and caregivers:** Families will benefit from having better mental health resources, support systems and awareness around suicide prevention, which will enable them to access appropriate help and support for their children.
- **Mental health service providers (e.g. CAMHS):** Access to comprehensive data on suicide risk factors will enable providers to identify trends, allocate resources where they are needed most, and improve service accessibility and effectiveness, particularly in high-risk communities.
- **Policy-makers and public health authorities:** Accurate, up-to-date data will allow policy-makers to understand the scope of youth suicide and address it through evidence-based policies, targeted funding and support for mental health services, ensuring that resources are directed to where they are needed most.
- **Educational institutions and community organisations:** Schools and community organisations will gain a better understanding of suicide risk factors, enabling them to implement preventative mental health programmes, provide support for vulnerable students and foster safe environments for discussing mental health openly.

Recommended actions for improvement and implementation

- NOCA should provide additional detail on the circumstances of potential suicide deaths among older children through the review of post-mortem examination reports (this should include identifying commonalties).
- NOCA should engage with the HSE National Office for Suicide Prevention to facilitate the optimal availability of data in order to enhance our understanding of suicide deaths among CYP, and to inform the development of the required data points for collection on this subset of CYP deaths in stage 2 of the NPMR data collection.
- Data collection by the NPMR should include health equity stratifiers in the minimum core dataset in order to ensure that national suicide prevention strategies can be appropriately targeted towards the most vulnerable people and places.

Action owners/leads

- NOCA

Recommended prioritisation of actions

- NOCA should make contact with the NOSP without delay following the publication of this report. This action should be prioritised in order to provide an update for the next NPMR report.

RECOMMENDATION 4

Detailed, accurate, and timely information regarding the circumstances of SIDS deaths is required to make further improvements in the prevention of these deaths. NOCA should support the HSE Child Health Public Health function in its investigation of SIDS deaths in order to help establish the epidemiological profile of SIDS deaths in Ireland and identify any high-risk groups and supporting actions.

Rationale

- Analysis of death registration information indicates an increase in the SIDS rate in Ireland in 2022–2023 relative to 2019–2021, and this is the highest rate recorded since 2013. Despite a decline in the mortality rates of the main cause of death categories during the same period, the overall infant mortality rate in Ireland has not declined since 2019 and is no longer lower than the EU average. As SIDS was the leading cause of postneonatal death in 2022–2023, an increase in the SIDS rate may have contributed in part to the slightly increased infant mortality rate during this period.
- The overall decline in SIDS rates in Ireland since the mid-1990s is evidence that SIDS is potentially avoidable and that education and awareness of risk factors and safe sleep guidelines are essential for reducing the number of deaths due to SIDS. Safe sleep guidelines are available to all parents and healthcare professionals through the HSE National Healthy Childhood Programme, but some families, particularly those in marginalised communities, may have greater difficulty accessing such resources or providing a safe sleeping environment for their infants.
- There is a gap in the information relating to the epidemiology and antecedents of SIDS in Ireland, particularly in relation to the presence or absence of known major risk factors; this information is necessary in order to inform targeted interventions and reduce the risk of further deaths due to SIDS.
- Other jurisdictions have reported a recent rise in SIDS rates, with concerns pointing to economic challenges and pressures on public health services, which may hinder some families' access and ability to adhere to safer sleep guidelines (Office for National Statistics, 2023; Healthcare Quality Improvement Partnership, 2022). In addition, some suggest that the increased SIDS rate may be linked to off-season surges in endemic infectious pathogens (Guare *et al.,* 2024).
- Information on the circumstances of death and risk factors for SIDS are often described in post-mortem reports, which are required for all SIDS deaths and are accessible to the NPMR.

Evidence base for implementation

- The rate of deaths from SIDS has declined substantially in Ireland since the introduction of prevention campaigns that are based on the avoidance of associated risk factors, including prone sleeping and exposure to tobacco smoke. Other associated risk factors include co-sleeping or infant–parent bed sharing, particularly where one or both parents are smokers or where the infant is of low birthweight or was premature. Examination of the prevalence of existing and potential risk factors can help provide explanations for the variation in SIDS rates and inform an evidence-based intervention policy.
- Death registration data for 2022 and 2023 are based on year of registration and are therefore subject to revision. The category of SIDS deaths is particularly affected by delayed registrations. However, the CSO is not currently in a position to provide more timely data on these deaths. The planned changes to the death registration process will improve the timeliness of mortality data, but they will not improve the availability of information on the cause of death for coroner's cases that are subject to a post-mortem examination. A large proportion of CYP deaths (up to 40%) are coroner's cases and are thus disproportionately impacted by delays in the registration of the cause of death. Further collection and review of data on risk factors for SIDS from other sources is required in order to monitor SIDS rates.
- Risk factors for SIDS may have either decreased or increased during the COVID-19 pandemic, and may have been impacted by changes in the temporal epidemiology of other infections as reported in other countries (Guare *et al.,* 2024).
- Deprivation has a significant impact on infant mortality, with a 2022 report from the NCMD concluding that families living in deprivation in England are 23% more at risk of experiencing infant deaths. The report also found a clear association between the risk of sudden infant death and social deprivation in England (Healthcare Quality Improvement Partnership, 2022).

Who benefits from this recommendation

- **Families and caregivers:** By providing clearer, timely insights into SIDS risk factors, this recommendation directly supports families and caregivers, empowering them with information and guidance in order to reduce risks and make safer sleep decisions for infants.
- **Healthcare providers and public health professionals:** Improved data access will equip healthcare providers and public health teams with essential information for developing targeted prevention programmes and guiding families to implement safer sleep practices. This can enhance clinical care by identifying high-risk families and providing additional resources for them as needed.
- **Policy-makers and healthcare system planners:** This recommendation enables policy-makers to assess the effectiveness of current public health interventions and to allocate resources more effectively, supporting systemic changes that may reduce the incidence of SIDS. It also provides a foundation for data-driven decisions in designing safer sleep initiatives and intervention strategies.
- **Researchers and epidemiologists:** Access to a detailed review of SIDS cases, including risk factors, supports ongoing research into the epidemiology of SIDS, helping to identify trends and contributing factors that may refine prevention efforts in Ireland.

Recommended actions for improvement and implementation

- **Data realignment and analysis:** Conduct a review and reclassification of SIDS data based on the year of occurrence rather than the year of registration in order to accurately assess recent trends and the timing of increases in SIDS rates.
- **Enhanced data collection and review:** NOCA should resume the systematic collection and analysis of post-mortem reports for SIDS cases, focusing on key risk factors such as sleep position, sleeping location, socioeconomic background, ethnicity and additional health conditions. This will support targeted risk assessments and intervention planning.
- **Integration of health equity indicators:** Include socioeconomic and health equity indicators in the data analysis in order to understand how factors such as income level, geographic location and access to healthcare impact on the incidence of SIDS. This will help to pinpoint high-risk populations and address disparities.
- **Timely data sharing for preventative action:** Prioritise the sharing of reviewed findings with the HSE National Healthy Childhood Programme in order to ensure timely updates to safe sleep guidelines and public health messaging based on identified trends and risk factors.
- **Data compilation:** Detailed information on SIDS cases must be compiled and examined in order to ascertain the impact (if any) of the COVID-19 pandemic on SIDS rates and to provide a description of the current epidemiology of SIDS in Ireland.
- **Development:** NOCA should support the Department of Public Health in defining essential data points for SIDS case reviews, leveraging insights from the NPMR's past data collection efforts to inform this guidance.
- **Resource allocation:** Advocate for the necessary resources in order to ensure that data collection, review and reporting are comprehensive and sustained. This may include allocating funding for dedicated staff, training for data handlers and technological support.

Action owners/leads

- NOCA

Recommended prioritisation of actions

- Data review should be conducted without delay in order to inform the HSE National Healthy Childhood Programme of any findings that may be pertinent to any planned interventions and to ensure the swift implementation and impact of such interventions.

CHAPTER 11
CONCLUSION

CONTENTS

CHAPTER 11: **CONCLUSION**

The purpose of this report was to provide an overview of CYP mortality in Ireland using death registration data for the period 2019–2023, and to build on the information outlined in the inaugural NPMR report, providing further support for the overall objective of the NPMR: to provide timely and reliable data on CYP mortality in Ireland. Learnings from the data collected via the NPMR child death notification process in one paediatric hospital were also provided.

The data show that while mortality in children post-infancy (1–18 years) has declined by more than 40% across all age groups since 2007, there has been no significant decline in the mortality rate of older children (10–years and 15–18 years) since 2013. The infant mortality rate has also plateaued, and is higher than those of many other European countries.

A large proportion of these child deaths, which are attributable to injury and sudden unexplained deaths in infancy and childhood (SUDI/SUDC), are potentially avoidable. However, there are limitations to the data presented in this report: there is insufficient detail to allow the accurate categorisation of all deaths or to provide a detailed description of the main causes of death. Hence, we cannot currently provide an overview of the characteristics of the various categories of CYP deaths; for example, an account of the sleeping position and location for SIDS deaths, or an accurate assessment of the impact of factors such as social deprivation or the COVID-19 pandemic on the various categories of infant mortality.

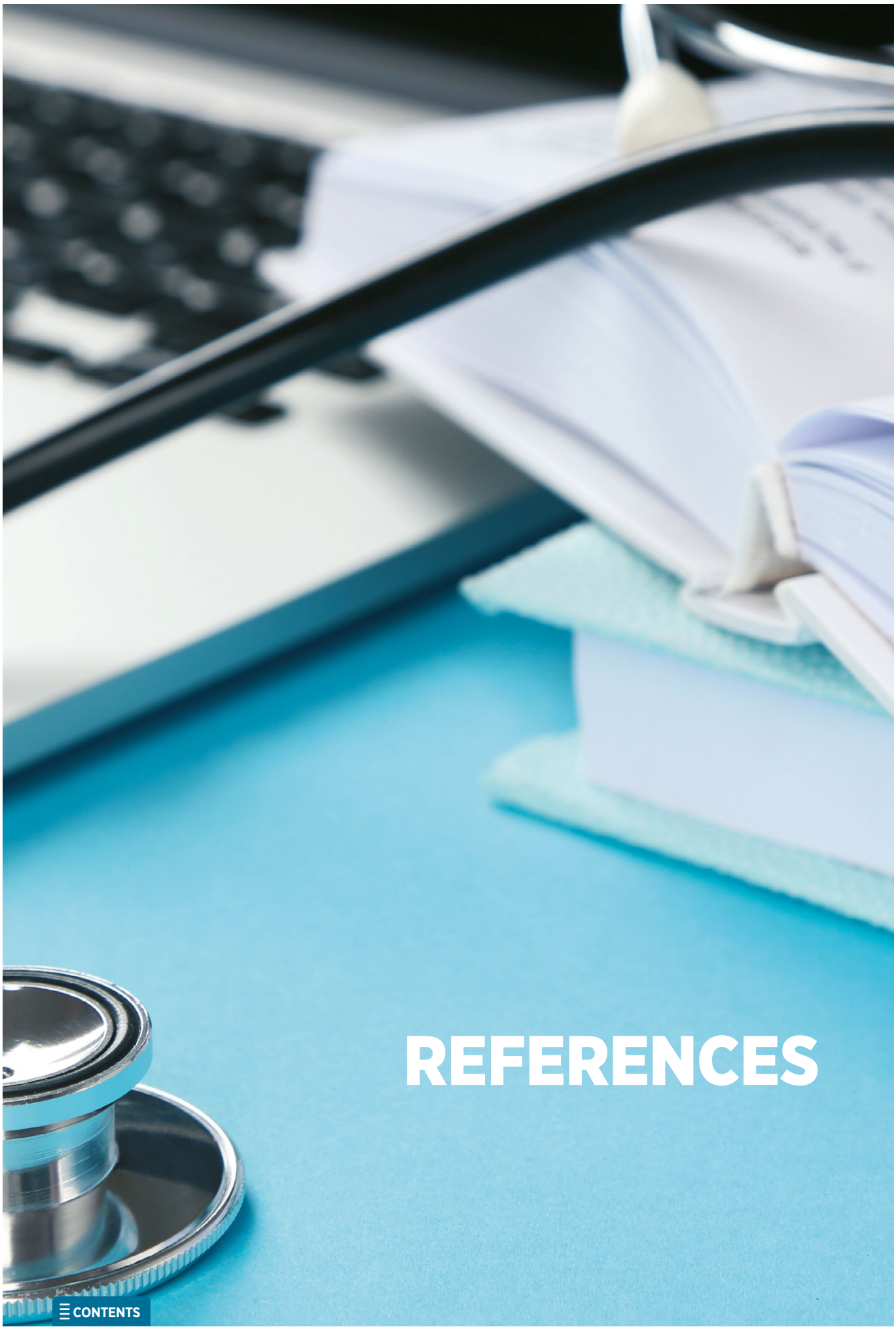
The data demonstrate variation in the pattern of mortality in infants and older children in 2022 and 2023 relative to previous years. However, these data must be interpreted with caution, as they are based on year of registration and may differ from final figures for each year in which the deaths actually occurred. Confirmation of these data is required through the collection of year of occurrence data.

Data on the main contributory cause of death categories among children in Ireland are consistent with international data, which report that external causes of injury or trauma are the main cause of CYP deaths (Eurostat, 2024; WHO, 2022). Trauma remains the leading cause of death among older adolescents aged 15–18 years, accounting for just over one-half of all deaths registered for this age group during 2019–2023. Unfortunately, due to the limitations of the data, it was not possible to provide a more informative description of these deaths. Despite the high burden of mental health conditions among adolescents, mental health support services are currently lacking. Additional data must be collected on CYP mortality in order to accurately establish the burden of both intentional and unintentional injury and of sudden unexpected and unexplained deaths in the Irish CYP population, and to aid in the identification of contributory and modifiable risk factors. These data should be used in order to increase awareness of the high incidence of such deaths among the Irish CYP population and support the development of prevention services and initiatives.

Similarly, although the rate of RTC fatalities among Irish children has declined substantially, the rates of these deaths remain higher than best-performing countries such as the United Kingdom, Norway and Sweden. Data are required in order to inform new strategies aimed at further reducing RTC fatalities among children, particularly among older children. This includes more detailed information on the circumstances of these deaths within different age groups, including factors specific to a child's development that increase their vulnerability.

The proposed NPMR Child Death Notification form will permit a more detailed and informative analysis of CYP deaths than is currently possible. Analysis of data collected using a paper version of the form in one paediatric hospital demonstrates the feasibility of this process. The system will also enable the more timely identification of emerging trends and issues as highlighted by the observed increase in the number of infection- and sepsis-related deaths in the period from 2022 to the end of Q3 2024 relative to the previous 3 years (2019–2021). The future NPMR dataset will also facilitate the reporting of CYP mortality statistics based on a classification that is more meaningful to clinicians.

Learnings from the implementation of the NPMR Child Death Notification form in CHI at Temple Street will be used to inform the piloting of a new electronic-based system for data collection in 2025. This central database can be supported by triangulating data from other sources using the individual health identifier. This will enable additional factors contributing to each death (including underlying conditions and comorbidities) to be considered, providing a rich evidence base with which to inform future strategies to reduce the number of CYP deaths in Ireland.



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APPENDIX 1:
NATIONAL PAEDIATRIC MORTALITY REGISTER GOVERNANCE COMMITTEE MEMBERSHIP AND MEETING ATTENDANCE, 2023–2024

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APPENDIX 2:
NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORM

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ANNUAL TRENDS IN MAIN CAUSES OF DEATH IN CHILDREN IN THE POSTNEONATAL AGE GROUP, 2007-2021

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APPENDIX 5:
HOSPITALS FROM WHICH CASES NOTIFIED TO THE NATIONAL PAEDIATRIC MORTALITY REGISTER WERE TRANSFERRED TO CHILDREN'S HEALTH IRELAND AT TEMPLE STREET

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COMPLETION RATE OF VARIABLES INCLUDED ON THE NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORM DURING THE PERIOD FROM 1 JAN 2022 TO 30 SEPT 2024 IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET

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APPENDIX 7:
TIMELINESS OF SUBMISSION OF COMPLETED NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORMS TO THE NATIONAL PAEDIATRIC MORTALITY REGISTER IN THE NATIONAL OFFICE OF CLINICAL AUDIT FOR THE PERIOD 2022 TO Q3 2024

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APPENDIX 8:
RULES FOR INTERPRETING STATISTICAL PROCESS CONTROL CHARTS

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