NOCA National Office of Clinical Audit

NPMR National Paediatric Mortality Register

NATIONAL PAEDIATRIC MORTALITY REGISTER 2023

A REVIEW OF MORTALITY IN CHILDREN AND YOUNG PEOPLE IN IRELAND

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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 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, 2022). NOCA supports hospitals to learn from their audit cycles.

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The National Office of Clinical Audit (NOCA) would like to thank all the providers of the data included in this report, particularly Marie Lawlor and Joyce Moore in CHI at Temple Street for coordinating and monitoring local data submissions; the staff of the Vital Statistics Division of the Central Statistics Office; the coroners; and the Healthcare Pricing Office for providing Hospital In-Patient Enquiry data.

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NOCA also wish to acknowledge and thank Professor Tom Matthews, Consultant Paediatrician, for his ground-breaking contribution to the formation of the NPMR and who, along with the Irish Sudden Infant Death Association (Firstlight), laid the foundations for the NPMR with the establishment of the National Sudden Infant Death Register. We are also grateful to Dr Philip Crowley for supporting the transition of the NPMR to NOCA.

Finally, NOCA wish to acknowledge and remember all of the children who died and whose data are included in this report. It is the 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 2023

A review of mortality in children and young people in Ireland

National Office of Clinical Audit

Dr Martina Healy
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21 September 2023

Dear Dr Healy,

I wish to acknowledge receipt of the *National Paediatric Mortality Register 2023 Report.*

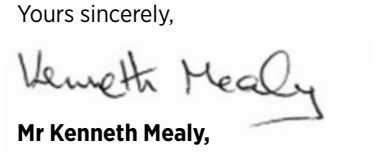
Following your presentation to the NOCA Governance Board on the 21 September 2023 and feedback garnered from our membership, we are delighted to endorse this report.

I wish to congratulate you, Audit Manager Cliona McGarvey PhD and your governance committee in the development of this report which is a valuable quality improvement initiative.

In future reports, the Board looks forward to seeing further progress on the audit recommendation for improving the way hospitals report on child deaths.

Please accept this as formal endorsement from the NOCA Governance Board of the *National Paediatric Mortality Register 2023 Report* and we wish you every success in your ongoing commitment to improving the information available to inform policy aimed at reducing child mortality.

Yours sincerely,



Mr Kenneth Mealy,
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FOREWORD

As countries develop and prosper, a variety of measures are often put in place (proper sanitation, clean drinking water, adequate housing, education, vaccination and healthcare) in order to improve the health and well-being of the population, and governments are judged based on how successfully these outcomes are achieved, particularly in relation to the number of infant deaths and adult longevity. In the 1920s, at the foundation of the Irish State, 11% of all children who were born alive were dying before their first birthday – an intolerable situation for any fledgling nation.

The NPMR has evolved from the Irish National Sudden Infant Death Register, which was established in the late 1980s and funded by the Department of Health on the foot of a written submission from interested parents and professionals with the goal of establishing the basic facts relating to sudden infant death syndrome (SIDS) in Ireland and offering bereavement support to affected Irish families. The Irish National Sudden Infant Death Register is one of the great success stories of childcare over the past 30 years. Epidemiologically determined SIDS risk factors (infants sleeping prone/on their stomach, maternal cigarette smoking, excessive infant bedding, etc.) formed the basis for infant care advice that has directly led to a reduction in the number of SIDS deaths in Ireland from 150–160 per year in the late eighties to less than 30 per year currently.

The National SIDS Register enabled deaths of children (i.e. individuals aged 0–18 years) in Ireland to be accurately documented in the first year after birth, with Government/health policy tailored to help mitigate the epidemiological risks identified by the Register's data. The deaths of children aged 1–5 years were also reasonably accurately captured, again enabling the development of effective policy to intervene and reduce death rates.

There is currently very little accurate data relating to the deaths of children, particularly those aged 5–18 years, leaving parents, professionals, healthcare officials and politicians with an information vacuum and making effective policy interventions difficult. The hurdles to remedying this situation are significant, as many of these deaths are unwitnessed, occur outside the home and are accidental; in addition, these deaths may involve a professional examination/review of the event by gardaí, a pathologist and a coroner, plus an independent review by a professional hired by the family, and each of these professionals have their own professional, ethical and legal requirements to satisfy.

However, Ireland has developed into a wealthy, data-centric society over the generations, and we owe it to our children and their parents, siblings, and friends to apply our considerable talents to solving this problem. I wish to personally thank the small group of officials and politicians (both local and national) from the Department of Health and the Health Service Executive who recognised the unglamorous but definite potential of the NPMR, especially in its early days, and protected its annual funding against often more vocal competition. I also wish to thank all those individuals (both voluntary and professional, paid and unpaid) who were involved in supporting the day-to-day work during the early days of the NPMR, as well as Children's Health Ireland at Temple Street for providing a home for so many years. It also gives me great hope for the future to see that so many of my younger professional colleagues have decided to commit their time and energy to becoming involved in the work of the NPMR.

It has been a personal and professional pleasure for me to have been involved in founding the Irish National Sudden Infant Death Register and to watch it grow and develop into a useful – and used – national database which is admired internationally, with only a handful of countries having a similar database. However, only comprehensive, accurate and timely national data relating to children's deaths will allow the collection of accurate data on incidents such as sudden death during exercise, and the subsequent development of effective policies enabling useful interventions in order to reduce the incidence of this terrible burden on families and society. If we can get this right, we will be a shining beacon for others to follow.

Tom Matthews
Emeritus Professor of Paediatrics, University College Dublin School of Medicine
Children's Health Ireland at Temple Street, Rotunda Hospital

POBLACHT NA H EIREANN.

THE PROVISIONAL GOVERNMENT
OF THE
IRISH REPUBLIC
TO THE PEOPLE OF IRELAND.

IRISHMEN AND IRISHWOMEN In the name of God and of the dead generations from which she receives her old tradition of nationhood, Ireland, through us, summons her children to her flag and strikes for her freedom.

Having organised and trained her manhood through her secret revolutionary organisation, the Irish Republican Brotherhood, and through her open military organisations, the Irish Volunteers and the Irish Citizen Army, having patiently perfected her discipline, having resolutely waited for the right moment to reveal itself, she now seizes that moment, and, supported by her exiled children in America and by gallant allies in Europe, but relying in the first on her own strength, she strikes in full confidence of victory.

We declare the right of the people of Ireland to the ownership of Ireland, and to the unfettered control of Irish destinies, to be sovereign and indefeasible. The long usurpation of that right by a foreign people and government has not extinguished the right, nor can it ever be extinguished except by the destruction of the Irish people. In every generation the Irish people have asserted their right to national freedom and sovereignty; six times during the past three hundred years they have asserted it in arms. Standing on that fundamental right and again asserting it in arms in the face of the world, we hereby proclaim the Irish Republic as a Sovereign Independent State, and we pledge our lives and the lives of our comrades-in-arms to the cause of its freedom, of its welfare, and of its exaltation among the nations.

The Irish Republic is entitled to, and hereby claims, the allegiance of every Irishman and Irishwoman. The Republic guarantees religious and civil liberty, equal rights and equal opportunities to all its citizens, and declares its resolve to pursue the happiness and prosperity of the whole nation and of all its parts, cherishing all the children of the nation equally, and oblivious of the differences carefully fostered by an alien government, which have divided a minority from the majority in the past.

Until our arms have brought the opportune moment for the establishment of a permanent National Government, representative of the whole people of Ireland and elected by the suffrages of all her men and women, the Provisional Government, hereby constituted, will administer the civil and military affairs of the Republic in trust for the people.

We place the cause of the Irish Republic under the protection of the Most High God, Whose blessing we invoke upon our arms, and we pray that no one who serves that cause will dishonour it by cowardice, inhumanity, or rapine. In this supreme hour the Irish nation must, by its valour and discipline and by the readiness of its children to sacrifice themselves for the common good, prove itself worthy of the august destiny to which it is called.

Signed on Behalf of the Provisional Government,

THOMAS J. CLARKE.
SEAN Mac DIARMADA. THOMAS MacDONAGH.
P. H. PEARSE. EAMONN CEANNT.
JAMES CONNOLLY. JOSEPH PLUNKETT.

1916
PROCLAMATION
"CHERISHING ALL OF THE CHILDREN OF THE NATION EQUALLY"

PROPOSAL FOR NEW PROCLAMATION

- The State values the life of every child and regards the death of every child as a seminal event that should be investigated to identify
  - Any failings that contributed to it
  - Any deficits in the support for the family enduring it
  - Any learning opportunities that might prevent recurrence of either

Dr Michael McDermott, Consultant Paediatric Pathologist, CHI at Crumlin.

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GLOSSARY OF TERMS AND DEFINITIONS

ACRONYM	FULL TERM
ACHI	Australian Classification of Health Interventions
ACS	Australian Coding Standards
Adolescent	The phase of life between childhood and adulthood, from ages 10–18 completed years
CDR	Child Death Review
Child mortality rate	The number of deaths of children aged from 1 to 14 completed years per 1,000 live births
CHI	Children's Health Ireland
COVID-19	coronavirus disease 2019
CYMRC	Child and Youth Mortality Review Committee
CYP	children and young people
CSO	Central Statistics Office
DRG	diagnosis-related group
ED	emergency department
ESRI	Economic and Social Research Institute
EU	European Union
EUROCAT	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 and 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
Homicide	The unlawful killing of one person by another
IHI	individual health identifier
HPO	Healthcare Pricing Office
HSE	Health Service Executive
ICD-10	International Classification of Diseases, Tenth Revision
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
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
IPCCA	Irish Paediatric Critical Care Audit
MeSH	Medical Subject Headings
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

ACRONYM	FULL TERM
NAHM	National Audit of Hospital Mortality
NCMD	National Child Mortality Database
Neonate	A newborn aged ≤28 days
Neoplasm	Abnormal growth of tissues that may or may not be cancerous
NOCA	National Office of Clinical Audit
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
NSW	New South Wales
PCCU	paediatric critical care unit
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
PICANet	Paediatric Intensive Care Audit Network
PMNCA	Perinatal Mortality National Clinical Audit
Postneonatal	The period between 29 days and 1 year
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
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 post-mortem examination and review of the circumstances of death and the infant's clinical history
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
TARN	Trauma Audit and Research Network
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)
USA	United States of America
WHO	World Health Organization

EXECUTIVE SUMMARY

Ireland currently has no centralised database for analysis and timely reporting of data on child deaths. To date, data relating to child deaths have been extracted from multiple databases with resultant gaps in information.

Accurate mortality data is essential for informing healthcare policy, planning and delivery of services, and for monitoring population health outcomes. Many child deaths are avoidable, and there is now an urgent need to identify the factors that contribute to these deaths so that appropriate intervention measures may be applied.

Available population mortality data (i.e. death certification details provided by Ireland's central death registration unit, the Central Statistics Office (CSO)) cannot be used to identify avoidable causes of death due to their limited information on contributory factors. The deficits in the current system, highlighted during the coronavirus disease 2019 (COVID-19) pandemic, have prompted a fresh proposal to review and change the death registration process in Ireland. The purpose of this report is to provide an overview of mortality in children and young people (CYP) in Ireland and to demonstrate the need for a universal, centralised system for the notification of deaths that will permit analysis and timely reporting of actionable data. This report examines the data which are currently available to us, and highlights the deficits in information at national level. Data provided include death registration information and the Hospital In-Patient Enquiry (HIPE) dataset. The findings from piloting of a National Paediatric Mortality Register (NPMR) Child Death Notification form are also provided.

Examination of these datasets led to the conclusion that there is currently no dataset that provides a complete, contemporaneous, annualised national dataset or the detail required in order to conduct an adequate national audit of deaths in children and young people. Recommendations from this report are aimed at improving the accessibility and quality of CYP mortality data.

"MANY CHILD DEATHS ARE AVOIDABLE, AND THERE IS NOW AN URGENT NEED TO IDENTIFY THE FACTORS THAT CONTRIBUTE TO THESE DEATHS SO THAT APPROPRIATE INTERVENTION MEASURES MAY BE APPLIED."

KEY FINDINGS

Key findings on data quality issues

There is currently no national database that provides complete contemporary data with which to conduct an informed national audit of deaths in children and young people (CYP) in Ireland. Existing data systems have significant limitations and are suboptimal for the purpose of reviewing and analysing CYP mortality to produce a detailed annual report.

A national register of standardised, high-quality data on CYP mortality is required to allow for the review of contributory factors. These data would be most adequately provided by the mandatory registration of all deaths in a national database at the time of death.

Current sources of CYP mortality data lack the detail to permit a thorough description of the main causes of CYP deaths and factors that contribute to these deaths. Furthermore, delays in the registration of some deaths means that timely reporting of CYP mortality estimates is not possible.

Linkage of data on children who die in hospital (HIPE data) with death registration information would permit a more in-depth and meaningful analysis of CYP mortality data by allowing additional information on underlying causes and pre-existing comorbidities to be considered.

A pilot of the NPMR Child Death Notification form demonstrated the feasibility of capturing timely, high-quality data on deaths in a tertiary paediatric hospital. The learnings from this NPMR pilot study will be used to inform the development of a national child death notification process.

KEY FINDINGS

Key findings from analysis of mortality data

The total number of deaths in infants aged under 1 year in Ireland during the period 2019–2021 was 542 (based on the year the deaths were registered). This equates to an overall infant mortality rate (IMR) of 3.1 per 1,000 live births, which is just below the European Union (EU) average of 3.4 per 1,000 live births.

The majority of infant deaths (75%) registered during the period 2019–2021 occurred during the neonatal period (aged ≤28 days), as a result of perinatal conditions (55%) and congenital malformations and chromosomal abnormalities (40%).

The greatest decline in infant mortality has occurred among infants in the postneonatal age group (aged 29 days to 1 year), due largely to a reduction in the number of deaths from sudden infant death syndrome (SIDS).

A total of 208 deaths in children aged 1–14 years and 142 deaths in young people aged 15–18 years were registered in Ireland during the period 2019–2021. Although mortality rates in children aged 1–14 years and young people aged 15–18 years have declined by more than 50% since 2007, many potentially avoidable deaths continue to occur across all ages.

Post-infancy, the leading cause of childhood death is external causes of accident and injury, accounting for more than one-fifth of deaths in children aged 1–14 years and more than one-half of deaths in young people aged 15–18 years during the period 2019–2021.

The greatest proportion (24.4%) of injury-related deaths in children aged 1–14 years were due to road traffic collisions (RTCs). Deaths from RTCs among adolescents (aged 15–18 years) declined from 26.3% (or 9.4 deaths per year) during the period 2012–2018 to 16.5% (or 4.3 deaths per year) during the period 2019–2021.

KEY FINDINGS

- The number and rate of deaths among children aged 1–14 years that are registered as homicide/filicide have increased. These deaths relate predominantly to violence occurring within a family unit.
- The leading cause of injury-related death among adolescents (aged 15–18 years) registered during 2019–2021 was ligature strangulation (58.2%), followed by RTCs (16.5%) toxicity related to drug and/or alcohol use (8.9%) and drowning (8%). There was insufficient detail in death registration information with which to confirm intent in many cases of injury-related fatalities in this age group.
- Neoplasms were the second leading cause of death in both age groups, accounting for 20% of deaths among children aged 1–14 years and 17% of deaths among young people aged 15–18 years.
- Based on available data, the majority of registered infant and child deaths (92.6% of those aged under 1 year and 66.3% of those aged 1–14 years) occurred in hospital. Thirty one percent of deaths in children aged 1–14 years and more than one-half (61.3%) of deaths in adolescents aged 15–18 years occurred at home or at the scene of injury outside of the home.
- More boys than girls died across all age groups; boys accounted for 52.5% of deaths in newborns aged ≤28 days, 50.8% of infants aged 29 days to 1 year, 57.9% of children aged 1–14 years, and 69.0% of young people aged 15–18 years who died during the period 2019–2021.

NATIONAL PAEDIATRIC MORTALITY REGISTER

KEY FINDINGS

CHILD MORTALITY ESTIMATES

542 INFANT DEATHS (BABIES UNDER 1 YEAR) WERE REGISTERED BETWEEN 2019-2021

This equates to an overall infant mortality rate of **3.1 per 1000** livebirths.

75% OF INFANT DEATHS OCCURRED IN BABIES AGED 28 DAYS OR UNDER

The most common causes of death in this age group were perinatal conditions (such as complications of extreme prematurity) at **55%** and genetic disorders at **40%**.

THE GREATEST NUMBER OF DEATHS POST-INFANCY ARE DUE TO INJURY

One in five deaths in children aged 1–14 years, and **one in two** deaths in young people aged 15–18 years were due to accident or injury. Cancer was the second leading cause of death in both age groups.

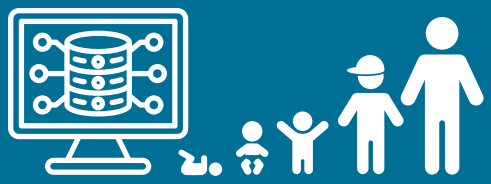
24% OF INJURY- RELATED DEATHS IN CHILDREN AGED 1-14 YEARS WERE DUE TO ROAD TRAFFIC COLLISIONS (RTC'S)

This is a reduction from previous years (2007–2018) when RTCs accounted for **34%** (10 deaths per year) of all injury-related deaths in this age group.

DATA QUALITY ISSUES

Current sources of child mortality data lack the detail to thoroughly describe the main causes of child deaths and factors that contribute to these deaths. Delays in the registration of some deaths mean that timely reporting of child mortality estimates is not possible.

There is currently no national database in Ireland that provides adequate data on deaths in children.



2019-2021*

* This data is based on the number of deaths registered by the CSO between 2019-2021. As registration of deaths can be a timely process, the number of deaths registered in a given year and the actual number of deaths in that year may differ.

INFANT MORTALITY IN 2021 WAS 58% LOWER THAN THAT RECORDED IN THE LATE 1990s

This is due largely to a reduction in the number of deaths from sudden infant death syndrome (SIDS).

50% DECLINE IN CHILD MORTALITY RATES SINCE 2007

208 deaths in children aged 1–14 years and **142** deaths in young people aged 15–18 years were registered. Despite a decline in child mortality, many potentially avoidable deaths continue to occur across all ages.

*58% OF INJURY RELATED DEATHS IN 15-18 YEAR OLDS WERE DUE TO LIGATURE STRANGULATION***

17% by road traffic collisions (RTCs)
9% related to drugs and/or alcohol use
9% from drownings.

** Ligature strangulation occurs when an object is placed around the neck and provides compression.

18% OF ALL INJURY DEATHS AMONG CHILDREN AGED 1-14 YEARS WERE REGISTERED AS HOMICIDE/FILICIDE

Homicide is the killing of one person by another. Filicide is the killing of a child by a parent.

Linkage of hospital data with death registration information would permit a more meaningful analysis of child mortality data by allowing additional information on underlying causes and pre-existing medical conditions (co-morbidities) to be considered.

A pilot of the NPMR Child Death Notification form demonstrated the potential for capturing timely, high-quality data on deaths in a specialised paediatric hospital. The learnings from this NPMR pilot study will be used to inform the development of a national child death notification process.

RECOMMENDATIONS

RECOMMENDATION 1

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.

RECOMMENDATION 2

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.

RECOMMENDATION 3

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.

RECOMMENDATION 4

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.

RECOMMENDATION 5

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.

CAPTURING THE PARENT VOICE

My name is Kate, and I am the Public and Patient Interest Representative working on the National Office of Clinical Audit's National Paediatric Mortality Register (NPMR).

Our beautiful son, Kieran, was born on 31 August 1998. He had various health challenges throughout his first few years. However, he always showed an exceptional spirit and zest for life no matter what he encountered.

Kieran was due to start school at the end of August 2002, alongside his two older brothers in a new school for all three of them. A few days prior to this we noticed he seemed to lose energy and strength, and was bruising a lot. He also developed impetigo, which, given the healthy lifestyle we had, was unusual. We took him to our general practitioner, and he was referred to the Oncology Unit in Crumlin.

Oncology ruled out the more common childhood cancers pretty quickly, and the potential cause of Kieran's sudden decline in health was narrowed down to either a vitamin K deficiency (due to his bowel surgery when he was younger), which was the most likely and least worrying result, or a myelodysplastic syndrome (a rare blood cancer - so rare and unlikely in children that it seemed an impossible outcome). The day of his 4th birthday, our world began to implode. The call with the test results came as we were blowing out the

candles on his birthday cake, it was cancer. Unlike many of the more common childhood cancers, there was no tried and tested protocol to treat this. There followed quite a few weeks of research and collaboration with other centres of excellence before a treatment plan was formulated, and this commenced in earnest on 9 September 2002.

There were to be four rounds of the toughest chemotherapy possible, followed by a bone marrow transplant. All we knew about the eventual donor was that she was a 25-year-old from London; she remains an absolute hero in our eyes and I still pray for her daily. The treatment was gruelling for Kieran but he never

lost his sense of fun or joie de vivre throughout that whole period.

Kieran's transplant went remarkably well and he got home for Easter. The weekly bone marrow counts were going steadily up. By mid-July, we were getting ever more hopeful. The week before Kieran's 5th birthday, we were in for tests; when the call came with the results, it was to say that the bone marrow count had dropped from 97 to 87. We knew 90 was the Holy Grail and to drop below that was the worst news possible. Kieran was only ever given one shot at treatment. Nothing more needed to be said. Additional tests the following week gave us a timeline of 6–18 months – such was the decline.

Kieran's 5th birthday party was the party of a lifetime, but not for the reasons we had hoped. The coming months were about building memories and letting him live what life he had left. We had one last beautiful Christmas before Kieran passed away on 31 January 2004 (exactly 18 months to the day after he was diagnosed) aged 5½ almost to the hour. With the support of Crumlin, Harold's Cross Hospice, and the Irish Cancer Society nurses, we were blessed to have Kieran at home, wrapped up in the love of his family when he passed away.

After Kieran died, I was involved in setting up a peer support group for bereaved parents called Anam Cara. Sharing in the journeys of other bereaved parents has only confirmed to me how much the details matter, that our children are not just statistics – how important it is that if you ask us a question, you listen to the answer; e.g. how their name is spelt on their death certificate; the details of both our child's life and death are important. When dealing with the bureaucracy that follows the death of our child, we should be met with kindness, empathy and compassion. As bereaved parents, we want our children to be remembered and their names spoken. If the details of their story (whether it is an illness, accident, suicide or some other trauma) can prevent another family from walking in our shoes, then it is like a balm for our soul. We would do anything to have our children back, but we would also do anything to prevent another family from joining our ranks.

"We would do anything to have our children back, but we would also do anything to prevent another family from joining our ranks."

When I was asked to be a Public and Patient Interest Representative for the NPMR, I wasn't sure what I could bring to the table. However, if I can make people see that behind the statistics are real lives cut short and brokenhearted families, then that is something positive in itself. If the details of our children's deaths can be used to improve treatments, services or supports for families, then that is even better.

Kate Burke
Volunteer with Anam Cara

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 relating to child deaths in Ireland. Existing datasets relating 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.

AIM

The aim of the NPMR is to provide a national database of standardised information on all deaths in children and adolescents aged 18 years and younger in Ireland.

OBJECTIVE 1

Provide a system for continuous national surveillance of all deaths in children aged 29 days to 18 years, regardless of cause. This data collection will also capture deaths in neonates aged 0–28 days occurring in paediatric units.

OBJECTIVE 2

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

OBJECTIVE 3

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

OBJECTIVE 4

Conduct audit and research studies (in collaboration with the paediatric hospitals) relating to the occurrence and underlying causes of childhood deaths, and use this information to provide evidence for informing policy aimed at improving outcomes and reducing the number of child deaths.

OBJECTIVE 5

Liaise with senior decision-makers at both policy and operational level (e.g. the Health Service Executive (HSE) Department of Public Health, HSE Clinical Design and Innovation, the HSE Office of the Chief Clinical Officer, and other stakeholders) in order to implement these recommendations.

RATIONALE FOR MONITORING CHILD MORTALITY

Although mortality in children has declined globally, many potentially avoidable deaths continue to occur. 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). 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 may be applied. 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).

Currently available data (i.e. death certification details provided by Ireland's central death registration unit, the Central Statistics Office (CSO)) cannot be used 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 relating to the categorisation of some deaths (Macken *et al*., 2015; Shilling *et al*., 2013; Corcoran *et al.*, 2006). Previous reviews of death certification and of the causes of death in other jurisdictions have demonstrated errors, inaccuracies and misclassification of infant and CYP deaths (Pearson *et al*., 2011b; Johansson *et al*., 2006 Hunt and Barr, 2000). Accurate data are required in order to generate improvements in the quality of care for children and their families.

While providing more detailed information on deaths, other data sources – such as the National Cancer Registry Ireland, National Office of Clinical Audit (NOCA) audits (including the Trauma Audit and Research Network (TARN) and the Paediatric Intensive Care Audit Network (PICANet) in the United Kingdom), and the National Perinatal Epidemiology Centre (NPEC) – are specific to a disease, site or age and do not inform paediatric mortality reports. The WHO cites the collection of accurate national mortality data as an essential element of the paediatric mortality and morbidity auditing process (WHO, 2018).

Despite substantial reduction in CYP mortality globally, these rates remain higher among disadvantaged groups, and 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.

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 eighties and early nineties to less than 30 deaths per year currently (McGarvey *et al*., 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; it was thus renamed the National Paediatric Mortality Register. 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 the death is notified to the Coroner and the Coroner directs a post- mortem examination,the Coroner will determine the cause of death and complete a Coroner's certificate at the conclusion of the enquiry to allow the death certificate to issue from the GRO. This may involve an inquest in some cases.

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).

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

Mortality data are an important indicator of the health and well-being of the population. They are used for informing healthcare policy, provide data for international comparison and can inform quality improvement strategies. The purpose of this report is to demonstrate the deficits in existing paediatric mortality data and the need for a universal system for notification of all deaths in children and young people to a central database for analysis and reporting of data. Results of the analysis of currently available data on mortality in children are presented, but these data are limited and subject to revision. The feasibility of collecting timely mortality data directly from a paediatric hospital into NOCA using a child death notification form was examined and findings are presented in chapter 10.

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 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
- improves accuracy in the reporting of child mortality statistics
- allows for the population-based surveillance of child deaths for the purpose of monitoring trends
- provides baseline information for identifying broader areas of concern requiring further attention, and for informing the agenda for paediatric audit (e.g. highlighting differences between groups and identifying those at greater risk)
- provides actionable data to inform and evaluate public health policy relevant to infant and child health in Ireland
- facilitates the incorporation of all relevant paediatric post-mortem examination 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 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 2022–2023.

WHO IS THIS REPORT AIMED AT?

The report has been presented in two parts:

1. The main *National Paediatric Mortality Register: A review of mortality in children and young people in Ireland* report is primarily aimed at:
   - paediatricians and multidisciplinary teams in CHI and other units caring for families
   - coroners
   - healthcare professionals, hospital managers and Hospital Groups
   - 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 second report, the *National Paediatric Mortality Register 2022: Summary Report*, is aimed at parents and families, carers and advocates, patient advocacy organisations, and the general public.

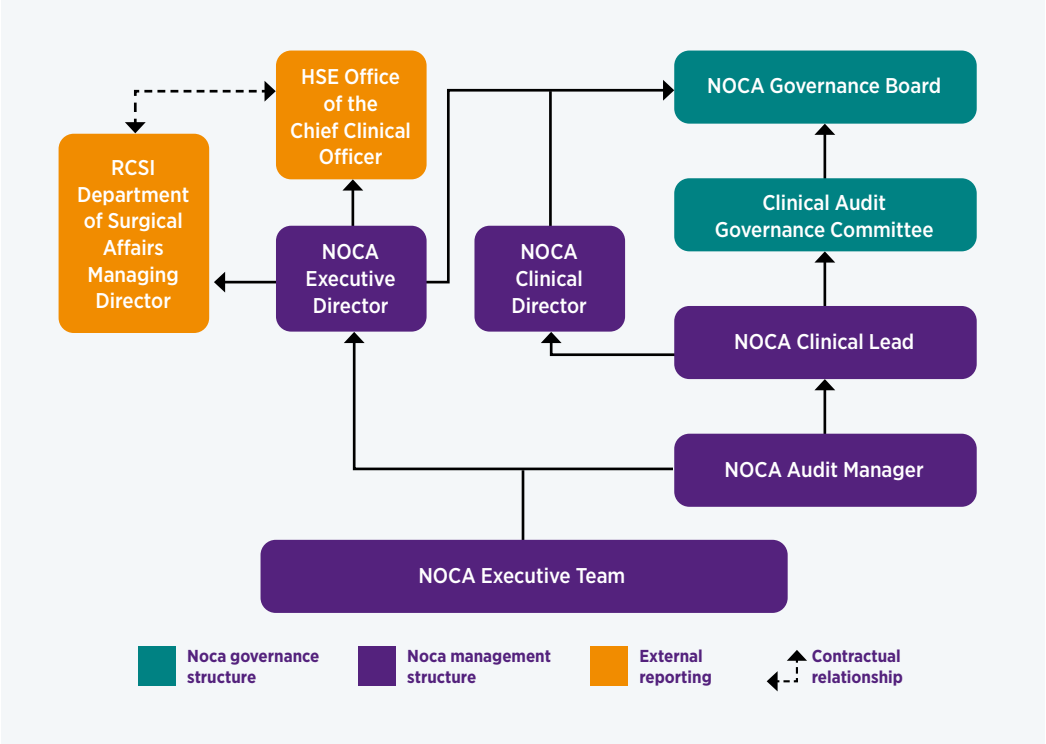

FIGURE 1.1: AUDIT GOVERNANCE AND MANAGEMENT TEAMS FOR THE NATIONAL OFFICE OF CLINICAL AUDIT

CHAPTER 2
METHODOLOGY

CONTENTS >

CHAPTER 2: **METHODOLOGY**

There are several components to this report, presented in the following chapters which were carried out in order to demonstrate the need for, and feasibility of a national CYP mortality reporting system in Ireland.

Chapter 4 which is a scoping review of existing relevant data sources and their limitations

Chapter 5 which provides a review of international experience and best practice

Chapters 6 - 9 which presents the results of the analysis of available mortality data

Chapter 10 describes the findings from the pilot of the NPMR Child Death Notification form.

DATA SOURCES

There are currently three data sources providing data to the NPMR:

1. CSO death registration information

2. the Hospital In-Patient Enquiry (HIPE) dataset

3. data generated from the pilot of the NPMR Child Death Notification form.

In addition to the above, post-mortem reports are retrieved on request from coroners nationwide by special arrangement. Retrieval of reports was paused during the coronavirus disease 2019 (COVID-19) pandemic, and these data are therefore not included in this report. Collection of reports has now resumed. Additional information will be extracted from these reports and entered into the NPMR database as the NPMR develops in the coming years. Currently, 23 out of 26 coroners nationally provide post-mortem reports on all child deaths to the NPMR.

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, 2022a). Access to RMFs is granted to researchers who meet the conditions and criteria designated by the CSO. NOCA's access to the RMF data is controlled by the CSO 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 less than 3 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), month and year 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 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 (EU) 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 2019–2021 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.

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: HIPE DATASET

Data collection

The HIPE dataset is the principle source of national data on discharges from, and deaths in, acute public hospitals nationally, and collects demographic, clinical and administrative information. Information is retrieved from medical charts or records and coded by trained clinical coders in line with national and international coding guidelines, and is then entered into the HIPE portal. The data are exported from acute hospitals to the Healthcare Pricing Office (HPO) on a monthly basis with an expected time lag of 28 days following patient discharge. The HPO provides HIPE data files to NOCA on request. The data extract includes the following data fields: medical record number, age, sex, hospital name, county of residence, date of discharge, diagnosis at discharge, and secondary diagnoses of all patients aged <18 years nationally. The total number of discharges annually was also requested in order to calculate mortality rates per 1,000 discharges.

Information governance

The HPO within the HSE oversees all functions associated with the operation of the HIPE database, including the development and support of the data collections and reporting software, training of coders, verification of data quality, audit, analysis and reporting. The HPO processes data in accordance with the General Data Protection Regulation (GDPR) 2018. Patient information is de-identified and the full date of birth is not available at national level; HIPE collects hospital-level healthcare information (such as the medical record number (MRN)), as well as the patient's month and year of birth. Use of the data is strictly for the purpose outlined in the NOCA access application. The pseudonymised dataset is forwarded to NOCA along with a password, which is provided to those NOCA personnel who have signed the HPO's Conditions of Use form.

Inclusion criteria

All children aged under 19 years who were admitted to hospital during the period 2009–2022 with the discharge code "deceased" are included in this analysis.

Exclusion criteria

Any registered deaths where the age of the deceased is 19 years or over and/or with a discharge code other than "deceased" are excluded from this analysis.

DATASET 3: NPMR CHILD DEATH NOTIFICATION FORM PILOT 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, where these children die, and from what cause. These data provide an indicator of performance in relation to infant and CYP mortality in CHI at Temple Street. 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 in CHI at Temple Street was approved by various relevant committees within the hospital, and is embedded in hospital policy and included on a checklist of actions for staff whenever a child dies in the (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 departments throughout CHI at Temple Street. 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 was required in order to allow follow-up on data anomalies. The form was available in paper format or could be completed online and either scanned or directly attached to the email. A copy of the form was included in the patient chart. Upon receipt of the form, NOCA personnel entered the data into an Excel spreadsheet using an associated coding system. Data were transferred to statistical software Stata for analysis.

Information governance

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

Inclusion criteria

All deaths in children aged under 19 years in CHI at Temple Street, 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 registered deaths where the age of the deceased is 19 years or over at the time of death are excluded from this analysis.

SCOPING REVIEW OF EXISTING RELEVANT DATASETS

In audit and registry design, it is important to review relevant existing and emerging data sources in order to determine how the information within these sources could potentially be used to assist with the audit objectives. Where data collection structures are already in place, access to these data for secondary use is very cost-effective and may be useful for validation purposes. International best practice on health information mandates that data should be collected once and used many times (Health Information and Quality Authority, 2018). The HSE Quality and Patient Safety Directorate publication, *A Practical Guide to Clinical Audit*, recommends that:

> Where possible, relevant, routinely collected raw data from existing sources should be used for the purposes of the clinical audit as this avoids duplication of information and work and allows for repeated data collection and re-audit with minimum effort. Examples of such sources are clinical information systems, service user records, HIPE and observation of practice. Collection of data from several sources may overcome the problem of incomplete data sources. (HSE Quality and Patient Safety Directorate, 2013 p.31)

All relevant data sources were reviewed for potential use, and their limitations are outlined in Chapter 4.

REVIEW OF INTERNATIONAL BEST PRACTICE

The following databases were used to search for English-language articles and reviews published within the last 5 years (2019 to present) related to child mortality: Embase, MEDLINE, Preprints, PubMed, and Cochrane Library. Keywords and Medical Subject Headings (MeSH) terms included 'child/infant/paediatric/adolescent', 'mortality/death' and country-specific search terms from other English-speaking common law jurisdictions. The age group of interest included those aged 0–17 years inclusive; material relating to patients aged under 26 years was included where relevant.

The initial review primarily yielded results relating to the development of the National Child Mortality Database in England. It was therefore necessary to hand search different country-specific national policy documents from each jurisdiction. The included countries and their associated approaches are provided here as a sample of current practice in English-speaking common law systems with a sociopolitical landscape that is similar to that of Ireland. They demonstrate various levels of completeness in their approach to child mortality databases, and they all offer learning points in the development of the NPMR in Ireland.

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. Analysis of HIPE data was conducted using the Statistical Package for the Social Sciences (SPSS V25).

As per NOCA information governance policy (NOCA,2022c), HIPE Data User agreement, and CSO guidance (Linehan, T. and Dineen, K. (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 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 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 rates for various subcategories were expressed as aggregate blocks of data over the course of 3 years in order to avoid disclosure issues and permit further analysis of the data. Overall percentage changes in rates relative to baseline were estimated using the following calculation:

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

EVIDENCE SYNTHESIS AND 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 literature review and the scoping exercise for the existing datasets. 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).

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, the HIPE dataset provided by the HPO, 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 2021 **HIPE dataset**: 1 January 2009 to 31 December 2021 **NPMR Child Death Notification form**: 1 January 2019 to 31 December 2021
TYPE OF DATA	The NPMR and HIPE datasets are final. CSO death registration information is subject to revision based on late registrations.

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 3-year period from January 2019 to December 2021. The CSO death registration information dataset is used to report on deaths in the following age groups of children and young people: 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. **HIPE dataset**: Data are collected on admitted hospital patients from all acute public hospitals nationally. Private hospitals are not included. The data extract provided to the NPMR included all cases coded as deceased on discharge during the period from 2009 to 2021. All variables in this extract had a capture rate of 100%. **NPMR Child Death Notification form**: The form is currently implemented in just one paediatric unit (CHI at Temple Street) as a pilot study to inform the feasibility and implementation of a national system for the timely collection of death notifications.
Completeness of data release 	**CSO death registration information**: Details of 100% of CYP deaths registered during the period 2019–2021 are contained in CSO datasets. However, the percentage of late registrations by the GRO is yet to be determined. 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. The proportion of late registrations for 2019, 2020 and 2021 was 34%, 33% and 44%, respectively. Completeness of the dataset was no less than 99.4% for all variables included, with most variables being 100% complete. **HIPE dataset**: All HIPE submissions must be completed within 30 days of each patient's discharge from hospital, and an audit tool is used to measure the percentage of eligible cases entered within the required time frame. In 2019, 2020 and 2021HIPE captured 99.5%, 98.9% and 99.6%of all care episodes eligible for inclusion on the database, respectively (Healthcare Pricing Office, 2020—2022). The HIPE dataset does not include patients who were not admitted inpatients (e.g. those who died in the emergency department (ED)). The data extract provided to the NPMR included all cases coded as deceased on discharge. All variables in this extract had a capture rate of 100%. **NPMR Child Death Notification form**: Submitted forms were cross-checked with the hospital 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 low capture rate in 2020 was due to staff absences during the COVID-19 pandemic. Data on identified missed cases were collected retrospectively by the dedicated local audit coordinator. Validation checks on NOCA pilot data showed a high degree of completeness for all variables included in the dataset: 70% of all variables included in the dataset had a capture rate of ≥80%.

TABLE 3.2: CHARACTERISTICS OF DATA QUALITY *CONTINUED*

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. 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. Validation checks by NOCA data analysts showed a high degree of completeness for all variables included in the CSO death registration information dataset. **HIPE dataset**: HIPE coordinators and clinical coders in each hospital adhere to Irish Coding Standards and classification systems, and the quality of HIPE coding in each hospital is reviewed by the HPO, which issues recommendations for improvement if there is a concern. The onus is on each hospital to implement any recommended improvements. Discharges are coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM), Australian Classification of Health Interventions (ACHI), Australian Coding Standards (ACS) Tenth Edition (collectively known as the ICD-10-AM/ACHI/ACS Tenth Edition). The Irish Coding Standards are published annually by the HPO in order to provide guidance on the use of the classification in Ireland. An updated clinical coding classification is adopted every 4–5 years in order to ensure standards remain current and comparable internationally. **NPMR Child Death Notification form data**: Validation checks are carried out by NOCA staff upon receipt of 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. NPMR records will be defined as complete when all validation checks have been fulfilled.

TABLE 3.3: ASSESSMENT OF DATA IN THIS REPORT

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. **HIPE dataset:** Advantages of using HIPE include the database's complete capture of all patients admitted to acute public hospitals nationally, as well as the timely availability of data. The data entry is also standardised, and the quality of this process is routinely audited. Furthermore, the data include information on associated comorbidities and underlying conditions alongside the primary diagnosis, which provides a broader overview of CYP deaths than reporting on cause of death alone. **NPMR Child Death Notification form**: The NPMR Child Death Notification form pilot in CHI at Temple Street will inform the process for the national implementation of a centralised system for the timely, standardised and complete notification of CYP deaths. This system will be 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.
Limitations of data in this report	**CSO death registration information:** Lack of detail on the circumstances of death limits the ability to report accurately on some cause of death categories, such as sudden unexplained deaths and external-cause deaths. Data for the CYP cohort of patients will have to be further classified in order to present them in a clinically meaningful way. Furthermore, current registration practices mean that it is not possible to collect and report on accurate, timely data based on the year of death due to delays associated with the registration of coroners' cases, particularly where there is an inquest into the death. **HIPE dataset:** There are limitations to how these data can be used for informing mortality statistics, notably the inability to differentiate cause of death from other additional diagnoses, including pre-existing conditions. Because HIPE is used to document episodes of care, the principal diagnosis responsible for the patient's admission to hospital may not necessarily be the cause of death. There is also a potential for double counting patients where there are errors relating to coding for patient identification. Each HIPE discharge record represents one episode of care. However, an individual may present to different hospitals and be assigned a different medical record number in each hospital; hence, in the absence of a unique patient identifier, it is not possible to report the number of hospital encounters per patient or to estimate the incidence or prevalence of a particular disease across the patient population nationally. The HIPE dataset is restricted to in-hospital deaths only, as patients dying outside of hospital and those pronounced dead in EDs are not included in the HIPE dataset. Moreover, private hospitals do not submit data to HIPE. **NPMR Child Death Notification form**: The proposed NPMR is not yet operational nationally. The optimal model for the NPMR will have the ability to link to various data sources relating to each individual, including CSO death registration information, HIPE data, post-mortem reports and NPMR data. This is currently not possible due to the lack of a unique patient identifier. The NPMR will measure the timeliness of data collection and present how many death events are completed on the NPMR database within 24 hours and 3 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 records will not be defined as complete until all validation checks have been fulfilled. The international standard used by the United Kingdom (UK) among others for official notification of deaths, is 48 hours from the time of death.

CHAPTER 4

CURRENT DATA ON MORTALITY IN CHILDREN AND YOUNG PEOPLE

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CHAPTER 4: **CURRENT DATA ON MORTALITY IN CHILDREN AND YOUNG PEOPLE**

A description of the currently available datasets relevant to CYP mortality and their limitations is outlined in this chapter and summarised in Table 4.1.

HIPE DATASET

The HIPE dataset is a national health information system designed to collect demographic, clinical and administrative information on each episode of care from all acute hospitals in Ireland. The data are used to assess activity levels, compare performance indicators, apply specialty costs, etc. (Healthcare Pricing Office, 2020).

The HIPE system collects a principal diagnosis for each discharge, as well as up to 29 additional diagnosis codes. The data can be reported in many ways, such as by diagnosis-related group (DRG), by Hospital Group, or by private/public hospital status. There are limitations to the use of these data for informing mortality statistics (see Table 3.3). Furthermore, from a health system viewpoint, patients who die outside of hospital and those pronounced dead in EDs are not included in the HIPE dataset; hence, it is suitable for describing hospital inpatient deaths only. Variation in coding practices may also cause issues (NOCA, 2022b).

INTEGRATED PATIENT MANAGEMENT SYSTEM

Some HSE hospitals use an iPMS to manage patient records. The advantage to using an iPMS over HIPE is that all cases are included, whereas HIPE does not include patients who only visit the ED. Disadvantages to using this system include that it is not used universally and that it records very little detail.

NATIONAL AUDIT OF HOSPITAL MORTALITY

The National Audit of Hospital Mortality (NAHM) analyses HIPE data for the purpose of identifying trends in mortality patterns for adults in acute hospitals. The NAHM methodology is not an appropriate tool for reporting mortality in paediatric units. The main objective of NAHM is to analyse and display mortality patterns across Ireland's adult and mixed (i.e. treating patients of all ages) hospitals in order to guide improvement measures. The key diagnoses reported by NAHM are not the principal causes of death in the paediatric population.

CSO DEATH REGISTRATION INFORMATION

By law, every death that occurs in Ireland must be registered with the GRO. These data have been reported by the CSO every year since 1864. Each year, the CSO publishes the number of deaths registered by the GRO in that particular year. The underlying cause of death is categorised according to the World Health Organization's (WHO's) International Classification of Diseases, Tenth Revision (ICD-10) (WHO, n.d.) using an automated coding system called Iris. The quality of the mortality coding depends on very good-quality medical certification on the death certificate. Although the CSO data are population based, there are limitations to their use, including the following:

- Delays in registration: This results 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. Data from the National Sudden Infant Death Register have shown that in as many as 40% of sudden infant death syndrome (SIDS) deaths from any given year will not be registered in the year in which the deaths occurred (McGarvey *et al*., 2015). Late registrations are not counted for annual publications but are included in a 'Late Deaths' data file. In subsequent years, the CSO publish more accurate year of occurrence figures and in some cases update or reclassify causes of death.
- Application of coding: In order to enable reliable and valid comparisons between countries, the WHO recommends using the International Classification of Diseases (ICD) in its current revision for uniform classification of causes of death (WHO, n.d.). Cause of death coding is complicated and has a subjective element, meaning that variation may occur. These discrepancies occur particularly in infection-related deaths, with the death often being classified according to the organ/system affected rather than according to the causative pathogen. Furthermore, this conventional categorisation of deaths based on ICD-10 coding is not optimal for use in the clinical setting in relation to infants, children and young people. 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 infants, children and young people.
- Lack of detail on circumstances of death: The presence or absence of co-morbidities, underlying conditions and modifiable factors should be considered when reviewing cause of death. Systematic capture and review of this information provides learning opportunities and can inform intervention measures. Standardised, high-quality data should be provided for inclusion on a paediatric mortality register in order to allow for the review of such factors.

POST-MORTEM REPORTS

Many child deaths reportable to the coroner will undergo a post-mortem examination (Coroners Act 1962-2020). Post-mortem reports provide important supplementary information for the accurate confirmation of cause of death and are a valuable quality assurance tool (O'Rahelly *et al.,* 2021; Newton *et al*., 2004; Bayer-Garner *et al*., 2002; Kumar *et al*., 1998). A minimum accepted standard of necropsy is required, particularly with regard to sudden unexplained deaths in order to make a correct diagnosis of the cause of death and should ideally be performed by a specialist paediatric pathologist (Sheehan *et al*., 2003, Tracey *et al*., 2013). A recent review identified a major discrepancy in 14.1% of pre-mortem clinical interpretations and post-mortem findings (O'Rahelly *et al*., 2021). This negatively impacts on the likelihood of establishing a cause of death and the accuracy of cause of death certification (McGarvey *et al*., 2012; Sheehan *et al*., 2005). Particularly in the case of sudden unexpected deaths, because a death scene investigation is not mandatory in Ireland, additional information on the circumstances of the death – including information on factors such as sleeping location and position – can inform accurate cause of death classification and aid in determining intent. A study published in 2021 reported that the rate of post-mortem examinations among Irish childhood deaths was 25%, and that most of these were performed under the direction of a coroner (O'Rahelly *et al*., 2021). The NPMR receives copies of post-mortem reports relating to all deaths in children aged under 19 years nationally (by special arrangement and at the discretion of individual coroners).

IRISH PAEDIATRIC CRITICAL CARE AUDIT

The Irish Paediatric Critical Care Audit (IPCCA) captures data on the activity and outcomes of patients admitted to paediatric critical care units (PCCUs) in Ireland, and also includes data on children aged under 16 years who are treated in adult intensive care units nationally as well as in the regional high dependency unit in University Hospital Limerick. The objective of this data collection is to measure the quality of care being provided in PCCUs and benchmark this against other PCCUs across the UK. The overall purpose of the IPCCA is to improve critical care services provided to patients. The data collection is conducted in partnership with the Paediatric Intensive Care Audit Network (PICANet) in the UK. The mortality rate in PCCUs is one of five key metrics monitored by the IPCCA and PICANet in order to measure the quality of care being delivered. A paediatric index of mortality scoring system is used to predict the risk of mortality of patients admitted to PCCUs, and risk-adjusted standardised mortality ratios (SMRs) are reported for each PCCU and benchmarked against 32 PCCUs across Ireland and the UK. The number of deaths in Irish PCCUs is low and accounts for approximately one in five deaths in the childhood population in any given year (NOCA, 2021).

NATIONAL PERINATAL EPIDEMIOLOGY CENTRE'S PERINATAL MORTALITY NATIONAL CLINICAL AUDIT

The National Perinatal Epidemiology Centre (NPEC), based in Cork University Maternity Hospital, collaborates with all Irish maternity services to translate clinical audit data and epidemiological evidence into improved maternity care for families in Ireland. The NPEC conducts a range of clinical audits, including a Perinatal Mortality National Clinical Audit (PMNCA). The aim of the PMNCA is to provide a national review of perinatal deaths. The NPEC has developed a surveillance system which collects pseudonymised data from all 19 Irish maternity hospitals. A significant recent development is the endorsement of this PMNCA by the National Clinical Effectiveness Committee.

The PMNCA notification dataset is completed for all perinatal deaths nationally, including stillbirths delivered from 24 weeks gestation and/or with a birthweight of ≥500 g, and all neonatal deaths occurring within 28 days of birth, regardless of gestational age at delivery or birthweight. However, some neonatal deaths occur in paediatric units where babies have been transferred for specialist treatment. While the NPEC endeavours to ensure that such cases are reported back to the maternity units and are subsequently included in NPEC data analysis and reporting, a small number of cases are missed every year (seven per year from 2018 to 2020). In the absence of a structured reporting system between paediatric units and maternity units where babies are delivered, the number of missing cases (including SIDS cases) cannot be verified.

NATIONAL DISEASE-SPECIFIC REGISTRIES

Following mortality in the first year of life, attention is given to the main causes of death (i.e. heart disease, cancer, etc.) as opposed to age-specific causes. This is evident in the number of disease-specific registries in existence, most of which collect data for all ages. Registries that capture paediatric data include the National Cancer Registry Ireland and the NOCA Major Trauma Audit, which collects detailed information on injury-related deaths, one of the main causes of paediatric death outside of infancy. The Major Trauma Audit dataset does not include deaths that occur outside of hospital, although it does include deaths pronounced in the ED. The Irish Childhood Diabetes National Register (ICDNR) collects detailed information on all children aged under 15 years who are diagnosed with type 1 diabetes; however, as data are collected only at the point of diagnosis, there are no mortality data available from the ICDNR. Other national registries include the Cystic Fibrosis Registry of Ireland and the European network of population-based registries for the epidemiological surveillance of congenital anomalies (EUROCAT). The limitation of such registries is that the data are collected for a specific purpose cannot be shared for other purposes. Such data sharing would be best facilitated by the implementation of the individual health identifier (IHI).

SUMMARY OF FINDINGS

There is currently no existing dataset that provides complete and accurate national data that would be required in order to conduct an informed national audit of CYP deaths in Ireland. Currently available population based data such as from national death registration (Central Statistics Office) cannot be used to identify avoidable causes due to its' limited information on contributory factors as well as delayed publication and issues relating to categorisation of some deaths (Corcoran *et al.*, 2006, Shilling *et al*., 2013). Furthermore, as highlighted by Duke *et al*. in a recent review of death registration information, "the current practice of categorising and reporting child deaths according to a single cause of death limits the information and opportunities for improvement because broader factors affecting mortality including underlying conditions and co-morbidities are not considered" (Duke *et al*., 2019). The retrospective nature of the datasets discussed in this chapter means that they are subject to problems with missing data, and there are also data quality concerns relating to the accurate categorisation of the cause of death.

Without a unique identifier for each patient, the linkage of all databases containing death registration information is not currently possible. This would be most adequately facilitated by the mandatory registration of all deaths on a national database at the time of death, which would then be communicated to the NPMR. Mandatory notification of deaths would be the optimal model for ensuring the complete and timely capture of deaths in Ireland.

TABLE 4.1: SOURCES OF DATA ON PAEDIATRIC MORTALITY

Hospital In-Patient Enquiry (HIPE) dataset					
Governance	**Description**	**Data fields**	**Coverage**	**Potential**	**Limitations**
HPO	The HIPE dataset collects demographic, clinical and administrative data relating to discharges from and deaths in acute public hospitals in Ireland. It includes data on patients in intensive care units and high dependency units; transfers; and same-day admissions and discharges. Data are taken from medical charts and records and coded by trained clinical coders before being entered into the HIPE system.	Admission date, time, transfer, type, length of stay, days in critical care bed, principal diagnosis, procedures and codes, age, sex, public/private hospital status, case mix, and primary and all secondary diagnoses, with specific codes for distinct complications. Multiple ways of reporting, e.g. by Hospital Group, diagnosis-related group (DRG), public/private hospital status, and patient type, as well as Hospital Group by DRG, etc.	All acute public hospitals nationally; hospital inpatients only; 99.5% of discharges are coded and included.	Complete national data on deaths occurring in hospital. This dataset enables the analysis of the case mix of hospital deaths, including information on comorbidities and underlying conditions alongside cause of death. Linkage of HIPE data with cause of death registration details would enable a more informative analysis of mortality data.	Patients dying outside of hospital or pronounced dead in ED are not included. Does not specify cause of death, which may differ from primary diagnosis.

National Audit of Hospital Mortality (NAHM)					
Governance	**Description**	**Data fields**	**Coverage**	**Potential**	**Limitations**
NOCA	This dataset is taken from the National Quality Assurance Improvement System portal in the National Health Intelligence Unit, Strategic Planning and Transformation, HSE, which is based on HIPE data; hence, it relates to hospital admissions only, but also excludes personal information such as a patient's name, area of residence and date of birth.	As with the HIPE dataset, NAHM collects patient demographics, comorbidities, admission source and type, and principal and secondary diagnoses. In addition, standardised mortality ratios (SMRs) are calculated and reported for six key diagnoses. SMRs are mortality estimates adjusted for factors such as patient age and presence of other serious illnesses in order to ensure comparability across diverse hospitals.	National; data are routinely collected by all publicly funded acute public hospitals in Ireland. Hospital inpatients only.	The NAHM dataset can provide mortality estimates for paediatric units. NAHM does not provide any direct advantage to the NPMR over and above that of the HIPE dataset.	The audit tool used is not suitable for paediatric hospitals. SMRs cannot be used to compare paediatric units due to the influence of many factors unrelated to quality of care. Data are available for in-hospital deaths only and exclude deaths occurring outside of hospital and deaths that are pronounced in ED.

TABLE 4.1: SOURCES OF DATA ON PAEDIATRIC MORTALITY *CONTINUED*

CSO death registration information					
Governance	**Description**	**Data fields**	**Coverage**	**Potential**	**Limitations**
CSO, on behalf of the Minister for Social Protection	Death registration information is forwarded electronically from the Department of Social Protection's GRO to the CSO. This information is collected under the Vital Statistics and Births, Deaths and Marriages Registration Act, 1952 and Section 73 of the Civil Registration Act 2004. Data are published quarterly and annually.	Name, address of residence of the deceased, place of death, age and sex of the deceased, date of death, occupation of the deceased, marital status, and cause of death (ICD-10 cause of death coding scheme used, Socioeconomic group, social class).	All deaths nationally are officially registered with the GRO.	Data are complete for the population 0-18yrs. This can serve as a validation tool for NPMR data.	Subject to delayed publication, insufficient detail on the circumstances of death.

Post-mortem reports					
Governance	**Description**	**Data fields**	**Coverage**	**Potential**	**Limitations**
Coroners nationally	Post-mortem reports include details relating to investigations conducted as part of a post-mortem (e.g. external examination, internal examination, toxicology, biochemistry, microbiology, etc.).	Varies by pathologist and by category of death (e.g. trauma versus sudden unexplained deaths, etc.).	The post-mortem rate for paediatric deaths nationally is between 25% and 40%. Reports are provided to the NPMR by special arrangement with the Coroners Society of Ireland, at the discretion of individual coroners.	Post-mortem reports contain important supplementary information that can inform the accurate classification of the cause of death. Post-mortem reports are useful for confirmation of cause of death and validation purposes.	Not all deaths require a post-mortem examination. Post-mortem reports are not standardised; hence, the level of detail varies by report. Not all autopsies meet the standards/ guidelines recommended by the Royal College of Physicians of Ireland Faculty of Pathology, particularly for sudden unexpected deaths and when a specialist paediatric pathologist is not involved (RCPI, 1996).

TABLE 4.1: SOURCES OF DATA ON PAEDIATRIC MORTALITY *CONTINUED*

Irish Paediatric Critical Care Audit (IPCCA)					
Governance	**Description**	**Data fields**	**Coverage**	**Potential**	**Limitations**
NOCA	The IPCCA includes data submitted to PICANet in the UK, as well as data on children treated in adult intensive care units throughout Ireland and in the high dependency unit in University Hospital Limerick.	Demographics, ethnicity, admissions details, diagnoses and procedures, transfer and retrieval information, and discharge information.	The IPCCA covers all paediatric intensive care units nationally, all adult intensive care units admitting paediatric patients, and the high dependency unit in University Hospital Limerick.	The IPCCA provides a rich dataset of information on each case and includes mortality as one of five key quality indicators, along with other clinical information. These data can provide validation for the number and cause of deaths occurring in paediatric intensive care units in Ireland.	The IPCCA captures deaths relating to specific sites only (e.g. paediatric intensive care units); it does not capture deaths occurring in ED, wards, or outside of hospital. Data are anonymised and cannot be linked to other data sources.

Perinatal Mortality National Clinical Audit (PMNCA)					
Governance	**Description**	**Data fields**	**Coverage**	**Potential**	**Limitations**
NPEC	Designated coordinators within all maternity units collate data on all perinatal deaths in their unit and submit these data to the NPEC using a specific, detailed notification form. Data are submitted via a secure online database.	Anonymised data, including: maternal details (past medical history, current pregnancy details (including delivery and maternal outcomes)); hospital details; and baby's details (including cause and time of death).	The PMNCA covers all 19 maternity units in the Republic of Ireland.	Only neonatal deaths occurring in paediatric units are relevant to the NPMR. However, this dataset will be of value in validating the number of deaths certified as SIDS (a small number of SIDS cases every year are in the neonatal age group) and the number of late neonatal deaths (i.e. babies who die after 7 days of life but before 28 completed days of life) occurring in paediatric units. Furthermore, there is great potential in completing vital national information on post-mortem uptake and cause of neonatal deaths that occur in paediatric units.	The PMNCA is restricted to neonatal deaths.

TABLE 4.1: SOURCES OF DATA ON PAEDIATRIC MORTALITY *CONTINUED*

National disease-specific registries					
Governance	**Description**	**Data fields**	**Coverage**	**Potential**	**Limitations**
Various disease-specific registries	There are numerous disease-specific registries and audit datasets (e.g. the UK's Trauma Audit and Research Network (TARN), the ICDNR, the Cystic Fibrosis Registry of Ireland, the National Cancer Registry Ireland, and Rare Diseases Ireland). These datasets have potential for the NPMR via data linkage in order to enable more in-depth review of specific cause of death categories (e.g. injury-related deaths).	Varies according to the purpose of each registry.	Most disease-specific registries are national registries with good coverage, particularly where registration is mandatory (e.g. the National Cancer Registry Ireland).	These datasets have the potential to aid validation of a number of paediatric deaths relating to specific cause of death categories.	Disease-specific registries collect data on registry-specific cases, which represent only a proportion of all paediatric deaths. The data being collected for the purpose of a specific registry cannot be shared for secondary uses without consent of patient and/or families.

CHAPTER 5

INTERNATIONAL APPROACHES TO CHILD MORTALITY DATABASES

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CHAPTER 5: INTERNATIONAL APPROACHES TO CHILD MORTALITY DATABASES

INTRODUCTION

As NOCA works towards developing a robust paediatric mortality database in Ireland, an understanding of the processes of comparable systems was sought, including those used in England, Australia (New South Wales), New Zealand and the United States of America. This chapter provides a summary of the key elements of child mortality data collection and analysis in each of these jurisdictions.

ENGLAND, UK

The National Child Mortality Database (NCMD) is a world leader in the field of child mortality research, having established a database with a statutory basis for mandatory reporting. In England, all deaths must be registered within 5 days of death. Data on all registered deaths are centrally collated, analysed and published annually by the UK's Office for National Statistics. Additionally, under the Children Act 2022 Child Death Overview Panels have a statutory obligation to collect information from every agency that has had contact with the child. The goal of such a panel is multi-factorial, including understanding why the child has died, as well as making recommendations to improve paediatric survivorship in the future.

After a lengthy process, with its foundations in Child Death Overview Panels, the NCMD became fully operational on 1 April 2019 (note that children who died prior to this date were also included even if their death review was ongoing at the time). Data are collected on all deaths among children aged 0–18 years. Data points include: number of child death notifications; infant and child death rates; age group and sex; level of social deprivation; ethnic group; place of death; gestational age at birth; category of death; modifiable factors; perinatal/neonatal events; and duration of child death review.

In addition to this core dataset, the NCMD also collects supplementary information on specific conditions and circumstances, including deaths as a result of: asthma and anaphylaxis; a cardiac disease (congenital or acquired); a chromosomal, genetic or congenital anomaly, excluding cardiac conditions; fire, burns or electrocution; an oncological condition; injuries sustained from a falling object; a life-limiting condition; diabetic ketoacidosis; drowning; epilepsy; falls; infection; poisoning; sudden unexpected deaths; suicide or self-harm, including alcohol or substance abuse; trauma or external factors; vehicle collisions; and violent or maltreatment-related deaths, as well as deaths in a neonatal unit, delivery suite or labour ward. The NCMD also makes use of data collected by the Office for National Statistics in order to calculate paediatric mortality rates per 100,000 population.

The lesson from the NCMD is twofold: a statutory basis for mandatory reporting ensures the provision of consistent data, and a standardised death notification form (as well as supplementary reporting on specified conditions) ensures that such data are of high quality, are relevant, and can be used to improve child health outcomes.

NEW ZEALAND

The Child and Youth Mortality Review Committee (CYMRC) is a statutory body with its basis in the Pae Ora (Healthy Futures) Act 2022, and is accountable to New Zealand's Health Quality & Safety Commission. All deaths are registered by the funeral director within 3 days of burial or cremation. Data on all registered deaths are centrally collated, analysed and published annually by the New Zealand Ministry of Health and the CYMRC.

Although the CYMRC has a statutory foundation, there is currently no legislative basis for the mandatory reporting of child deaths. Instead, the CYMRC meets four times per year to review data collected from the Department of Internal Affairs; the Ministry of Health; Oranga Tamariki (the Ministry for Children); coroners; Coronial Services (in the Ministry of Justice); the Ministry of Education; Water Safety New Zealand; the Ministry of Transport; and local child and youth mortality review groups.

The CYMRC reviews deaths among children aged 28 days to 24 years and aims to collect a standardised core dataset, including the number of deaths, cause of death categories and demographics. It has produced 15 reports as of 2023, incorporating retrospective data collection from 1939 to 1999 and concurrent data collection from 2002 onwards.

This structured approach provides an example of a functioning model with a significantly lower barrier to entry (as it is retrospective). However, the lack of mandatory and standardised data reported directly to the CYMRC results in inconsistent information (e.g. on specific conditions). Additionally, while a wider age group is included compared with that covered by the NPMR in Ireland, neonatal deaths (which account for a sizeable portion of paediatric deaths) are excluded.

NEW SOUTH WALES, AUSTRALIA

Although data on all registered deaths are centrally collated, analysed and published annually by the Australian Bureau of Statistics, each state or territory handles the process of child death review within its own district. In New South Wales (NSW), the funeral director must register each death within 7 days of burial or cremation. The NSW Ombudsman is notified of child deaths by the NSW Registry of Births, Deaths and Marriages. The NSW Ombudsman further supports the NSW Child Death Review Team (and Register) under the Community Services (Complaints, Reviews and Monitoring) Act 1993. Of note, this legislation makes specific provision for the review of deaths of children who die in circumstances of abuse or neglect, and of children who die in care or detention.

Although deaths are notified to the NSW Ombudsman and there is a statutory basis for child death reviews to be carried out and the register maintained, the Child Death Review Team must then collate further information from government and non-government agencies, including NSW Health; the NSW Department of Education; the NSW Department of Communities and Justice; the NSW Police; and the coroner.

Data are collected on children aged 0–17 years, inclusive. Key data points include number of deaths, demographics, cause of death, ethnicity, and socioeconomic status. The Child Death Review Team produces an annual report on its process, as well as biennial reports on reviewable child deaths (available from 2003 onwards).

While limitations exist, similar to the process outlined for New Zealand, this approach provides an example of a consistent, centralised statutory body (i.e. the NSW Ombudsman) to which all child deaths are notified. Of particular importance is the statutory provision for specific review by the NSW Ombudsman directly into the deaths of children that occur while those children are in the care of the state.

UNITED STATES OF AMERICA

The National Center for Fatality Review and Prevention operates as a national technical support and data centre serving Child Death Review (CDR) and Fetal and Infant Mortality Review programmes throughout the United States of America (USA). A process of CDR is operational in all 50 states, the District of Columbia, Guam, and the Navajo Nation. Eighty-eight percent of CDRs use the centralised National Fatality Review-Case Reporting System to collect data from such reviews.

As in other jurisdictions with large populations, the specific process and associated legislative basis of mortality reporting varies by state. Seventy-one percent of states mandate a state CDR programme, 18% permit CDR based on legislation or administrative rule, 35% of states mandate local CDR teams, and 27% permit local CDR teams. All reviews conducted at state level are retrospective and/or periodic.

Case selection and the data reviewed vary by state as well. However, reviews exist across all 50 states relating to deaths as a result of sudden and unexplained infant death; unintentional injuries; suicide; homicide; and abuse and neglect, as well as the deaths of children who were wards of the state or had a history with Child Protective Services. Local and state reviews also contribute to thematic reviews, which include Fetal and Infant Mortality Reviews, Suicide Fatality Reviews, and other child abuse and neglect reviews. In an effort to improve injury prevention, some states and local bodies also review serious injuries and near fatalities (27% review at state level, and 17% review at local level).

The vast and varied approach in the USA provides useful examples of thematic registries, including the Sudden Unexpected Infant Death Case Registry, which is similar to the National Sudden Infant Death Register previously established in Ireland. Additionally, the inclusion of near fatalities and serious injuries provides impactful information that aligns with the goal of improved survivorship in the paediatric population.

CHILD DEATH REVIEW PROCESS

Child death review groups are a feature of all countries we reviewed, although their structure varies by region and their function is manifold.

The following is a summary of notable findings:

1. Child death review groups provide a centralised body to which to report child death. Presently, the NCMD in England is the only body with a statutory basis that requires mandatory input reporting (i.e. there is a legal obligation to report to a child death review group).
2. Concurrently or independently, depending on the legislative basis, child death review groups provide a centralised body that is responsible for the collection of mortality data. This exemplifies the 'meitheal' approach, allowing for coordinated, multi-agency input. From this perspective, there is a statutory obligation on child death review groups to gather this information, as distinct from a legal obligation to report to it. A useful example of this is seen in New Zealand, where the CYMRC is a statutory body accountable to the Health Quality & Safety Commission; it must collect, analyse and report data from multiple sources in order to fulfil its legal requirements.
3. Child death review groups develop special areas of interest. For example, the USA has state-level registries that focus on deaths as a result of sudden and unexplained infant death, suicide, and unintentional injury.

SUMMARY OF FINDINGS

A summary of the processes for reporting child deaths in the selected countries is provided in table 5.1. This review of international practice provides valuable insight to the functionality of a centralised body with a statutory basis for reporting key data relating to child deaths. The approach in most cases is reporting of a standardised data set (including e.g., ethnicity, social deprivation) to a statutory body. Where reporting is not mandatory, collection from multiple sources is used to report to a statutory committee. Official death registration in all countries occurs between 3-7days with the exception of the US where it varies by state.

To maintain a single national epidemiological database of information on all paediatric deaths from multiple sources, analyse data and report trends in rates and factors impacting on child mortality, Ireland must evolve to meet international standards.

KEY FINDINGS OF INTERNATIONAL APPROACHES TO CHILD MORTALITY DATABASES INCLUDE THE FOLLOWING:

- The presence of a centralised body with a statutory basis that is tasked with reporting key data relating to child deaths.
- Mandatory reporting of a standardised dataset (including, for example, ethnicity and/or level of social deprivation) to that statutory body.
- The inclusion of all child deaths (i.e. those aged 0–18 years, and up to 26 years where they are in the care of a government agency as considered the UN Convention on the Rights of the Child).
- The development of thematic registries (e.g. specifically relating to deaths due to sudden infant death, suicide, or major injury).
- Additional review of near fatalities and severe injury; the deaths of children in the care of a government agency; and the deaths of children subject to maltreatment (where suitable, and relating to the review of data as distinct from the use of a registry alone).

TABLE 5.1: SUMMARY OF INTERNATIONAL PRACTICE

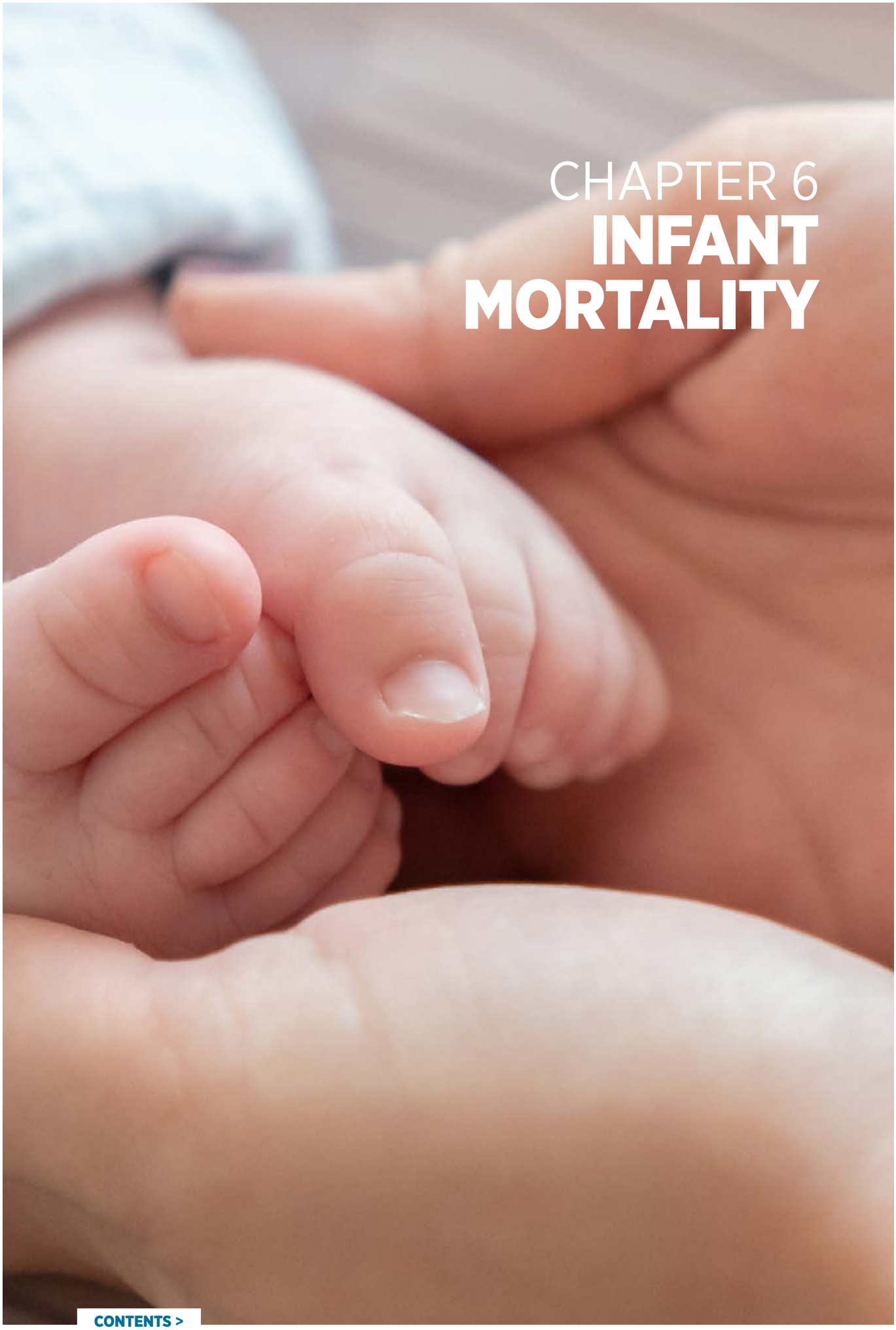
England, UK						
Years included	**Ages included**	**Key data sources**	**Key data points**	**Death registration**	**Legal basis**	**Mandatory reporting**
From 1 April 2019 (as well as for children who died prior to that date where their child death review was still ongoing).	0–18 years	Child Death Overview Panels	• Number of deaths • Mortality rate • Demographics (age group and sex; social deprivation; ethnic group) • Place of death • Gestational age • Category of death • Modifiable factors • Perinatal/neonatal events • Duration of reviews • Disease-specific information	Registered by family within 5 days of death.	Health and Care Act 2022.	Yes.

New Zealand						
Years included	**Ages included**	**Key data sources**	**Key data points**	**Death registration**	**Legal basis**	**Mandatory reporting**
Retrospective collection from 1939 to 1999; concurrent collection from 2002 onwards (15 data reports produced to date).	28 days to 24 years	Department of Internal Affairs; the Ministry Health; the Ministry of Justice; the Ministry of Education; the Ministry of Transport; Oranga Tamariki (the Ministry for Children); coroners; Water Safety New Zealand; and local child and youth mortality review groups.	• Number of deaths • Demographics • Categories of death	Registered by the funeral director within 3 days of burial or cremation.	Pae Ora (Healthy Futures) Act 2022 (the Act): the CYMRC may appoint mortality review committees to carry out any of the functions specified in Section 82(1) of the Act.	The CYMRC is a statutory body accountable to the Health Quality & Safety Commission. However, it collects data from multiple sources as distinct from direct/mandatory reporting to the CYMRC.

TABLE 5.1: SUMMARY OF INTERNATIONAL PRACTICE *CONTINUED*

NSW, Australia						
Years included	**Ages included**	**Key data sources**	**Key data points**	**Death registration**	**Legal basis**	**Mandatory reporting**
2003 to present	0–17 years	Australian Bureau of Statistics, as well as government and non-government agencies and service providers, including NSW Health; the NSW Department of Education; the NSW Department of Communities and Justice; the NSW Police; and the coroner.	• Number of deaths • Demographics (including ethnicity and socioeconomic status) • Cause of death	Registered by the funeral director within 7 days of burial or cremation.	Statutory child death review responsibilities under the Community Services (Complaints, Reviews and Monitoring) Act 1993 (CS CRAMA). Analysis of the deaths of all children in NSW for the NSW Child Death Review Team: Under Part 5A of CS CRAMA, the Child Death Review Team has to maintain a register of child deaths occurring in NSW, classify those deaths, and undertake research to help prevent or reduce the likelihood of child deaths.	Yes, insofar as the NSW Ombudsman is notified of the deaths of all children aged 0–17 years in NSW by the NSW Registry of Births, Deaths and Marriages. However, the onus is on the Child Death Review Team to glean further information and report same.

USA						
Years included	**Ages included**	**Key data sources**	**Key data points**	**Death registration**	**Legal basis**	**Mandatory reporting**
Varies by state	Varies by state	CDR programmes in all 50 states, the District of Columbia, Guam, and the Navajo Nation. Forty-four states use the National Fatality Review-Case Reporting System to collect data from CDR cases.	Selection of cases to be reviewed varies by state. Throughout the USA, there are state-level teams that review deaths as a result of sudden and unexplained infant death; unintentional injuries; suicide; homicide; and abuse and neglect, as well as the deaths of children who were wards of the state or had a history with Child Protective Services.	Varies by state	Varies by state: 71% of states mandate a state CDR programme, 18% of states permit CDR based on legislation or administrative rule, 35% of states mandate local CDR teams, and 27% of states permit local CDR teams.	Not at federal level; however, 71% of states have a mandated CDR programme.



CHAPTER 6
INFANT MORTALITY

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CHAPTER 6: **INFANT MORTALITY**

BACKGROUND

The WHO defines infant mortality rate 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 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.

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 impacting on infant mortality include maternal health, quality of and access to medical care, socioeconomic conditions, and public health practices. Globally, the infant mortality rate has 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 has declined from 8.7 million in 1990 to 4.0 million in 2018 (WHO, 2023). Data presented in this chapter are derived from CSO death registration information.

ANNUAL TRENDS IN INFANT MORTALITY IN IRELAND

The examination of IMRs in Ireland has demonstrated a gradual and consistent downward trend over time, with deaths decreasing from 8.2 per 1,000 live births in 1990 to a low of 2.8 per 1,000 live births in 2019 (see Figure 6.1). The IMR in Ireland is currently one of the lowest worldwide, with the most recent available estimate being 3.1 deaths per 1,000 live births for 2021. This rate is almost half of the rates recorded for the early 2000s, and is 58% lower than the high IMRs reported in Ireland in the late 1990s.

The decline in overall IMRs is reflected in a similar pattern of decline in both neonatal and postneonatal mortality, although mortality rates in the neonatal age group are consistently higher than those in the postneonatal age group. The postneonatal mortality rate has seen a greater reduction than the neonatal mortality rate, due largely to the decline in the incidence of SIDS deaths. The postneonatal mortality rate recorded for 2021 is the lowest recorded for the period 1990–2021, and has stabilised between 2015 and 2021, fluctuating between 0.7 and 0.8 deaths per 1,000 live births.

The raw data behind all figures are provided in corresponding frequency tables in Appendix 3.

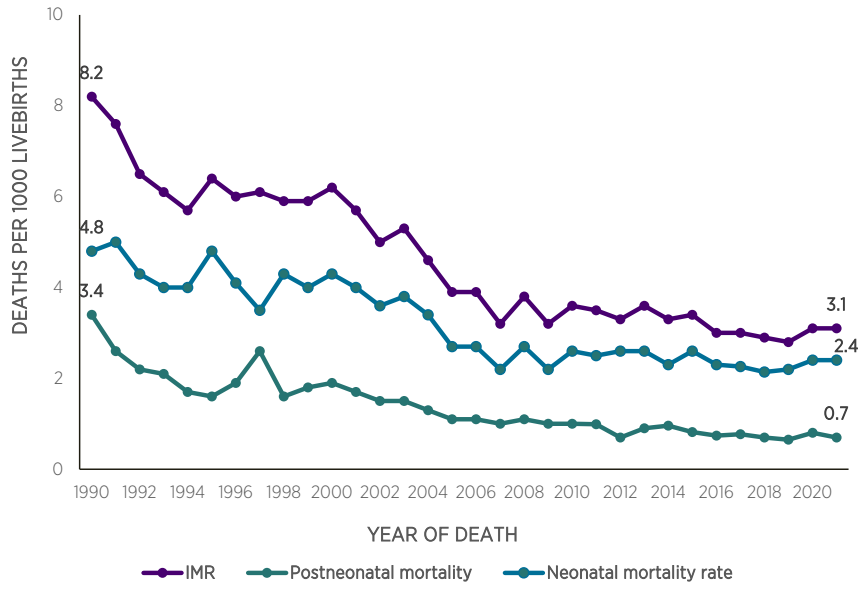

FIGURE 6.1: ANNUAL TRENDS IN INFANT, POSTNEONATAL AND NEONATAL MORTALITY RATES IN IRELAND, 1990–2021

COMPARISON WITH INTERNATIONAL RATES

The most recent available IMRs reported for various European Union (EU) countries and the UK (for the year 2019) are outlined in Figure 6.2. The IMR in Ireland is lower than the EU average of 3.4, but is higher than that in many EU countries, including Sweden (2.2 deaths per 1,000 live births), Finland (2.1 deaths per 1,000 live births), Estonia (1.5 deaths per 1,000 live births) and Iceland (0.9 deaths per 1,000 live births). Data on EU IMRs were obtained online from the Eurostat Data Browser, available at https://ec.europa.eu/eurostat/databrowser/view/HLTH_CD_AINFO__custom_4790448/default/table?lang=en. 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 (Eurostat, 2023).

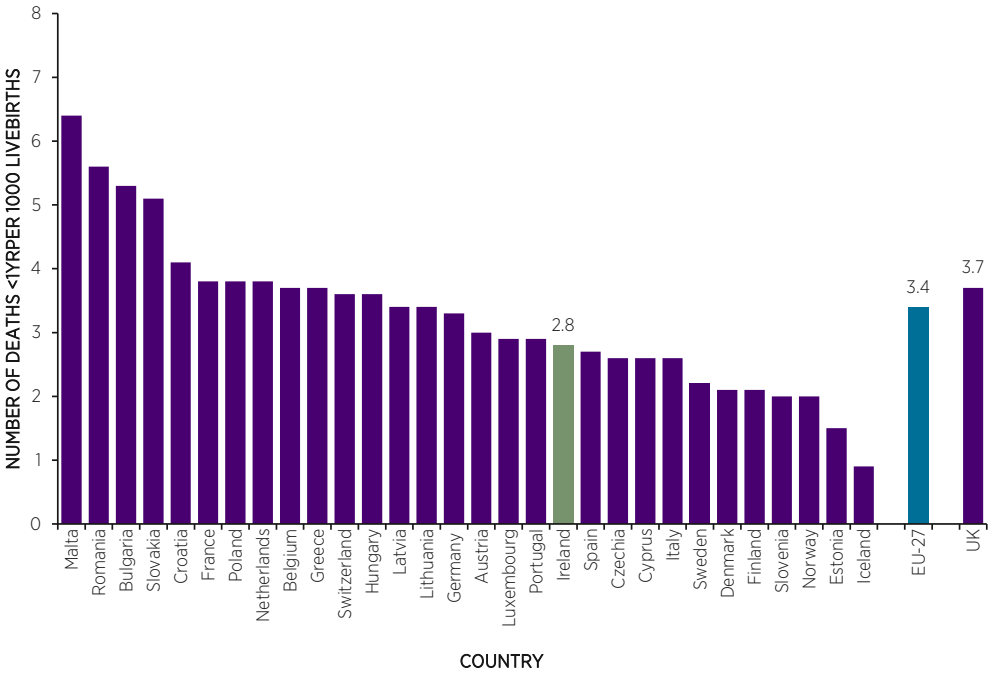

FIGURE 6.2: INFANT MORTALITY RATES IN EUROPEAN UNION COUNTRIES AND THE UNITED KINGDOM, 2019

INFANT, POSTNEONATAL AND NEONATAL MORTALITY RATES IN IRELAND, 2019–2021

Table 6.1 provides the number of deaths registered with the GRO in Ireland for the period 2019–2021, alongside adjusted figures based on the year in which the deaths occurred as reported by the CSO. The number of late registrations for the population aged 0–18 years is provided in Table 6.2. Year of occurrence data are used to calculate accurate infant, neonatal and postneonatal mortality rates per 1,000 live births during the same period. These data indicate an increase in the overall number of deaths and in the infant, neonatal and postneonatal mortality rates in 2020 and 2021 in comparison with 2019. Neonatal deaths accounted for 76.5% of all infant deaths during this 3-year period.

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 from the 3-year registration period are used to provide estimates of those variables.

TABLE 6.1: NUMBER AND RATE OF INFANT, POSTNEONATAL AND NEONATAL DEATHS IN IRELAND, BY YEAR OF DEATH AND YEAR OF REGISTRATION, 2019–2021.

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 <29 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)**	**Postneonatal mortality rate (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	58 443	199	154	45	3.4	2.6	0.77
2019–2021	174 549	542	408	134	3.1	2.3	0.75
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 <29 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)**	**Postneonatal mortality rate (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	58 443	180	140	40	3.1	2.4	0.68
2019–2021	174 549	525	402	123	3.1	2.3	0.71

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

TABLE 6.2: NUMBER OF REGISTERED DEATHS AND LATE REGISTRATIONS IN IRELAND, 2019–2021

Year	Total deaths registered	Late registrations*	
	N	N	%
2019	311	106	34%
2020	268	89	33%
2021	314	138	44%

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

AGE AND SEX DISTRIBUTION OF INFANT DEATHS, 2019–2021

The age and sex distribution of all deaths in children aged under 1 year in Ireland during the period 2019–2021 is outlined in Figures 6.3 and 6.4. Every year, the majority of infant deaths occur during the neonatal period, and during the period 2019–2021, neonatal deaths accounted for 75.3% of all infant deaths.

As in previous years, the distribution of deaths in 2019, 2020 and 2021 according to sex showed a slight male predominance, although this was less evident in 2020 and 2021 than in 2019. The average distribution of deaths according to sex for the 3-year period (2019–2021) was 52% male versus 48% female. This higher death rate for male infants has been evident each year during the reporting period for all age groups (Figures 6.4 and 6.5).

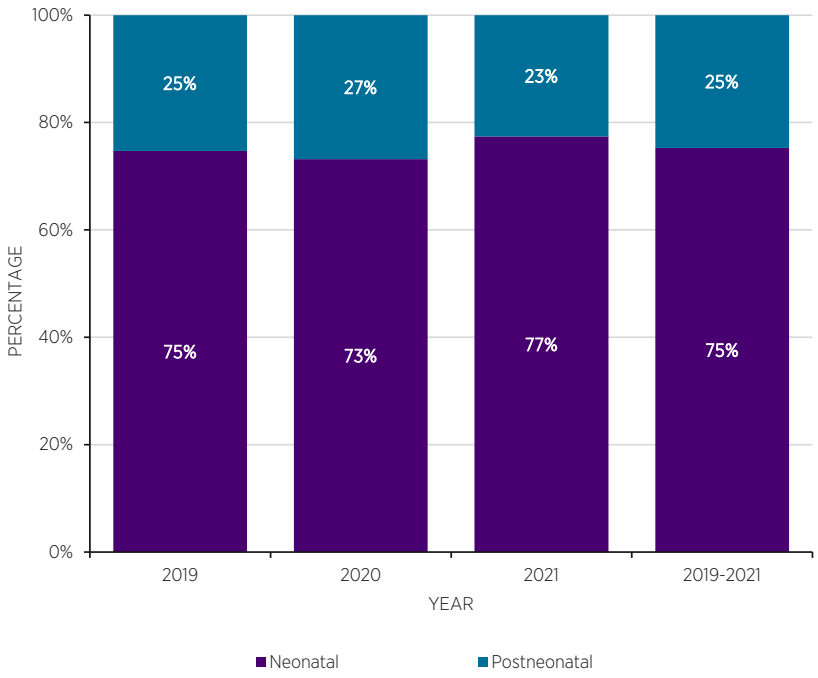

FIGURE 6.3: AGE DISTRIBUTION OF INFANT DEATHS REGISTERED IN IRELAND, 2019–2021 (n=542)

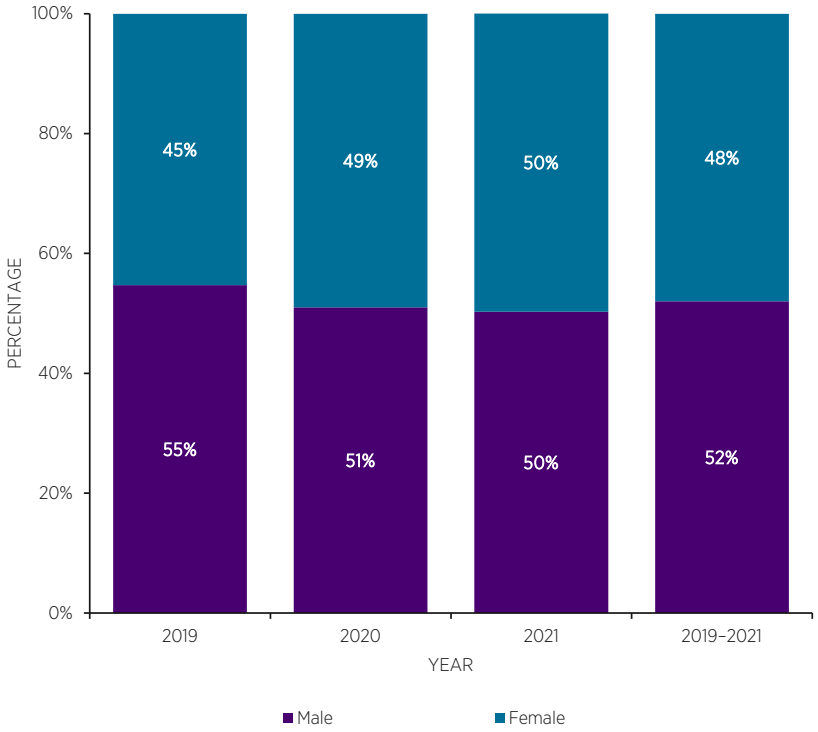

FIGURE 6.4: SEX DISTRIBUTION OF INFANT DEATHS REGISTERED IN IRELAND, 2019–2021 (N=542)

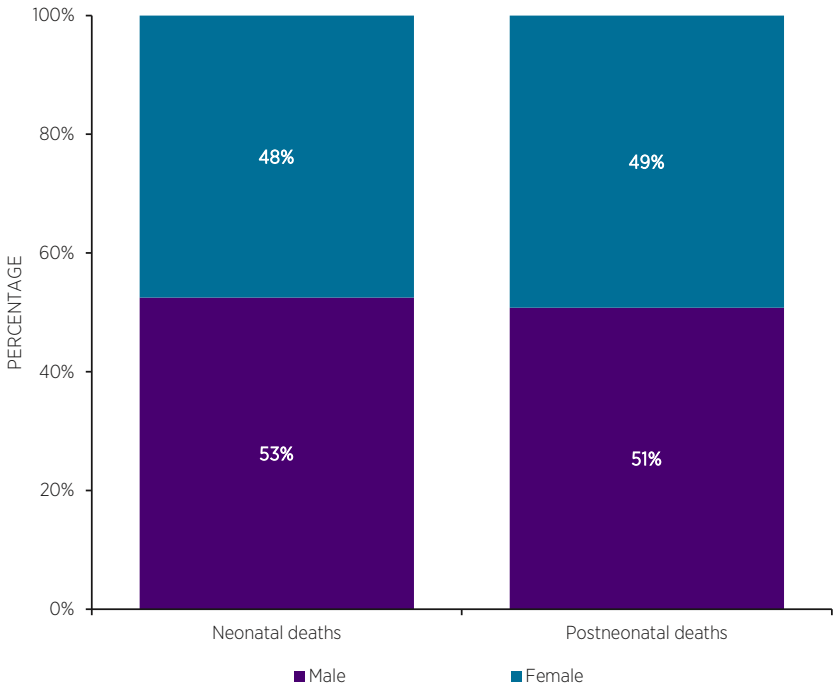

FIGURE 6.5: SEX DISTRIBUTION OF INFANT DEATHS REGISTERED IN IRELAND, BY AGE GROUP, 2019–2021 (N=542)

PLACE OF DEATH, 2019–2021

The vast majority of infant deaths (92.6%) occurred in a hospital (see Figure 6.6). A higher proportion of infant deaths occurred in Children's Health Ireland (CHI) units than in general hospitals, due to both the higher population in the Dublin area than in the rest of Ireland, as well as the transfer of cases requiring critical care to specialist units in CHI hospitals (NOCA, 2023).

Most infant deaths (i.e. deaths among children aged under 1 year) that occurred at home were due to SIDS. In the period 2019–2021, 49% of SIDS cases occurred at home and 35% were registered as occurring in CHI units; the latter cases were likely pronounced in the emergency departments (EDs) of the CHI hospitals, with the patients having been brought in deceased by ambulance (see Table 6.3).

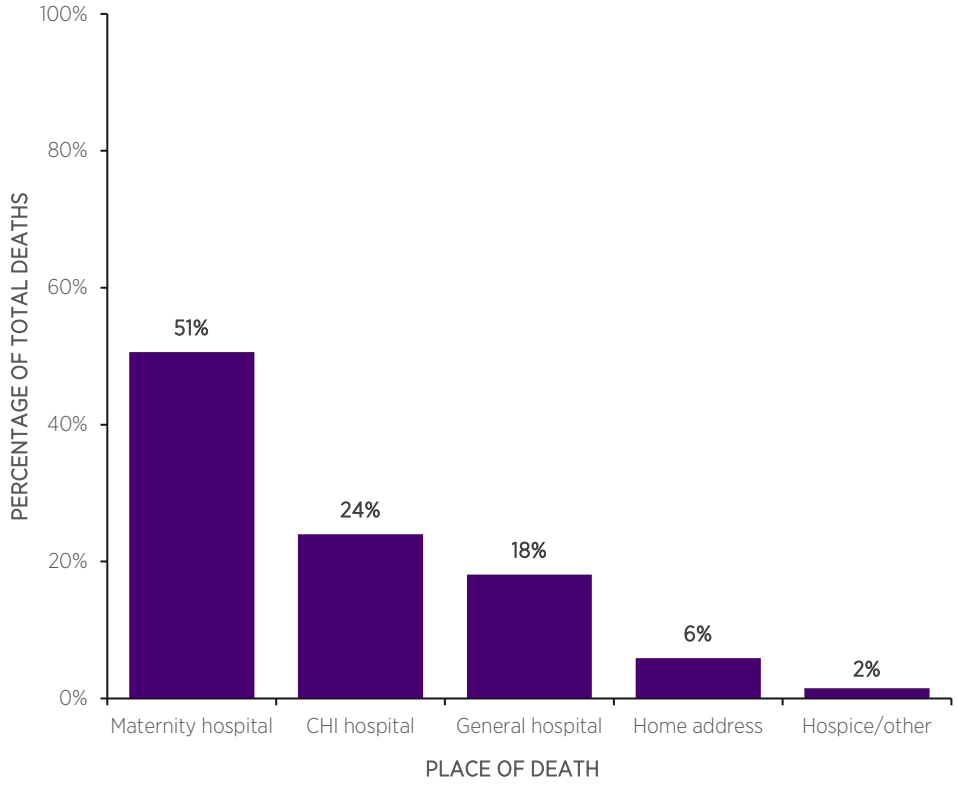

FIGURE 6.6: INFANT MORTALITY IN IRELAND BY PLACE OF DEATH, 2019–2021 (N=542)

TABLE 6.3: PLACE OF DEATH OF INFANTS REGISTERED AS SUDDEN UNEXPLAINED DEATHS IN INFANCY AND CHILDHOOD, 2019–2021

Place of death	n	%
CHI unit	13	35%
General or maternity hospital	6	16%
At home or other address	18	49%
Total	37	100%

OCCURRENCE OF DEATHS BY YEARLY QUARTER

Figure 6.7 depicts the proportion of infant deaths in Ireland by quarter during the period 2019–2021. This data showed a lot of variation in the number of deaths with no distinct pattern evident.

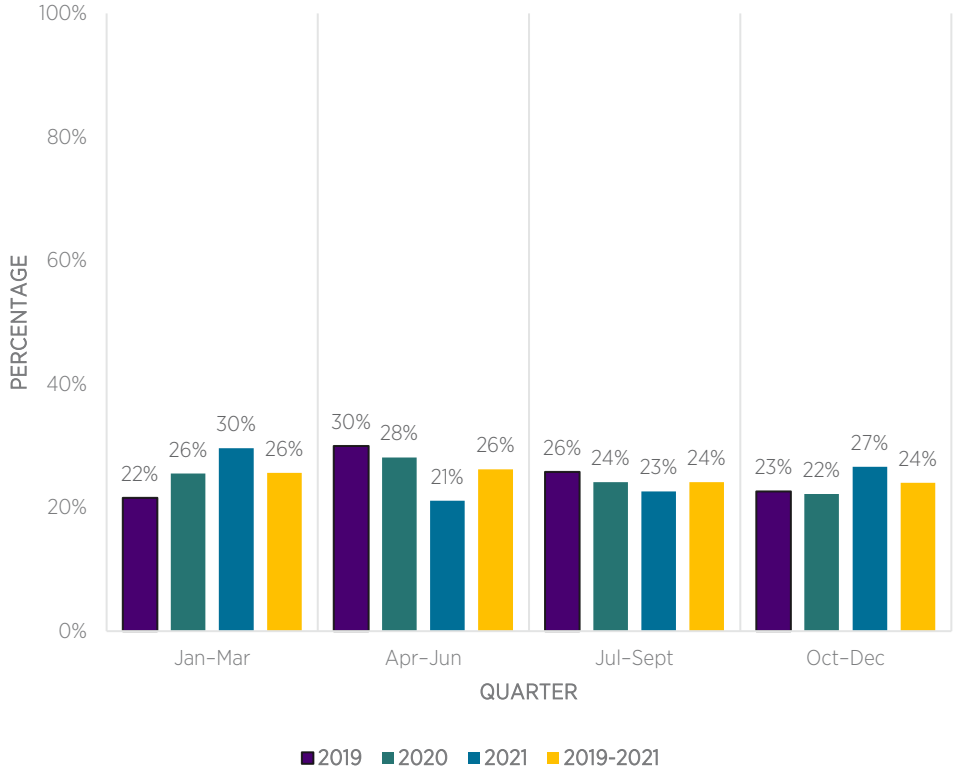

FIGURE 6.7: INFANT MORTALITY IN IRELAND BY YEARLY QUARTER, 2019–2021 (N=542)

PRINCIPAL CAUSES OF INFANT MORTALITY IN IRELAND, 2019–2021

The principal causes of infant mortality in Ireland during the period 2019–2021 (grouped according to the International Classification of Diseases, Tenth Revision (ICD-10) classification) are given for both neonatal and postneonatal age groups in Table 6.4. The considerable difference between the neonatal and postneonatal mortality rates, with more than three times the number of neonatal deaths as postneonatal deaths, is due to the large number of babies with congenital malformations and chromosomal abnormalities and with perinatal problems who die during the first 4 weeks of life.

The greatest percentage of neonatal deaths that occurred during the period 2019–2021 (54.9%; n=224) was attributable to conditions arising in the perinatal period. The majority of these conditions were due to extreme prematurity, but causes of death also included necrotising enterocolitis, sepsis, and hypoxic ischaemic encephalopathy. After perinatal conditions, the second most common cause of neonatal deaths was congenital malformations and chromosomal abnormalities, which accounted for 40% of deaths (n=163).

Of the remaining neonatal deaths that occurred during the period 2019–2021, 1.2% were registered as being due to SIDS or an unexplained cause. Conversely, SIDS accounts for a much greater proportion of deaths in the postneonatal age group, and, prior to 2005, was the single leading cause of death in this age group (McGarvey *et al.,* 2016). However, as the number of SIDS deaths has declined, there has also been a decline in the percentage of postneonatal deaths attributed to SIDS, and congenital malformations and chromosomal abnormalities are now the leading cause of death in this age group.

Congenital malformations and chromosomal abnormalities accounted for 40% of postneonatal deaths (n=55) during the period 2019–2021. The second largest category of deaths in the postneonatal age group was deaths due to SIDS or an unexplained cause, the majority (31/37) of which were categorised as SIDS with ICD-10 code R95 or R959. SIDS and unexplained causes of death now account for less than one-quarter of all postneonatal deaths, with another 18.7% of postneonatal deaths being due to perinatal conditions.

Together, these three cause of death categories accounted for 81.8% of all postneonatal deaths registered in Ireland during the period 2019–2021. Disorders of the circulatory and nervous systems accounted for 4.5% and 5.2% of postneonatal deaths, respectively, with all other causes accounting for 7.5%. These data are outlined in Table 6.4.

TABLE 6.4: CAUSE OF DEATH CATEGORISATION OF NEONATAL AND POSTNEONATAL DEATHS REGISTERED IN IRELAND, 2019–2021 (N=542)

NEONATAL AGE GROUP			
Rank	**Cause of death category**	**n**	**%**
1	Perinatal conditions	224	54.9%
2	Congenital malformations and chromosomal abnormalities	163	40.0%
3	SIDS and undetermined/unexplained cause of death	5	1.2%
	All other causes	16	3.9%
	Total	408	100.0%
POSTNEONATAL AGE GROUP			
Rank	**Cause of death category**	**n**	**%**
1	Congenital malformations and chromosomal abnormalities	55	40.0%
2	SIDS and undetermined/unexplained cause of death	31	23.1%
3	Perinatal conditions	25	18.7%
4	Disorders of the nervous system	7	5.2%
5	Disorders of the circulatory system	6	4.5%
	All other causes	10	7.5%
	Total	134	100.0%

SUMMARY OF FINDINGS

The data outlined in this chapter provide estimates of the age and sex distribution of infant mortality in Ireland along with the main causes of infant death for the period 2019–2021. The data shows that while overall infant mortality in Ireland is below the EU average, there is still room for improvement.

Timely and more detailed information is required to provide an accurate account and review of infant mortality in order to inform policy aimed at reducing the number of deaths. There are limitations to the available data presented in this chapter, mainly an inability to report accurate mortality estimates based on year of occurrence and a lack of detail to permit detailed descriptions of the main causes of death. Hence NOCA 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 of 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. Information on date of death was not available in this dataset; hence, more detailed analysis of key variables, such as the day of the week of a death was not possible. This detail is important when reviewing many categories of CYP deaths including SIDS and other sudden unexpected deaths (Mooney *et al*., 2004). It is also an important variable to consider when reviewing in-hospital deaths. Death registration information also does not document the location within a hospital in which a child dies, which is more informative for service planning. The proposed NPMR Child Death Notification form will provide more information on the precise location within a hospital where a death occurs, and will also permit a more detailed and informative analysis of CYP deaths than is currently possible.

CHAPTER 7

MORTALITY IN CHILDREN AND YOUNG PEOPLE

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CHAPTER 7: 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: older 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.

CHILD MORTALITY IN IRELAND DURING THE PERIOD 2019–2021: AGE AND SEX DISTRIBUTION

The age distribution of child deaths registered in 2019, 2020 and 2021 is outlined in Table 7.1. The average estimates for this 3-year 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 2019–2021 was 350. Figures for infant deaths are included in Table 7.1 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 in children aged under 5 years, due to the large number of deaths that occur during infancy. Numbers of deaths then drop substantially for children aged 5–14 years, and then increase again among adolescents aged 15–18 years. This pattern was evident for each of the three years examined.

TABLE 7.1: NUMBER AND PERCENTAGE OF CHILD DEATHS REGISTERED IN IRELAND, 2019–2021 (N=892)

NUMBER OF DEATHS REGISTERED												
Year	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	199	63.4%	19	6.1%	19	6.4%	22	7.0%	54	17.2%	313	100.0%
2019–2021	542	60.7%	75	8.4%	67	7.6%	66	7.4%	142	16.0%	892	100.0%

The sex distribution of deaths in children aged 1–18 years by year and gender is shown in Figures 7.1 and 7.2. The larger proportion of deaths among males is more evident in these older age groups than for infant deaths (those aged under 1 year). This is a consequence of the higher proportion of deaths attributable to external causes in older children.

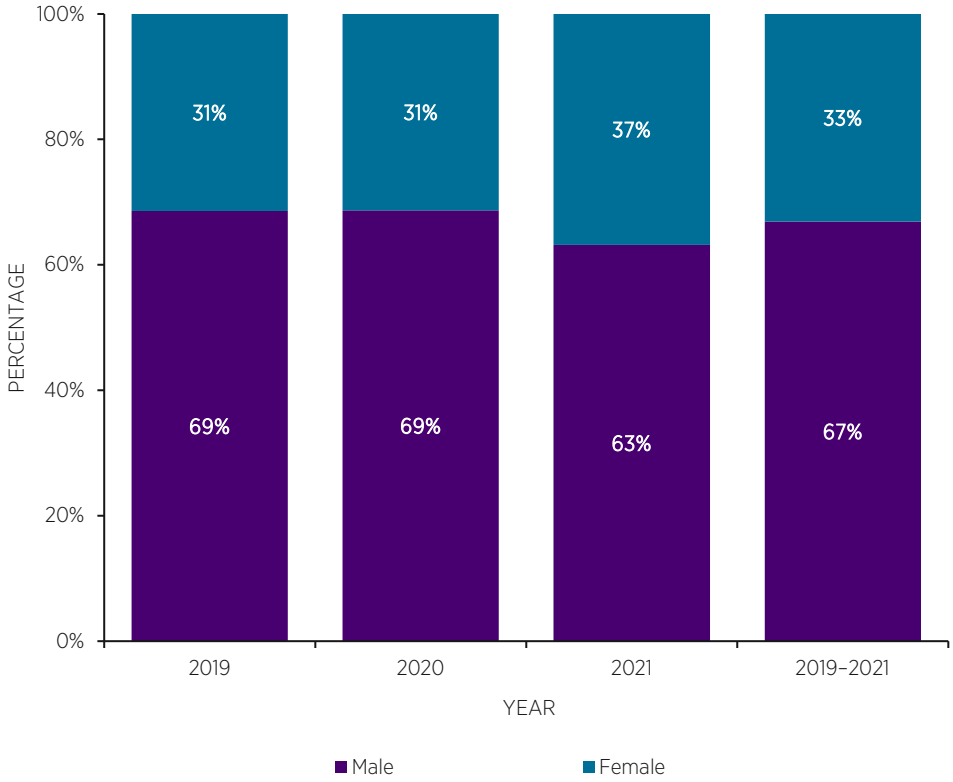


FIGURE 7.1: SEX DISTRIBUTION OF DEATHS AMONG CHILDREN AGED 1–18 YEARS IN IRELAND, 2019–2021 (n=350)

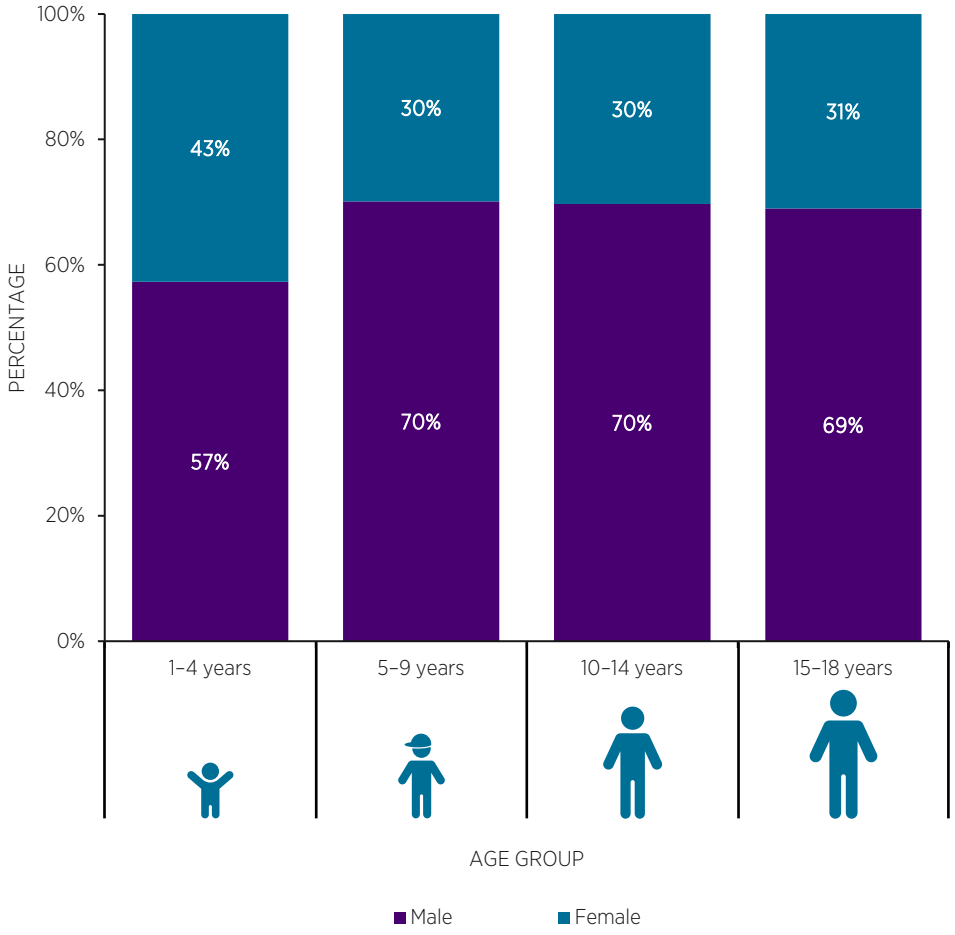


FIGURE 7.2: SEX DISTRIBUTION OF CHILD DEATHS, BY AGE GROUP, 2019–2021 (n=350)

PLACE OF DEATH, 2019–2021

As with infant deaths (i.e. those aged under 1 year), the greatest proportion (66.3%) of child deaths (i.e. those aged 1–14 years) occurred in hospital; this figure was lower than the 92.7% of deaths occurring in hospital reported for the infant population. Twenty-six percent of deaths in this older age group occurred at home, in comparison with just 6% of infant deaths. This proportion increased even further in the 15–18 year age group, in which almost one-half (48.6%) of all deaths occurred at home.

The increased 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 5.3% of deaths in children aged 1–14 years and 12.7% of deaths in adolescents aged 15–18 years occurred at the scene of an injury during the period 2019–2021 (Figure 7.3). A small number of deaths in both age groups occurred in hospices and care homes, although the exact proportion of each is not reported due to small numbers and the associated disclosure risk.

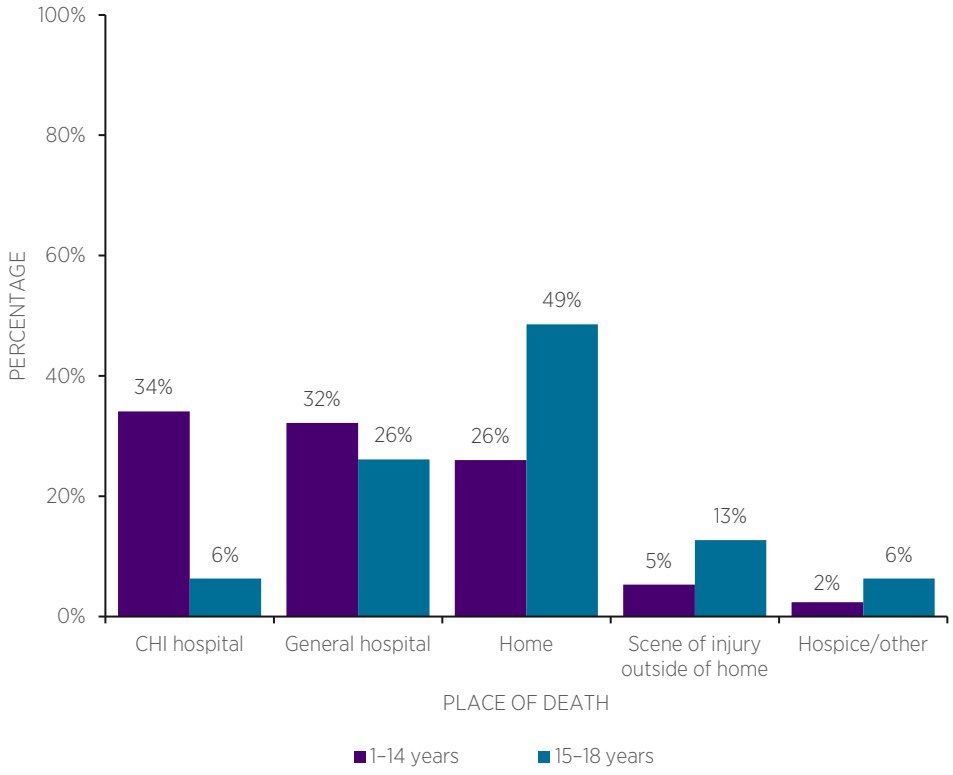


FIGURE 7.3: PLACE OF DEATH OF CHILD DEATHS, BY AGE GROUP, 2019–2021 (n=350)

CYP DEATHS BY YEARLY QUARTER OF OCCURRENCE

The distribution of deaths by annual quarter demonstrated a similar pattern for both age groups (i.e. aged 1–14 years and 15–18 years), with the highest number of deaths occurring in the first and second quarter of the year and the lowest number occurring in the fourth quarter.

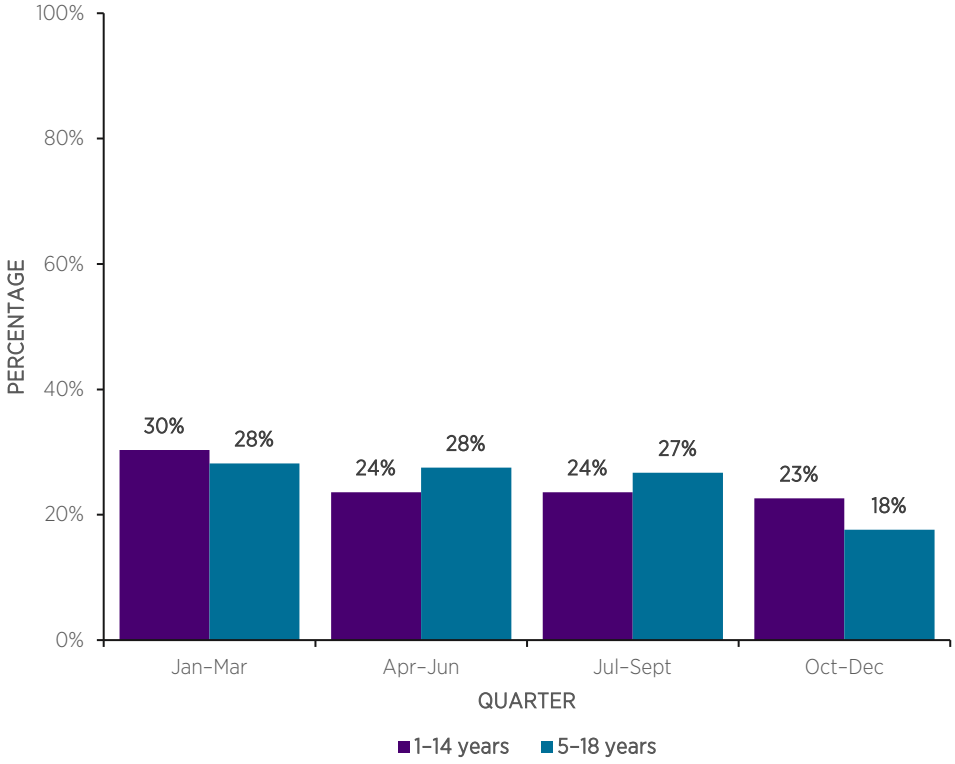


FIGURE 7.4: OCCURRENCE OF CHILD DEATHS BY ANNUAL QUARTER, BY AGE GROUP, 2019–2021 (n=350)

ANNUAL TRENDS IN CYP MORTALITY RATES IN IRELAND

The annual trends in Ireland's child mortality rates for the period 2007–2021 are illustrated in Figure 7.5. These CSO data are presented in the format of 3-year average rates in order to eliminate random variation. This 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 50% in mortality rates in all age groups since 2007, with the exception of children aged 5–9 years. The overall percentage decline in this age group was 8.1% between 2007 and 2021, in comparison with 59.4%, 57.0% and 56.4% declines in the mortality rates of children aged 1–4 years, 10–14 years and 15–19 years, respectively (CSO data provided as 15–19 years).

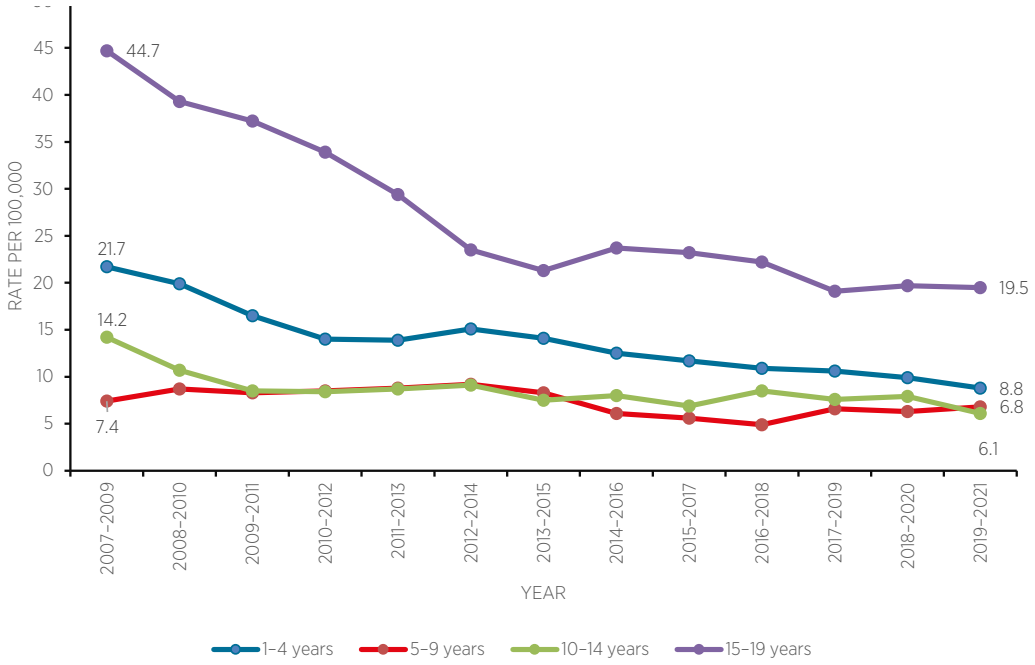


FIGURE 7.5: ANNUAL TRENDS IN CHILD MORTALITY RATES IN IRELAND, BY AGE GROUP, 2007–2021 (3-YEAR MOVING AVERAGE RATES)

Note: This figure is based on year of occurrence data retrieved from the CSO online database (Central Statistics Office). This dataset provides age grouping for 15–19 years.

PRINCIPAL CAUSES OF CYP DEATHS IN 2019–2021, AS CATEGORISED BY ICD-10 CODING

The main contributory causes of childhood death as assigned by the CSO according to ICD-10 classification are outlined in Table 7.2 and in Figures 7.6A to 7.7B, inclusive. Post-infancy, the leading cause of childhood death is external causes of accident and injury, which accounted for more than one-fifth of deaths in children aged 1–14 years and more than one-half of all deaths in the adolescent age group during the 2019–2021 period (Figures 7.6A and 7.7A).

Neoplasms were the second leading cause of death in both age groups. In the adolescent age group (i.e. those aged 15–18 years), external causes and neoplasms together accounted for 73% of all deaths, while diseases of the circulatory and nervous systems and congenital malformations and chromosomal abnormalities each accounted for 5.6% of deaths. This pattern is similar to that observed in the period 2012–2018 (Figure 7.7B).

Other important causes of death among children aged 1–14 years were congenital malformations and chromosomal abnormalities (18.3%), diseases of the nervous system (10.1%) and diseases of the circulatory system (8.2%). A small proportion (2.4%) of deaths among children aged 1–14 years were categorised as unexplained and fell under the classification of 'symptoms, signs and abnormal clinical findings'. There is a need for more detailed classification data in order to allow a more granular analysis of cause of death.

Analysis of mortality data relating to children aged 1–14 years in 2019–2021 showed some slight variation when compared with data reported in previous years (2007–2018), although the four leading causes of death remained the same during these two time periods. Diseases of the circulatory system ranked fifth in 2019–2021 and accounted for 8.2% of all registered deaths during this period, in comparison with just 3.4% in the period 2007–2018. External causes remained the leading cause of death in this age group, but the overall proportion decreased from 27.3% in 2007–2018 to 21.6% in 2019–2021. The decline in the proportion of external-cause deaths has led to an increase in the overall proportion of deaths due to other causes, with a narrowing of the gap between the leading causes (Figure 7.6A and Figure 7.6B). The proportion of sudden unexplained deaths in this age group declined only slightly over the two time periods; from 2.9% to 2.4%.

TABLE 7.2: CAUSE OF DEATH CATEGORISATION OF DEATHS OF CHILDREN AND YOUNG PEOPLE REGISTERED IN IRELAND, 2019–2021 (n=350)

AGED 1–14 YEARS			
Rank	**Cause of death category**	**n**	**%**
1	External causes	45	21.6%
2	Neoplasms	41	19.7%
3	Congenital malformations and chromosomal abnormalities	38	18.3%
4	Diseases of the nervous system	21	10.1%
5	Diseases of the circulatory system	17	8.2%
6	Diseases of the respiratory system	11	5.3%
7	Infectious diseases	9	4.3%
8	Endocrine, nutritional and metabolic diseases	8	3.9%
9	Symptoms, signs and abnormal clinical findings	5	2.4%
10	Other	13	6.3%
AGED 15–18 YEARS			
Rank	**Cause of death category**	**n**	**%**
1	External causes	79	55.6%
2	Neoplasms	24	16.9%
3	Diseases of the circulatory system	8	5.6%
3	Diseases of the nervous system	8	5.6%
3	Congenital malformations and chromosomal abnormalities	8	5.6%
	All other causes	15	10.6%
	Total	142	100.0%

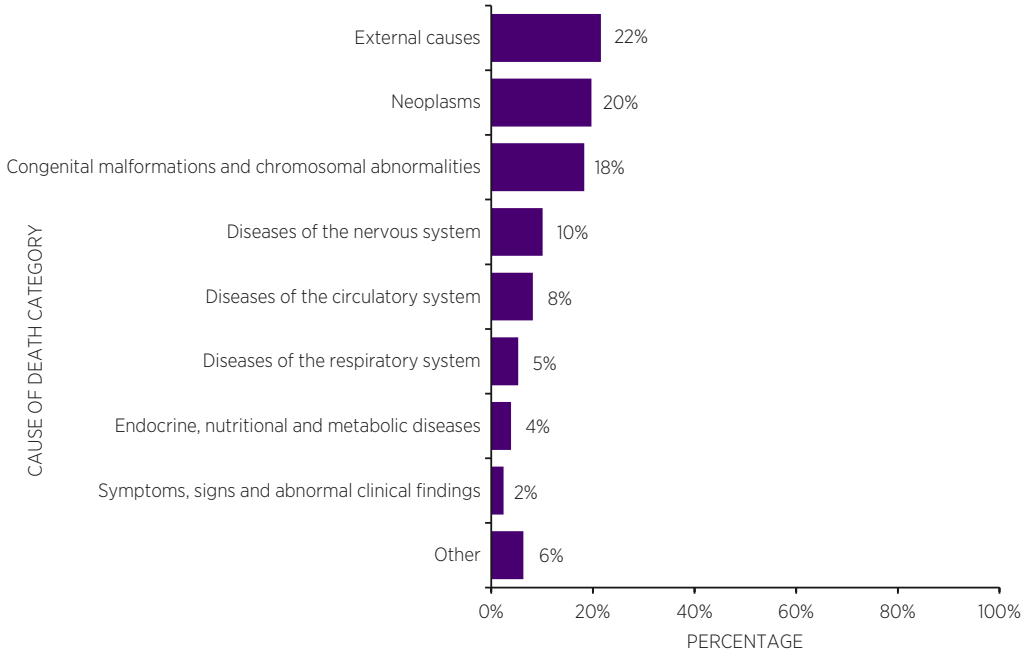


FIGURE 7.6A: PRINCIPAL CAUSE OF DEATH CATEGORIES IN CHILDREN AGED 1–14 YEARS, 2019–2021 (N=208)

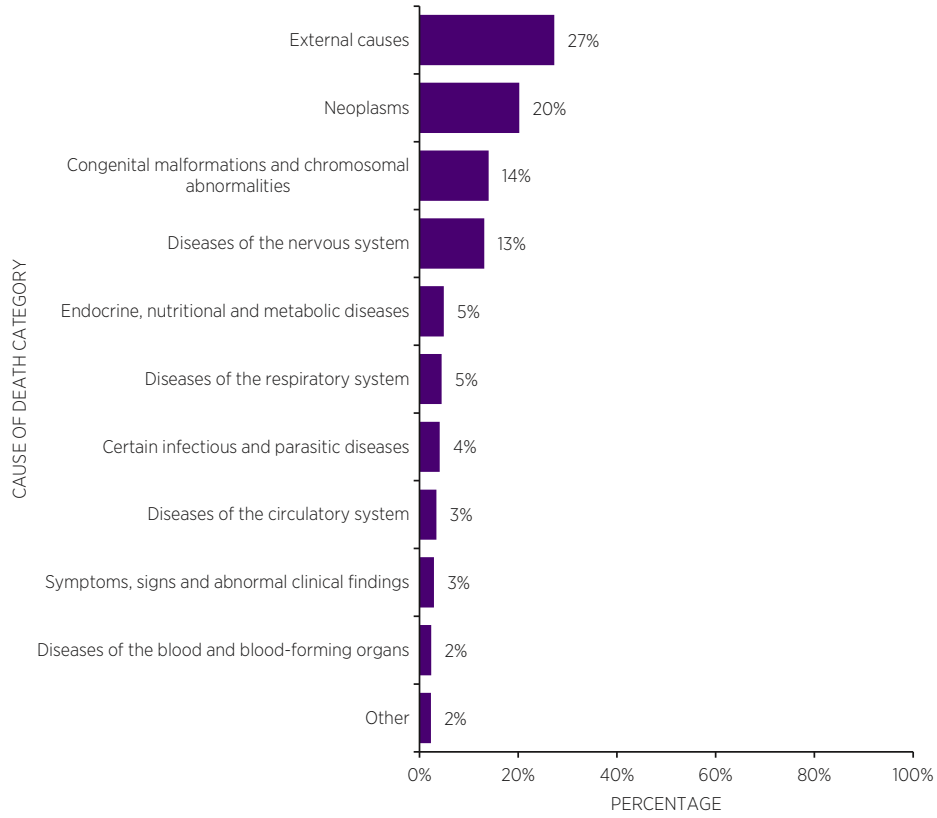


FIGURE 7.6B: PRINCIPAL CAUSE OF DEATH CATEGORIES IN CHILDREN AGED 1–14 YEARS, 2007–2018 (n=1124)

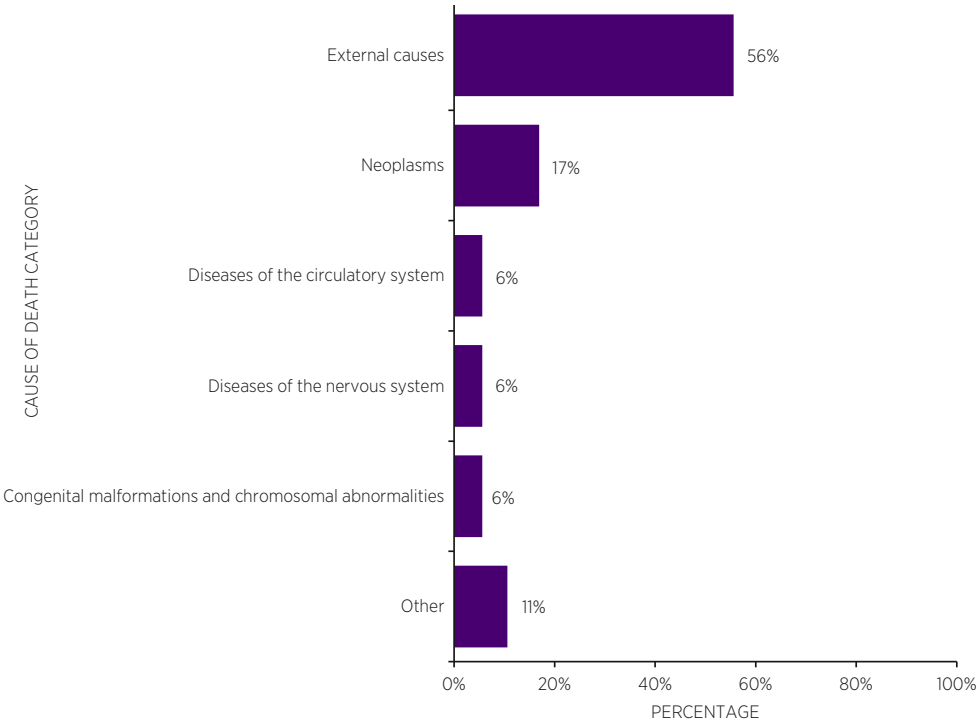


FIGURE 7.7A: PRINCIPAL CAUSE OF DEATH CATEGORIES IN ADOLESCENTS AGED 15–18 YEARS, 2019–2021 (n=142)

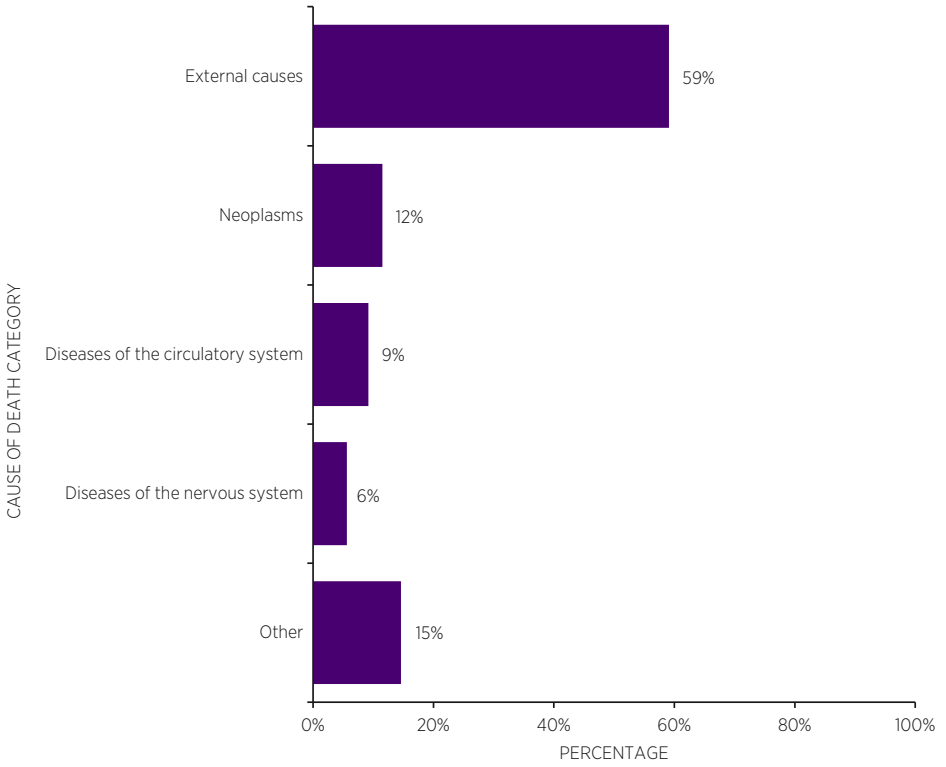


FIGURE 7.7B: PRINCIPAL CAUSE OF DEATH CATEGORIES IN ADOLESCENTS AGED 15–18 YEARS, 2012–2018 (n=425)

SUMMARY OF FINDINGS

Mortality in children post-infancy has declined by more than 50% across all age groups since 2007, with the exception of children aged 5–9 years, who had a lower baseline mortality rate than other age groups.

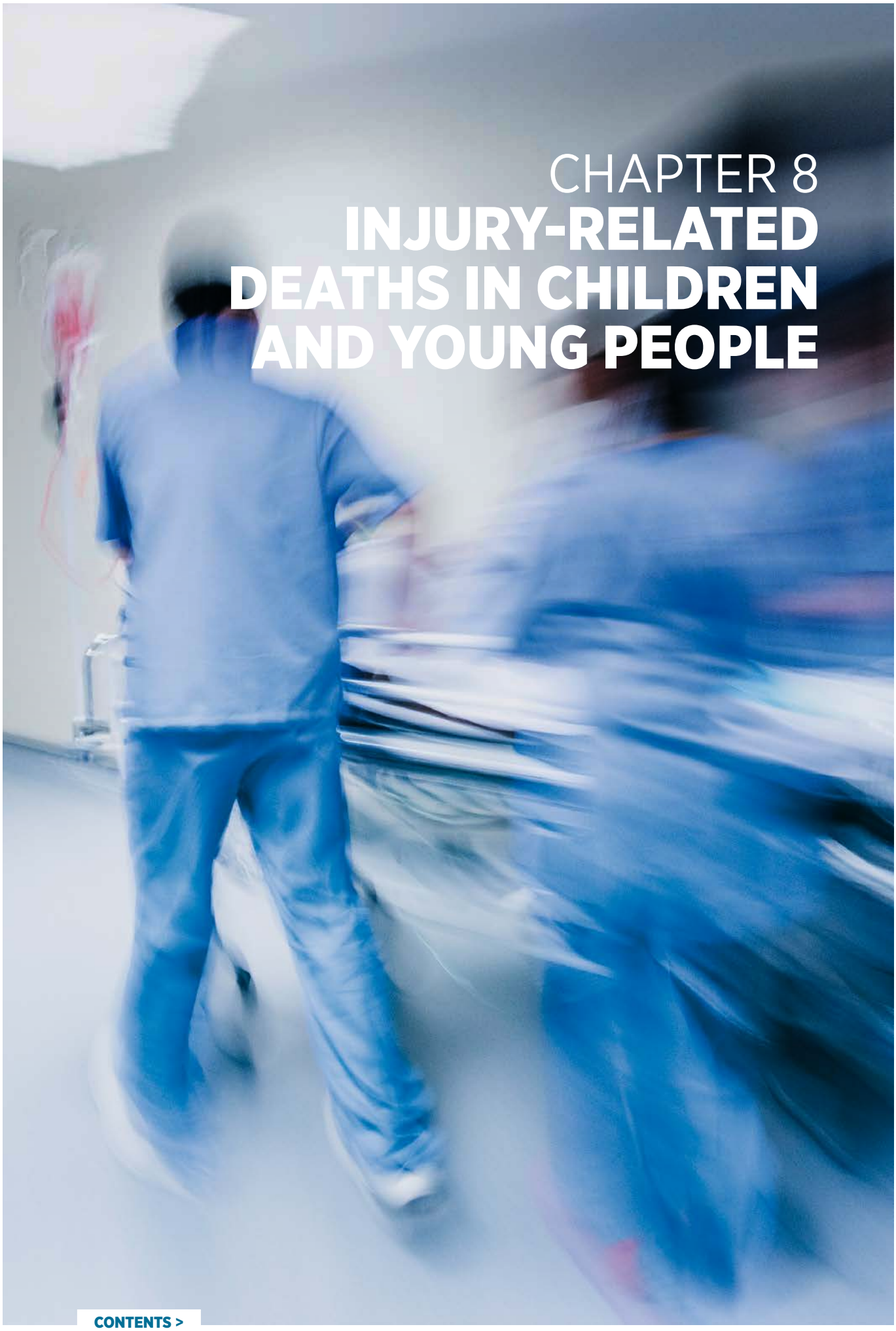
These data on the main contributory cause of death categories among children in Ireland are consistent with international data, which report external causes of injury are the main cause of death of children and young people. However, the number of external-cause deaths has declined overall. This decline has led to an increase in the overall proportion of deaths due to causes other than external factors, with a narrowing of the gap between the leading causes of death. However, as with data on infant deaths, these data must be interpreted with caution, as they are based on year of registration and may differ substantially from final figures for each year in which the deaths actually occurred. Confirmation of this data is required with year of occurrence data and additional detail required to determine the reason/(s) for this decline in external cause deaths.

The proportion of sudden unexplained deaths (categorised as ICD-10 code for 'symptoms, signs and abnormal clinical findings') in children and young people aged 1–14 years changed only slightly over the two time periods compared. This too must be confirmed with accurate data and further analysis is warranted to determine the characteristics and epidemiological profile of sudden unexplained deaths among the Irish CYP population currently.

The larger proportion of deaths among male children and young people becomes more evident with increasing age. This is a consequence of the increasing proportion of deaths attributable to external causes in older children, the majority of which have been shown to be the result of road traffic collisions (McGarvey *et al.,* 2019).

As with infant deaths (i.e. those aged under 1 year), the greatest proportion of child deaths (i.e. those aged 1–14 years) occurred in hospital. However, a greater proportion of deaths in adolescents (i.e. those aged 15–18 years) occurred at home, a reflection of the high number of suicide deaths in this age group. Twenty-six percent of deaths in children aged 1–14 years occurred at home, increasing to almost one-half of all deaths (49%) in adolescents aged 15–18 years.

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. Future examination of mortality in children and young people would also ideally include a more in-depth analysis of hospital-related deaths in order to provide information on the underlying causes and comorbidities.



CHAPTER 8
INJURY-RELATED DEATHS IN CHILDREN AND YOUNG PEOPLE

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CHAPTER 8: INJURY-RELATED DEATHS IN CHILDREN AND YOUNG PEOPLE

Data presented in this chapter are derived from CSO death registration information.

CHILDREN AGED 1–14 YEARS

A breakdown of the main causes of injury-related deaths among children aged 1–14 years and adolescents aged 15–18 years is outlined in Figures 8.1A and 8.2A. Comparative data for previous years are provided in Figures 8.1B and 8.2B, and in Table 8.1. A more detailed description of injury-related deaths by narrower age groups and type is not possible for the 3-year period from 2019 to 2021 due to the disclosure risk associated with low numbers; hence, deaths attributable to all other specific injury causes are combined as 'other'. This includes choking; accidental strangulation; drowning; farm and workplace accidents; quad bike accidents; high falls; and other injuries.

At 24.4%, the overall greatest proportion of injury-related deaths in children aged 1–14 years was due to road traffic collisions (RTCs), with 11 deaths registered during the period 2019–2021. This 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, which equates to an annual average of 10 road traffic deaths per year in this age group. This is likely a reflection of the impact of the lockdown during the COVID-19 pandemic, when the number of cars and pedestrians on the road were reduced and children were not attending school.

Deaths due to homicide/filicide were the second leading cause of injury-related deaths among children aged 1–14 years, accounting for 17.8% of all injury-related deaths during the period 2019–2021. In comparison, homicide/filicide accounted for 6.6% of injury-related deaths among children aged 1–14 years during the period 2007–2018. This is the equivalent of 8 child deaths (or 2.7 deaths per annum) in 2019–2021 and 23 child deaths (or 1.9 deaths per annum) during the period 2007–2018. However, 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. 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. A detailed breakdown of external-cause deaths registered for all age groups during the period 2007–2021 is outlined in Table 8.1.

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 more detailed description of drowning deaths is not provided here, due to the small number of drowning deaths recorded during the period 2019–2021. This data must be confirmed by year of occurrence data.

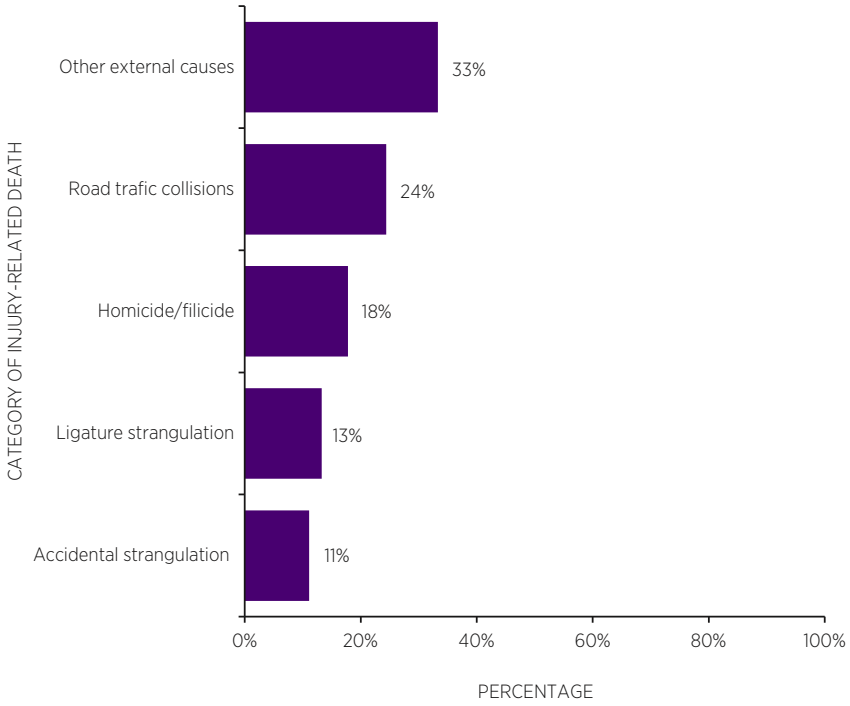

FIGURE 8.1A: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN CHILDREN AGED 1–14 YEARS, BY TYPE, 2019–2021 (N=45)

*Accidental asphyxiation other than ligature strangulation.

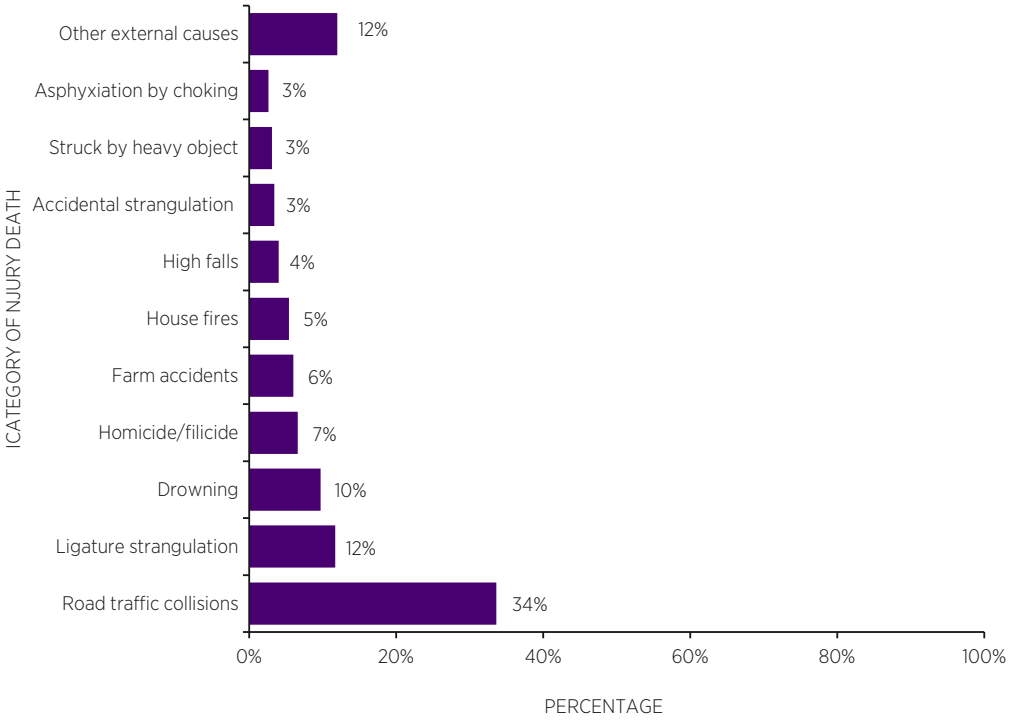

FIGURE 8.1B: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN CHILDREN AGED 1–14 YEARS, BY TYPE, 2007–2018 (n=351)

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.

CHILDREN AND YOUNG PEOPLE AGED 15–18 YEARS

In the older adolescent age group (aged 15–18 years), the leading cause of injury-related deaths was ligature strangulation, followed by RTCs, toxicity related to drugs and/or alcohol and drowning. Together, these four categories accounted for 92% of injury-related fatalities in this age group during the period 2019–2021. The proportion of deaths from RTCs declined from 26.3% (or 5.5 deaths per year) during the period 2012–2018 to 16.5% (or 4.3 deaths per year) during the period 2019–2021.

The data also show that the proportion of deaths due to ligature strangulation increased from 47.8% during the period 2012–2018 to 58.2% during the period 2019–2021. However, this does not represent an increase in the number of these deaths, which equates to an average of 15 per year during the period 2019–2021, compared with 17 per year during the period 2012–2018; this is due to the decline in the overall number of external-cause deaths in this age group in 2019–2021 (Table 8.1).

Regrettably, there was insufficient detail in death registration information to accurately confirm intent in many cases of injury-related fatalities in this age group; hence, these figures should not be interpreted as accurate estimates for suicide deaths. Furthermore, it is important to note that a number of injury-related deaths categorised as 'other' were specified as being due to suicide, and as such, interpretation of ligature strangulation figures as a proxy for suicide rates in this age group is likely to be an underestimate. Additional detail from post-mortem 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 analysed and remains at an annual average of two deaths per year.

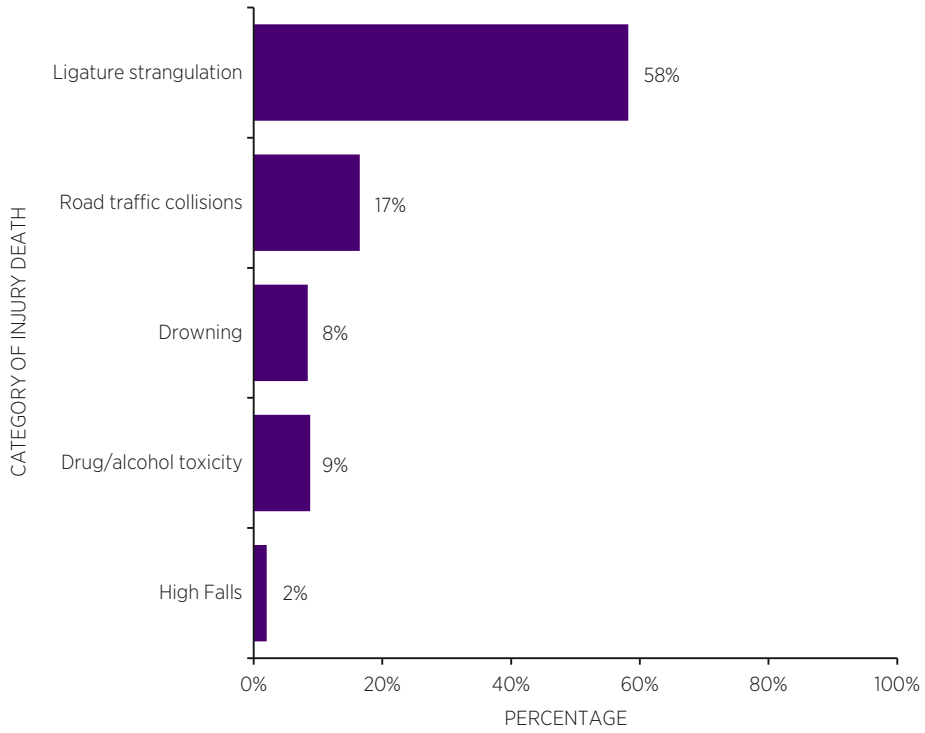

FIGURE 8.2A: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN ADOLESCENTS AGED 15–18 YEARS, BY TYPE, 2019–2021 (n=79)

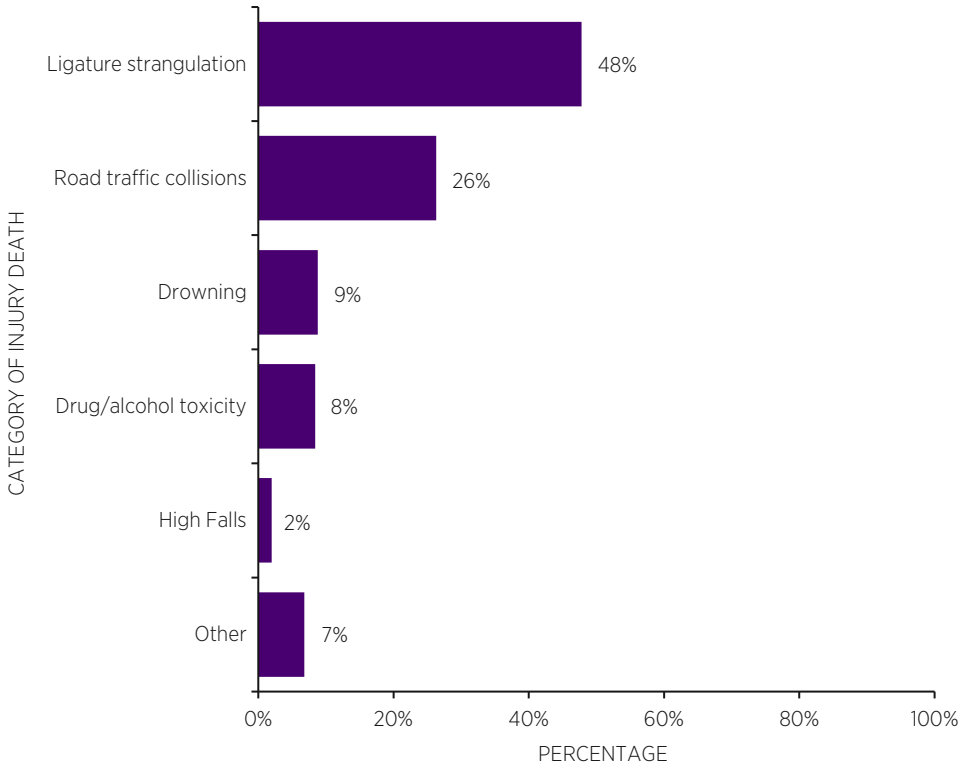

FIGURE 8.2B: BREAKDOWN OF EXTERNAL-CAUSE DEATHS IN ADOLESCENTS AGED 15–18 YEARS, BY TYPE, 2012–2018 (n=251)

ANNUAL TRENDS IN EXTERNAL-CAUSE DEATH RATES

The annual trends in the rate of external-cause deaths per 100,000 population for both age groups (those aged 1–14 years and those aged 15–18 years) are illustrated in Figures 8.3A and 8.3B.

The decline in injury-related deaths for children aged 1–14 years is clearly evident in Figure 8.3A. Injury-related deaths went from a peak of 5.4 deaths per 100,000 population in 2008 to 1.6 deaths per 100,000 population during the 2019–2021 period, which is a reduction of 70%. The fatality rate reported for the 2019–2021 period is the lowest injury fatality rate reported for this age group to date. This decrease is reflected in a similar pattern of decline in RTC fatalities for this age group: RTCs decreased by 84%, from a peak rate of 2.5 deaths per 100,000 population in 2008 to 0.4 deaths per 100,000 population during the period 2019–2021. The decline in RTC fatalities continued during the period 2019–2021, with a mortality rate that was 33.3% lower than that reported for 2018.

The reduction in the rate of injury-related fatalities was less pronounced in older adolescents (aged 15–18 years). Following an initial decline in 2013 and 2014, the mortality rate increased again in 2015 and remained high until 2018, when the rate dropped to 8.5 per 100,000 population. There was also only modest variation evident in the rate of RTC fatalities among this age group. The rate of deaths due to ligature strangulation 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, and may potentially be registered later than the 22-month deadline adopted by the CSO for annual publications. Adjusted figures will be provided in subsequent reports.

TABLE 8.1: ANNUAL NUMBER AND PERCENTAGE OF EXTERNAL-CAUSE DEATHS AMONG CHILDREN AND YOUNG PEOPLE AGED 1–14 YEARS AND 15–18 YEARS, 2007–2021

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
2007	37	28.2%		
2008	45	35.2%		
2009	46	35.1%		
2010	32	27.8%		
2011	26	27.7%		
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	13	17.6%	22	46.8%
2020	15	20.3%	21	51.2%
2021	17	28.3%	36	66.7%

Note: Data for the period 2007–2011 are unavailable for adolescents aged 15–18 years.

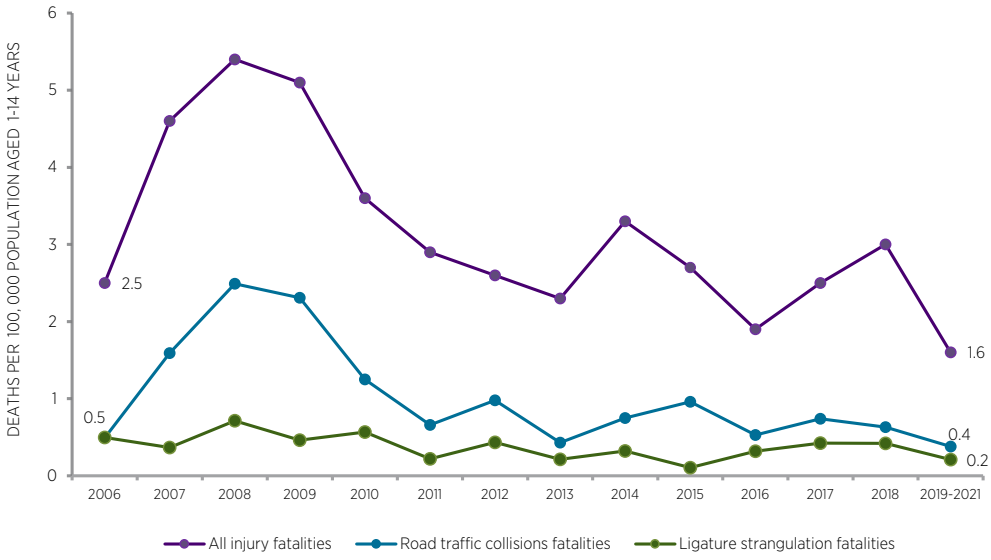

FIGURE 8.3A: ANNUAL TRENDS IN INJURY-RELATED DEATHS IN CHILDREN AND YOUNG PEOPLE AGED 1–14 YEARS IN IRELAND, 2006 TO 2019–2021

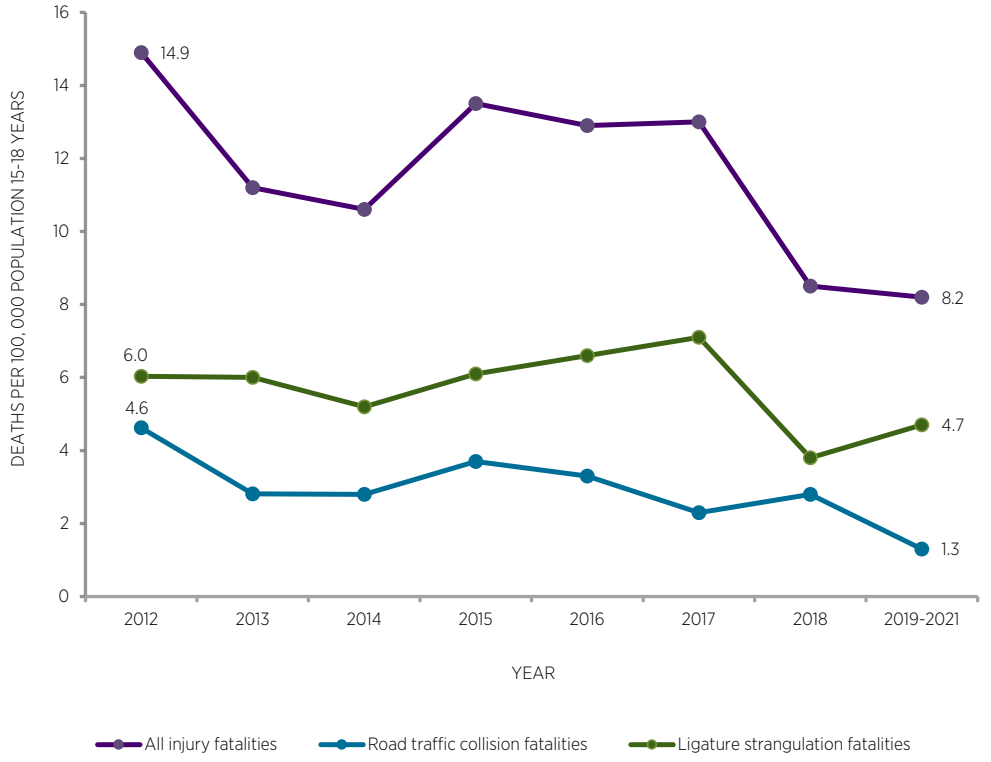

FIGURE 8.3B: ANNUAL TRENDS IN INJURY-RELATED DEATHS IN ADOLESCENTS AGED 15–18 YEARS IN IRELAND, 2012 TO 2019–2021

SUMMARY OF FINDINGS

There has been a decline in the overall number and rate of injury-related deaths registered during the period 2019–2021 among children aged 1–14 years and adolescents aged 15–18 years. The decline in the number of RTC and other external-cause deaths during this period compared with previous years is possibly a consequence of the Government's health measures introduced during the COVID-19 pandemic.

This decline is in keeping with data from the Road Safety Authority, which reported that 2021 saw the lowest number of road fatalities since recording began in 1959 (Road Safety Authority Research Department, 2023). The reduction in RTC fatalities was less pronounced in adolescents aged 15–18 years compared with children aged 1–14 years, and further action is required in order to address RTC fatalities among this age group.

The number of homicide deaths has increased slightly. These deaths relate predominantly to trauma occurring within a family unit and highlight the need for increased awareness around such deaths.

Regarding data on suicide deaths in CYP, improvements are required for data collection. The Health Service Executive's (HSE's) National Office for Suicide Prevention has outlined a number of projects aimed at improving surveillance, evaluation and research around suicidal behaviour in order to improve access to timely and high quality data. This includes the CSO Suicide Mortality Statistics Liaison Group, which will work to enhance the timeliness and accuracy of data captured by the Garda PULSE system. Other initiatives include the the Suicide and Self-Harm Observatory; and the Irish Probable Suicide Deaths Study, a collaborative study between the HSE National Office for Suicide Prevention and Irish coroners.

International studies have demonstrated that children from lower socioeconomic groups are disproportionately affected by external-cause deaths. There is a need to include health equity stratifiers in the data collection in order to ensure that accurate and timely data are available for informing child injury prevention policy.

Previous data has shown that children aged under 16 years are one of the most vulnerable road user groups, in particular child pedestrians, who account for the majority of child casualties across all road user types (McGarvey *et al.,* 2019). They are therefore particularly vulnerable to road traffic-related injuries and accidents. In some cases, there was insufficient information provided on death registration forms to accurately distinguish between passenger and pedestrian deaths. In addition, children die every year from accidents involving motorised vehicles other than cars, some of which are categorised as 'farm accidents' or 'accidents involving other vehicles'. Although appropriate codes exist for most possible scenarios, the application of such codes does not appear to follow a standardised approach. In general, information from death certificates was insufficient to allow for the accurate estimation of the various categories of external causes of death. For example, additional deaths attributed to head injuries without reference to the specific cause in the text or coding used to register the death means that the real proportion of deaths due to RTCs may be substantially higher than what is reported.

Additional data collections are required in order to provide a more detailed description of injury-related deaths among children and young people, including deaths due to RTCs, farm accidents, drowning and suicide. This will help increase public awareness of these causes of death.

CHAPTER 9
IN-HOSPITAL MORTALITY IN CHILDREN AND YOUNG PEOPLE

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CHAPTER 9: IN-HOSPITAL MORTALITY IN CHILDREN AND YOUNG PEOPLE

BACKGROUND

The Hospital In-Patient Enquiry (HIPE) dataset is a national health information system designed to collect demographic, clinical and administrative information from acute hospitals in Ireland on patient discharges and deaths (a detailed description of the HIPE dataset is provided in Chapter 4 of this report). This chapter relates to an analysis of data on all patients aged under 19 years admitted to hospital in Ireland during the period 2009–2021 whose discharge code was entered as "deceased" on the HIPE file. The dataset relates to episodes of care for inpatients only and does not include any deaths that occurred either outside of hospital or in the emergency department (ED). A list of variables included in the HIPE files is provided in Appendix 4, including the variable 'diagnosis-related group' (DRG).

The DRG variable enables patients to be disaggregated into homogenous groups which are expected to undergo similar treatment processes and incur similar levels of resource use. The data required in order to determine a patient's assignment to a DRG include principal and additional diagnoses, procedures performed, age, sex, and discharge status.

Figure 9.1 presents the in-hospital mortality rate for the population aged under 19 years during the period 2009–2021. The in-hospital mortality rate for this age group has remained more or less constant throughout the reporting period.

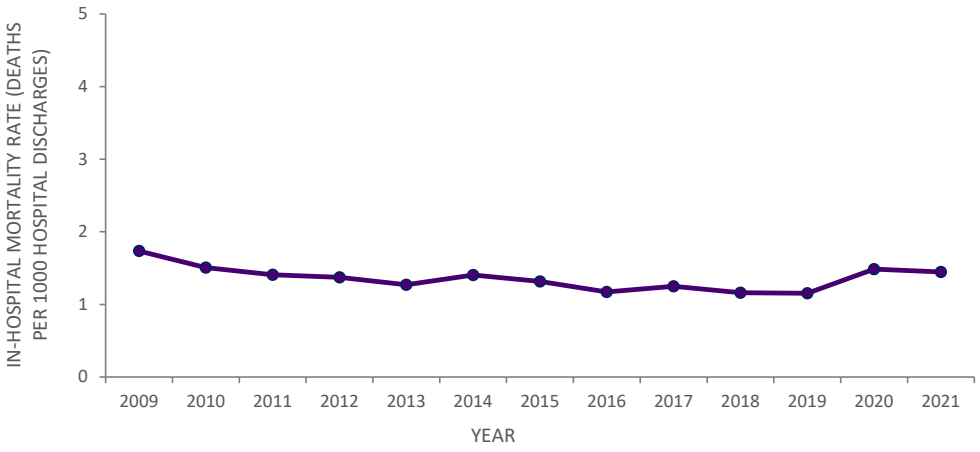


FIGURE 9.1: IN-HOSPITAL MORTALITY RATE FOR THE POPULATION AGED UNDER 19 YEARS, BY YEAR, 2009–2021

The majority of paediatric in-hospital deaths between 2009 and 2021 (62%; n=1681) were neonatal deaths (i.e. infants aged <=4 weeks) (Figure 9.2), with males having a higher mortality rate than females in all age groups (Figure 9.3).

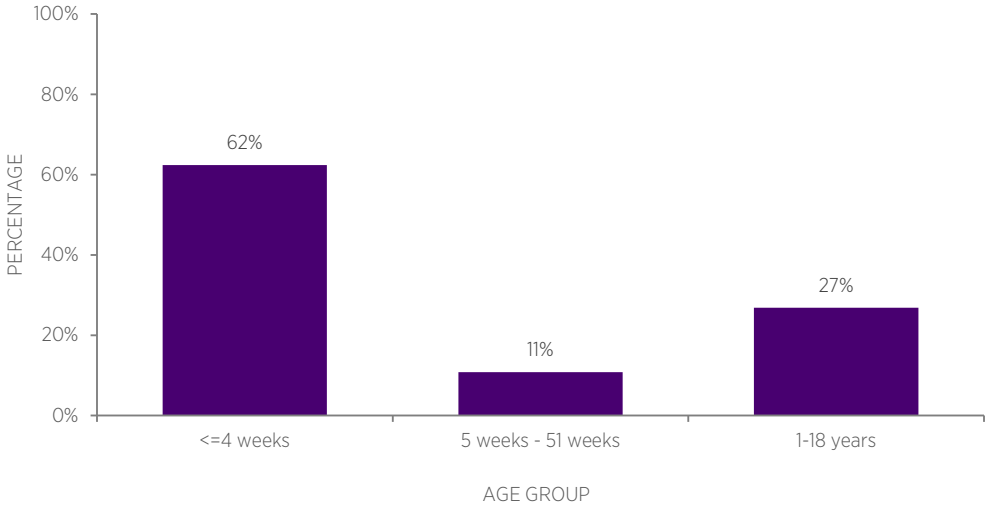


FIGURE 9.2: PERCENTAGE OF PAEDIATRIC IN-HOSPITAL DEATHS, BY AGE GROUP AT ADMISSION, 2009–2021 (N=2694)

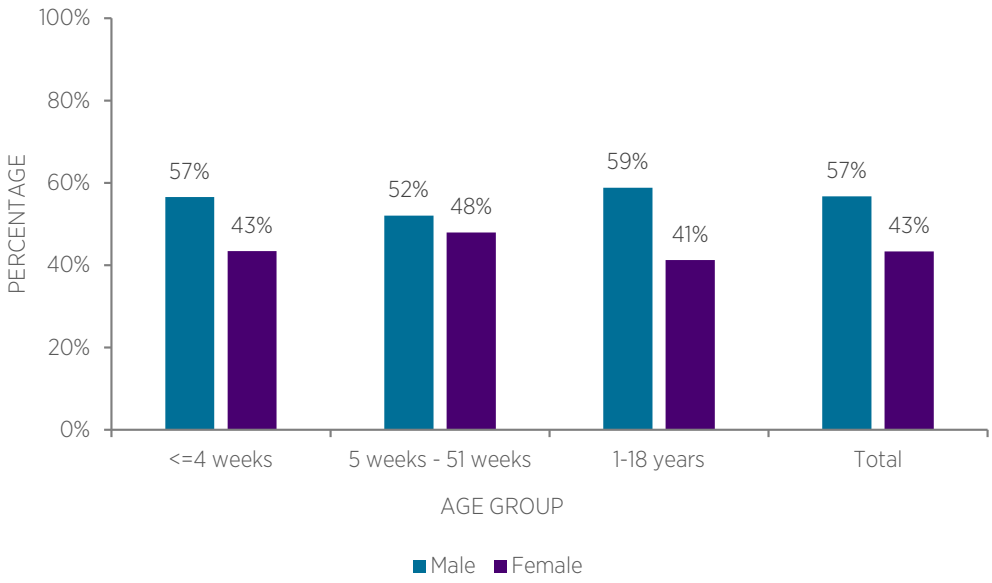


FIGURE 9.3: PERCENTAGE OF PAEDIATRIC IN-HOSPITAL DEATHS, BY AGE GROUP AT ADMISSION AND SEX, 2009–2021 (N=2694)

These data have the following limitations:

1. Although gestational age is an important variable for consideration with regard to neonatal deaths, data on gestational age are currently not available in the HIPE dataset.
2. It is not possible to accurately identify all neonatal deaths and stratify data accordingly (age is reported in weeks, and precise date of birth is not included in the dataset; hence, it is not possible to distinguish infants aged 28 days from those aged 29 days, and who are therefore in the postneonatal age group). This blind spot in the dataset could be rectified by linking HIPE and National Perinatal Reporting System (NPRS) data, which would also permit data on neonates to be analysed by gestational age.

The principal diagnoses associated with paediatric in-hospital deaths differ depending on the age of the child (see Figure 9.4). As would be expected, the diagnosis groups with the highest proportion of neonatal deaths were certain conditions originating in the perinatal period (n=1105; 66%) and congenital malformations and chromosomal abnormalities (n=489; 29%) (see Figure 9.5). Conditions originating in the perinatal period include birth trauma, disorders related to prematurity and foetal growth, haemorrhagic and haematological disorders, infections, and respiratory and cardiovascular disorders specific to the perinatal period.

For infant deaths, the diagnosis-related groups with the highest proportion of deaths were congenital malformations and chromosomal abnormalities (n=79; 27%) and diseases of the respiratory system (n=45; 16%) (see Figure 9.6). Furthermore, diseases of the respiratory system (n=168; 23%) and injury, poisoning and certain other consequences of external causes (n=142; 20%) were the diagnosis-related groups with the highest proportion of deaths among children and young people aged 1–18 years (see Figure 9.7).

In all age groups, the mean length of hospital stay was much higher than the median due to the fact that a small number of cases remained in hospital for an extended period. This is particularly evident within the infant cohort (see Table 9.1).

TABLE 9.1: MEAN AND MEDIAN LENGTH OF STAY OF PAEDIATRIC PATIENTS WHO DIED IN HOSPITAL, BY AGE GROUP AT ADMISSION, 2009–2021 (n=2694)

	AGE GROUP			
	≤ 4 weeks	5–51 weeks	1–18 years	Total
Number	1681	290	723	2694
Median length of stay (days)	3.0	10.0	4.0	4.0
Mean length of stay (days)	11.3	35.7	15.2	15.0
Standard deviation	23.8	67.7	45.8	38.2
25th percentile	1.0	2.0	1.0	1.0
75th percentile	11.0	40.0	14.0	13.0
Minimum length of stay (days)	0.5	0.5	0.5	0.5
Maximum length of stay (days)	309.0	638.0	851.0	851.0

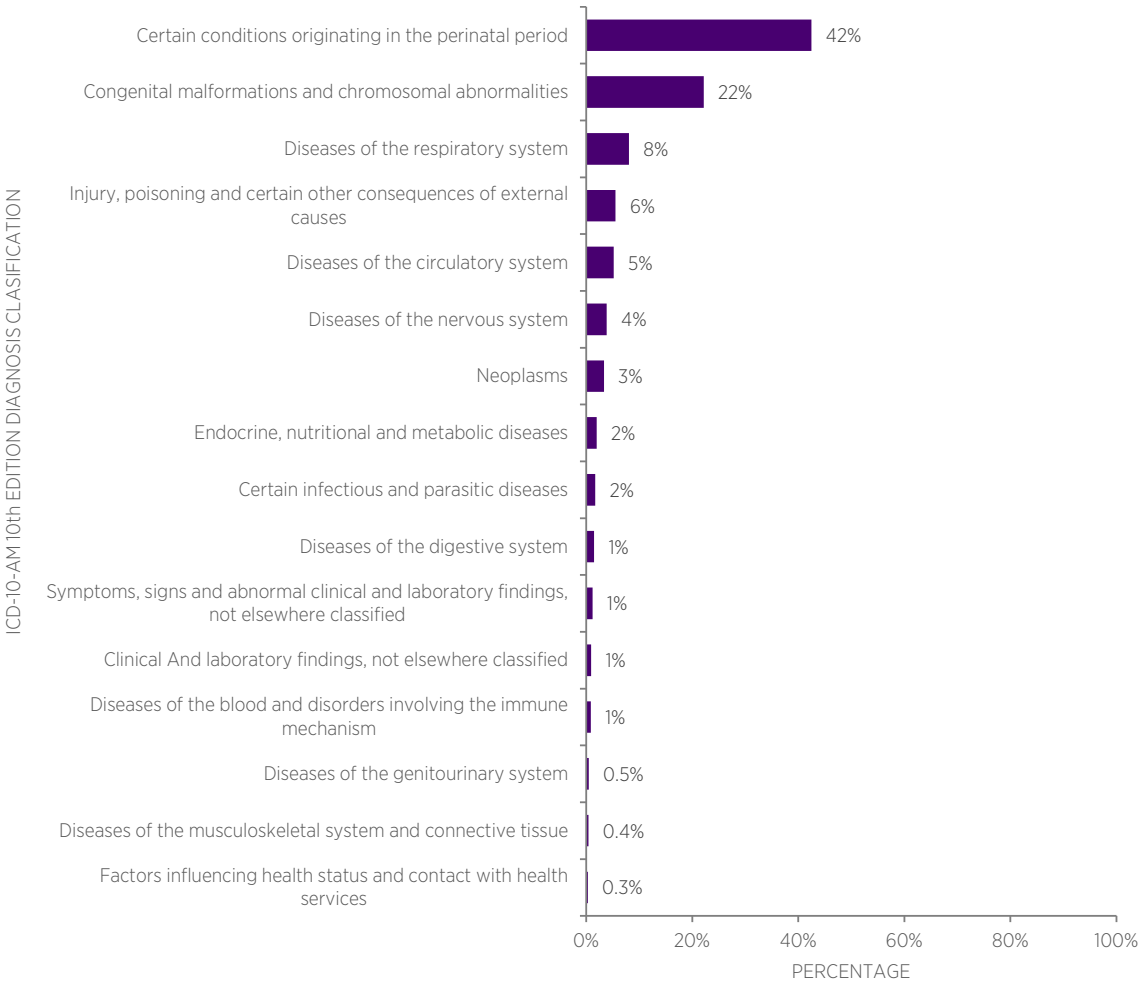


FIGURE 9.4: PERCENTAGE OF PAEDIATRIC IN-HOSPITAL DEATHS, BY MAIN DIAGNOSIS-RELATED GROUP, 2009–2021 (N=2694)

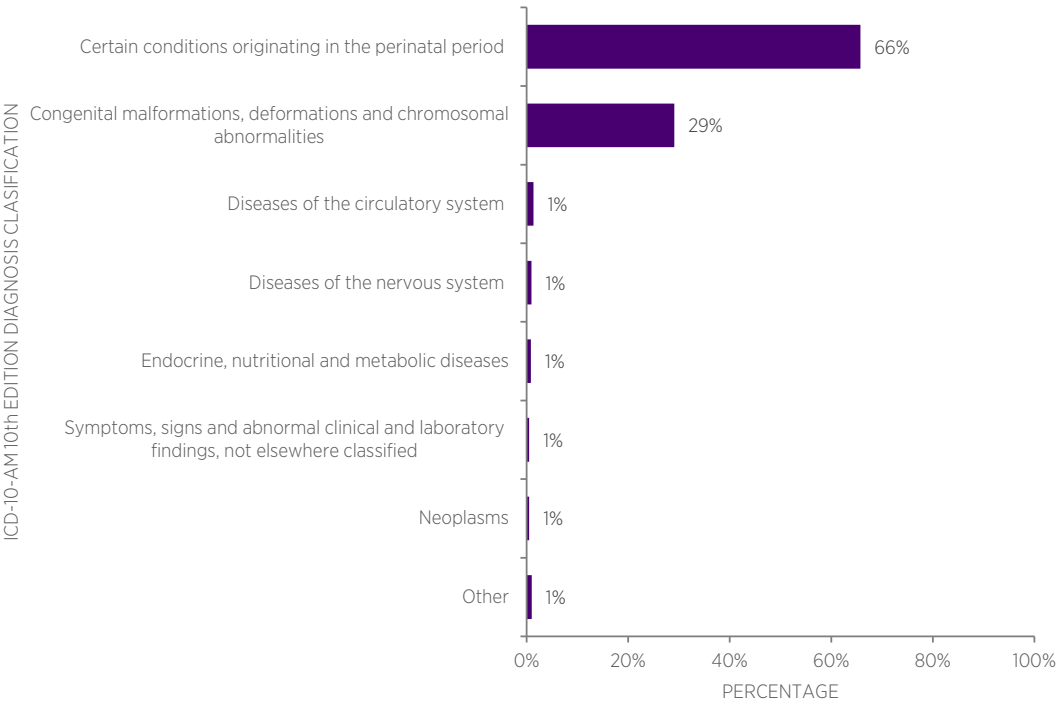


FIGURE 9.5: PERCENTAGE OF PAEDIATRIC IN-HOSPITAL DEATHS AMONG NEONATES (AGED ≤28 DAYS), BY MAIN DIAGNOSIS, 2009–2021 (n=1681)

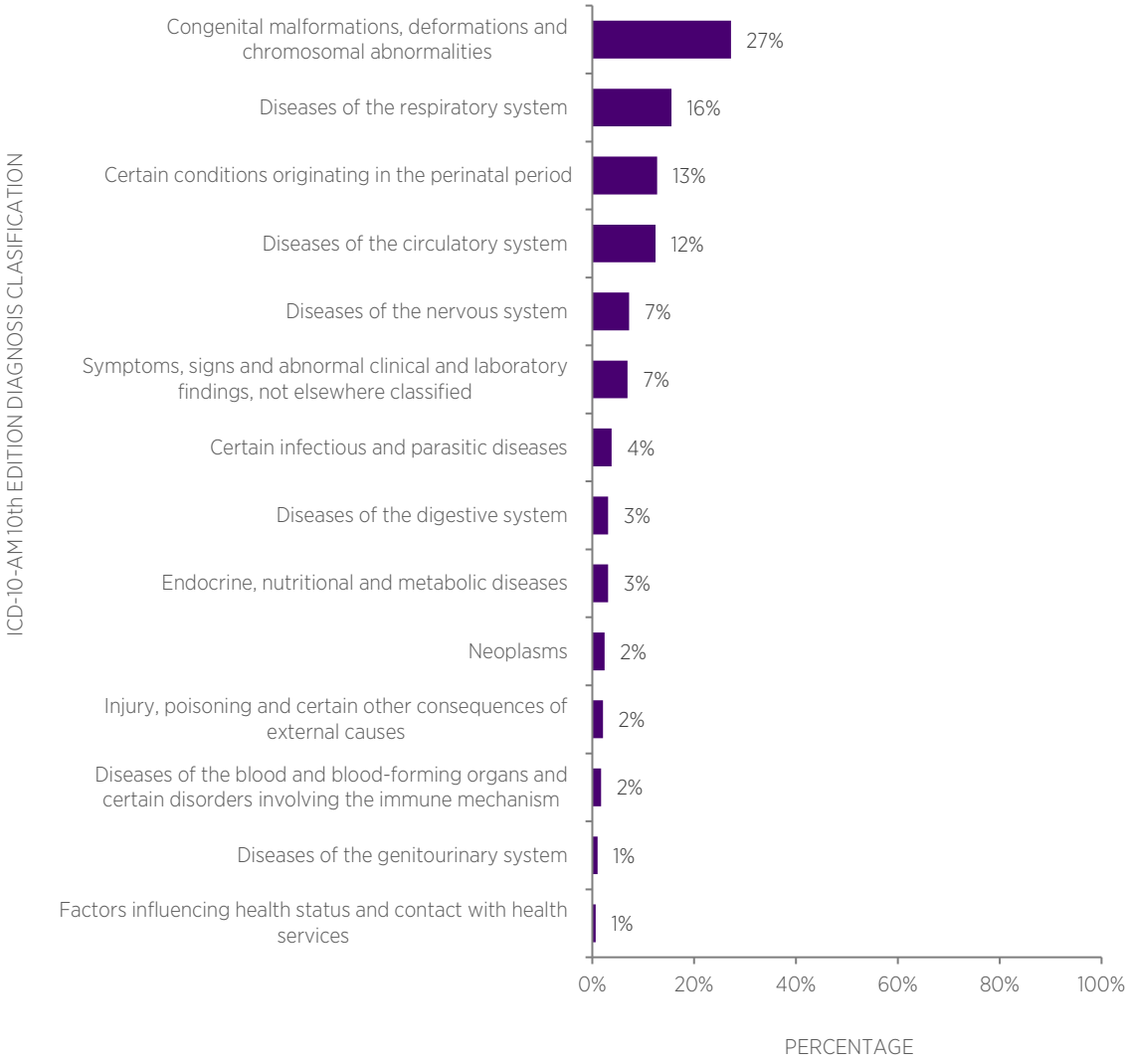


FIGURE 9.6: PERCENTAGE OF PAEDIATRIC IN-HOSPITAL DEATHS AMONG INFANTS (AGED 5 WEEKS TO < 1 YEAR), BY MAIN DIAGNOSIS, 2009–2021 (n=290)

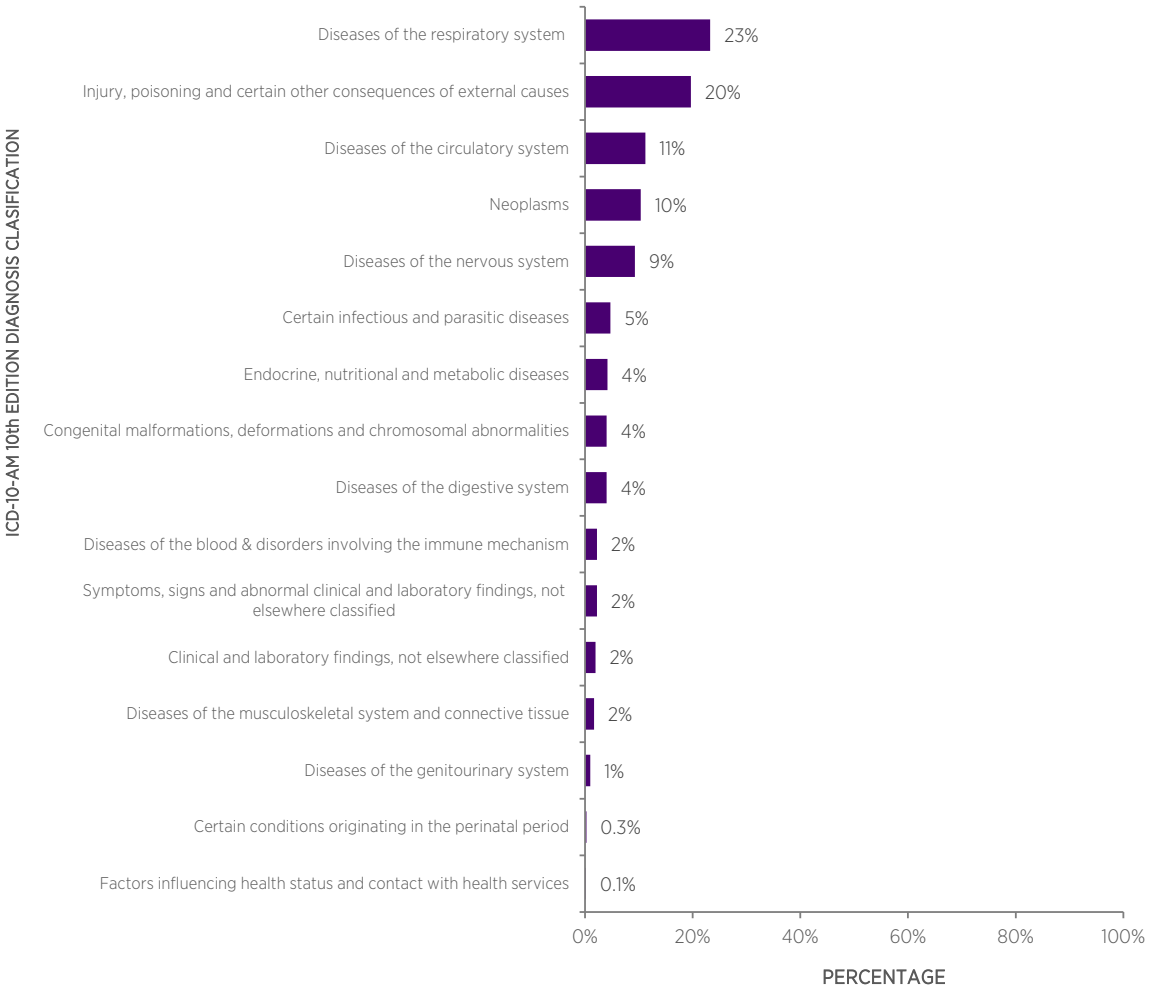
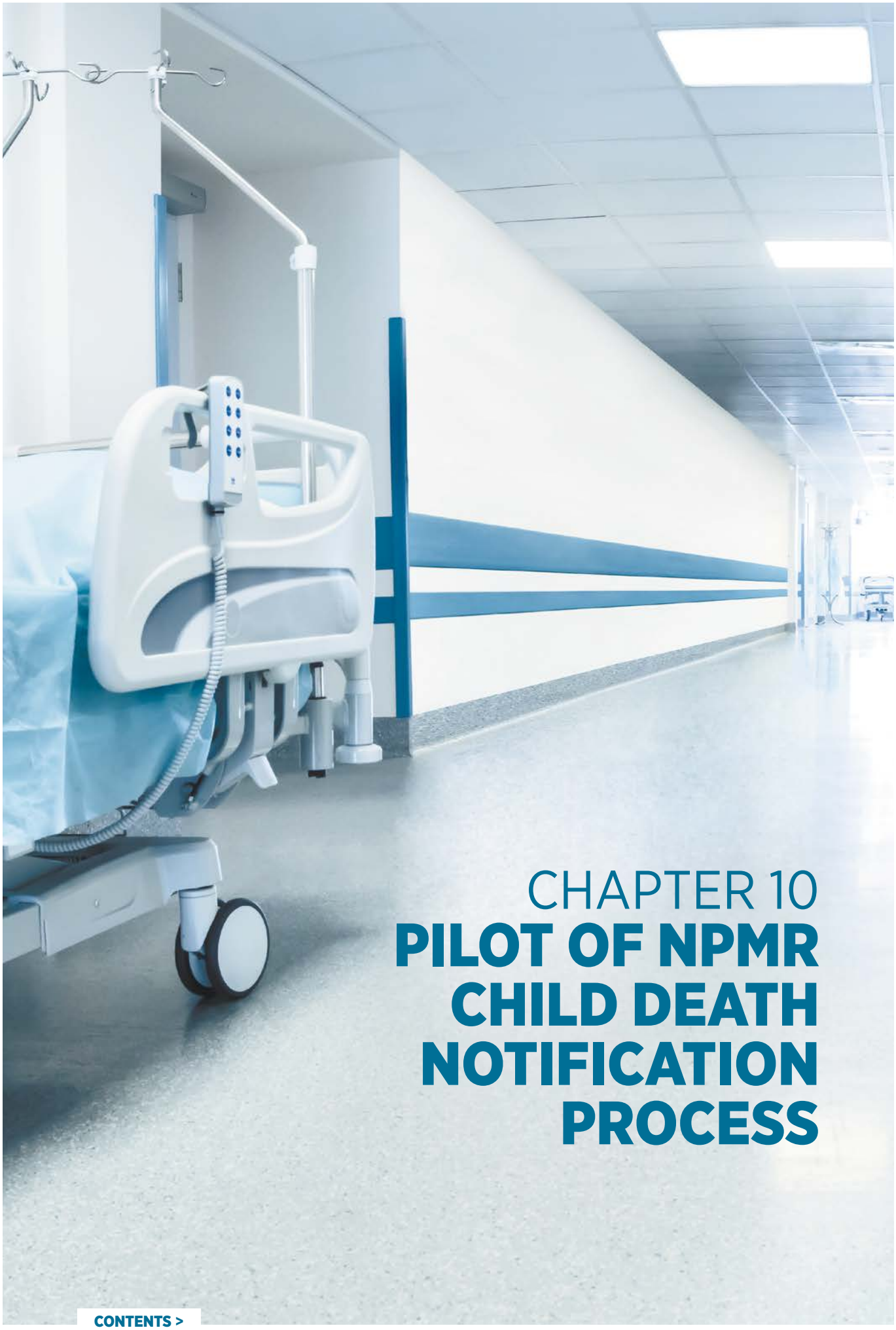


FIGURE 9.7: PERCENTAGE OF PAEDIATRIC IN-HOSPITAL DEATHS AMONG PATIENTS AGED 1–18 YEARS, BY MAIN DIAGNOSIS, 2009–2021 (n=723)

SUMMARY OF FINDINGS

Based on the HIPE dataset, the in-hospital mortality rate of patients aged under 19 years has decreased from 1.7 per 1,000 hospital admissions in 2009 to 1.4 per 1,000 hospital admissions in 2021. The principal diagnoses associated with paediatric in-hospital deaths differ depending on the age of the child. Similar to CSO data, HIPE data are not designed to provide accurate, detailed mortality information. HIPE classification relates to concurrent diagnoses, but it may not relate to the cause of death. Furthermore, gestational age is currently not available on the HIPE dataset, nor is it possible to accurately identify all neonatal deaths and stratify data accordingly (the patient's age is reported in weeks, and the precise date of birth is not provided in the dataset; hence, it is not possible to distinguish infants aged 28 days from those aged 29 days, and who are therefore in the postneonatal age group). The NPRS, however, contains this information on neonatal and gestational age, which is included on the birth notification form. NOCA therefore recommend the linkage of NPMR and NPRS data, which would permit data on neonates to be analysed by gestational age.



CHAPTER 10
PILOT OF NPMR CHILD DEATH NOTIFICATION PROCESS

CONTENTS >

CHAPTER 10: **PILOT OF NPMR CHILD DEATH NOTIFICATION PROCESS**

BACKGROUND

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 form aimed to capture a minimum core dataset of information on child deaths in 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 Children's Health Ireland (CHI) at Temple Street in December 2018, and was included on a checklist of tasks that staff must complete in the event of the death of a child in the hospital. The form was completed by the consultant in charge of the child's care at the time of death, or by another member of the team. The data discussed in this chapter were collected for the years 2019, 2020 and 2021. The data are reflective of children who died while inpatients in CHI at Temple Street and do not include patients who subsequently died at home and/or in palliative care settings.

AIM

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

METHODOLOGY

A detailed description of the methodology and data quality statement for this pilot study is provided in Chapters 2 and 3 of this report.

RESULTS

Completion rate of NPMR Child Death Notification forms in CHI at Temple Street, 2019–2021

The notification system captured the majority of deaths that occurred in CHI at Temple Street during the period 2019–2021. 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 is outlined in Table 10.1. Following initial high completion rates 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 decline in notifications in 2020 was largely due to difficulties relating to changes and staffing issues that occurred during the COVID-19 pandemic. Throughout the study period, the NPMR was not notified of cases which involved the Office of the State Pathologist. The low capture rate means that the data for 2020 must be interpreted with caution. In order to supplement the dataset, where possible, forms were completed retrospectively by a data collection coordinator (n=9).

Cross-checking of numbers with those recorded by the HIPE dataset (see Chapter 9 of this report) 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. The data for all three systems are outlined in Table 10.2.

TABLE 10.1: NUMBER AND COMPLETION RATE OF NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORMS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET, 2019–2021 (n=65)

Year	Total deaths recorded in hospital	Forms completed		Uncompleted forms		Additional data collected retrospectively	Total number of cases in dataset
	N	n	%	n	%	n	n
2019	24	20	83.3%	4	16.7%	0	20
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%	9	55

TABLE 10.2: 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, 2019–2021

Year	NPMR Child Death Notification form	HIPE dataset	iPMS
2019	20	16	24
2020	10	18	19
2021	16	24	22

The combined dataset presented here represents children under age 16 years as per the cut-off for referral and admission to CHI at Temple St. The median age of death of children who died during the 3-year period from 2019 to 2021 was 16.6 months. Forty-two percent of deaths over this 3-year period were among infants aged under 1 year (Figure 10.1).

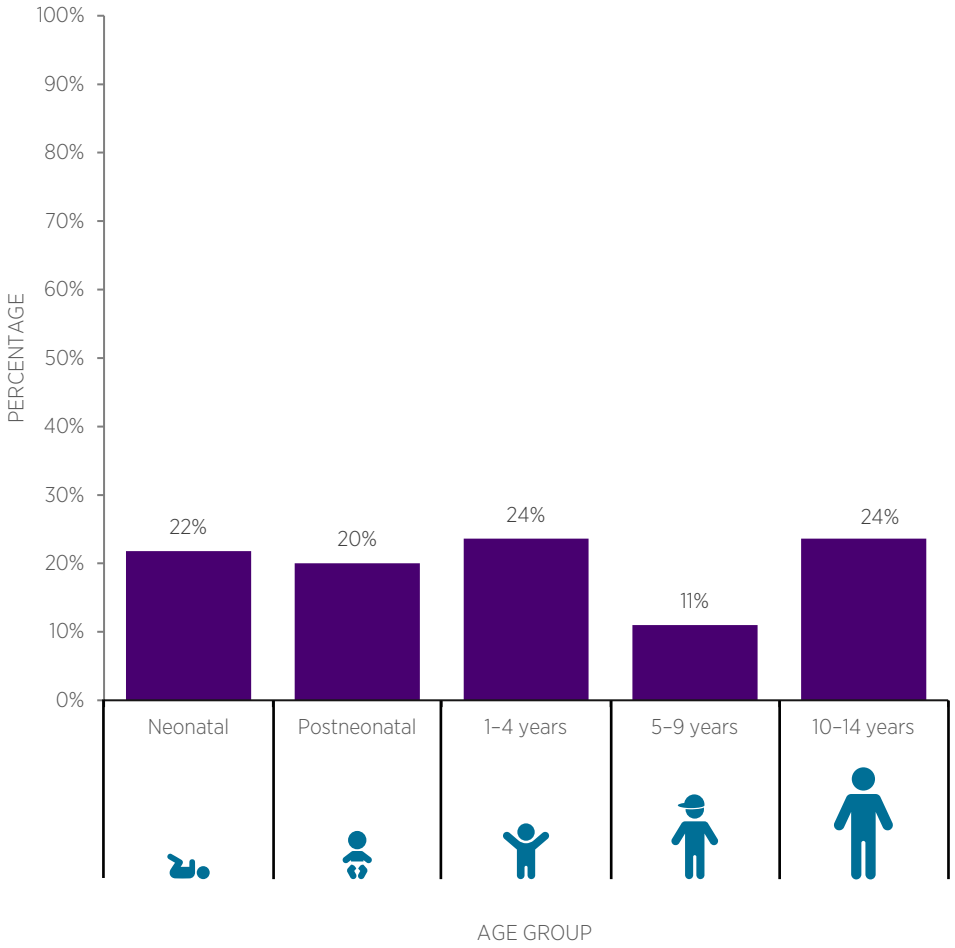


FIGURE 10.1: PROPORTION OF PAEDIATRIC INPATIENT DEATHS AMONG CHILDREN AGED UNDER 16 YEARS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET, BY AGE GROUP, 2019–2021 (n=55)

LOCATION AT TIME OF DEATH

Data on the location of death were captured for 72.3% (n=47/65) of all deaths in CHI at Temple Street in the period 2019–2021, as illustrated in Figure 10.2. During the 3-year period from 2019 to 2021, the majority of deaths (72.3%) were reported to have occurred in the paediatric critical care unit (PCCU). Other notifications included deaths that occurred in the ED, on hospital wards or at home (because of how few such cases there were, the exact numbers have been redacted in order to avoid disclosure issues). All deaths reported to have occurred at home were reported in 2019.

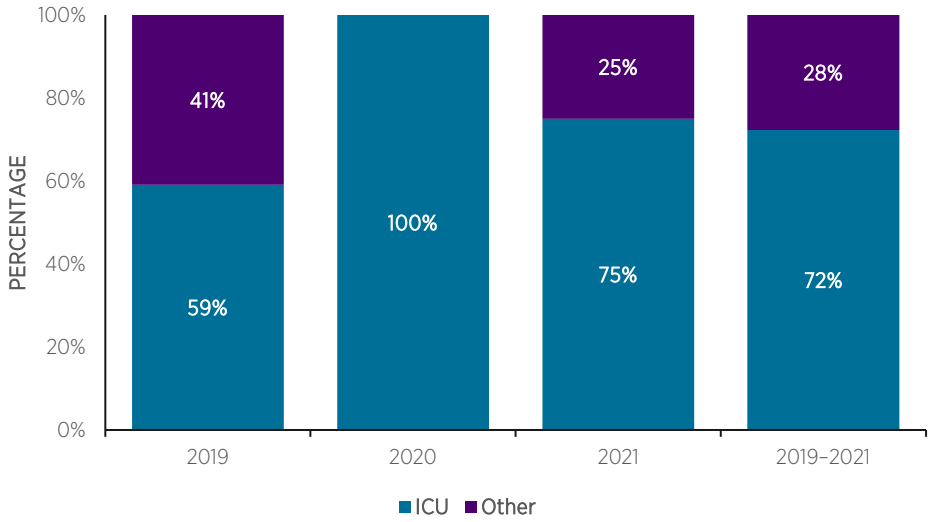


FIGURE 10.2: LOCATION OF DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET, BY YEAR, 2019–2021 (n=47)

PATIENT TRANSFERS

The majority (n=31) of the deaths in CHI at Temple Street reported to the NPMR during the period 2019–2021 were patients transferred from other hospitals. Fifteen hospitals transferred a small number of patients to CHI at Temple Street for treatment during this period (see Appendix 5).

PROVISIONAL CAUSE OF DEATH

The provisional cause of death for each child who died in CHI at Temple Street during the 3-year period from 2019 to 2021 is provided in Figure 10.3. Due to the small number of cases in some categories, it was not possible to examine annual trends, and data are thus provided collectively for the 3-year period. The greatest proportion of deaths (20%) were due to external causes (i.e. accident or injury). Another 18.2% of deaths were neonatal deaths, 16.4% were due to life-limiting conditions and illnesses, and 9.1% were due to infection. There was an insufficient number of total deaths to provide a stratified analysis of these data by year or age. It is possible that staffing changes in the ED in CHI at Temple Street in 2020 impacted on the notification process. Alternatively, there may have been a real reduction in injury-related deaths as a result of the lockdowns during the COVID-19 pandemic. Also during this period, cases of sudden unexpected death in infancy (SUDI) 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 information is unavailable from either the HIPE or iPMS datasets.

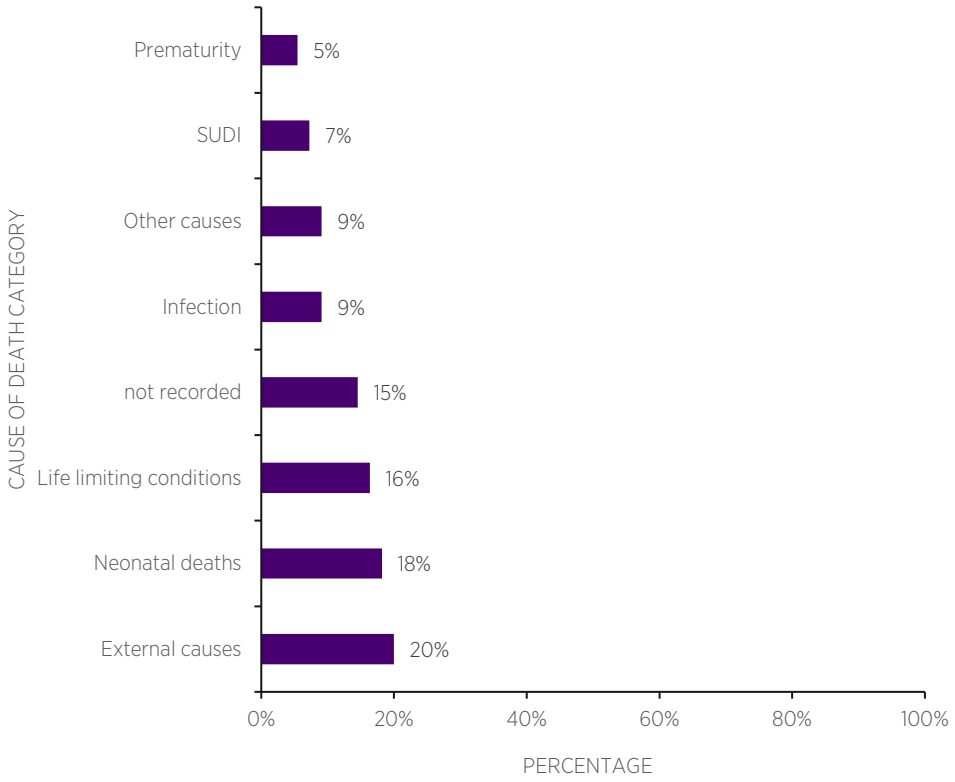


FIGURE 10.3: MAIN CAUSE OF DEATH CATEGORIES OF PAEDIATRIC DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET REPORTED TO THE NATIONAL PAEDIATRIC MORTALITY REGISTER, 2019–2021 (n=55)

MODE OF DEATH, ADVANCED CARE DIRECTIVES AND POST-MORTEM EXAMINATION RATE

A breakdown of data relating to variables for mode of death, post-mortem rates, number of coroner's cases and patients with an advanced care directive in place is outlined in Table 10.3.

TABLE 10.3: SUMMARY OF MODE OF DEATH AND PROCESSES SURROUNDING DEATHS IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET REPORTED TO THE NATIONAL PAEDIATRIC MORTALITY REGISTER, 2019–2021

VARIABLE	n	%
MODE OF DEATH		
Unexpected	17	40.5%
Expected/other	25	59.5%
Total	42	100.0%
ADVANCED CARE DIRECTIVE IN PLACE		
Yes	18	41.8%
No/other	25	58.2%
Total	43	100.0%
POST-MORTEM EXAMINATION CONDUCTED		
Yes	21	45.7%
No/other	25	54.3%
Total	46	100.0%
CORONER NOTIFIED		
Yes	37	84.1%
No	7	15.9%
Total	44	100.0%

CHAPTER 10

SUMMARY OF FINDINGS

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. The learnings included the following:

- Although the completion rate of NPMR Child Death Notification forms was high for 2019 and 2021, improvement is required to reach a 100% completion rate. Data collection during 2020 was impacted by the staffing changes and absences resulting from the COVID-19 pandemic. Only deaths occurring in the PCCU were reported using the NPMR Child Death Notification form during this time.
- 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 (see chapter 3, Table 3.2).
- The majority of data forms (89%) were completed by medical staff in charge of the child's care at the time of their death.
- Missed forms were completed retrospectively by PCCU staff, where possible. The presence of a data collection coordinator in the unit was critical for data collection, and makes the retrospective collection of missed cases a feasible option going forward in order to improve the completeness of the data. Increased awareness of the process should be supported by informing and training all new non-consultant hospital doctors.
- NPMR Child Death Notification forms were not completed following deaths which involved the Office of the State Pathologist. Measures should be taken to follow up on such cases and ensure that they are included in annual figures.
- The quality of the data collected was high, and issues/errors detected will be utilised to build additional validation checks into the data collection process. This information will be utilised to inform the next development phase of the child death notification process. The capture rate for most variables was ≥80% (see Appendix 6).
- The most common error in the data was indication of a death as a neonatal death where the child was more than 28 days old. Other issues included multiple omissions of responses to questions relating to whether the infant was dead on arrival. As such, a review of these variables is required.
- 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 by the death registration process.
- Unfortunately, due to the relatively low number of cases, it was not possible to stratify the data by age and cause of death, which would have provided insights into mortality within narrower age groupings. Additional data are needed in order to enable more detailed reporting on various cause of death categories.
- Continued collection of these data will permit analysis of annual trends in cause of death categories.

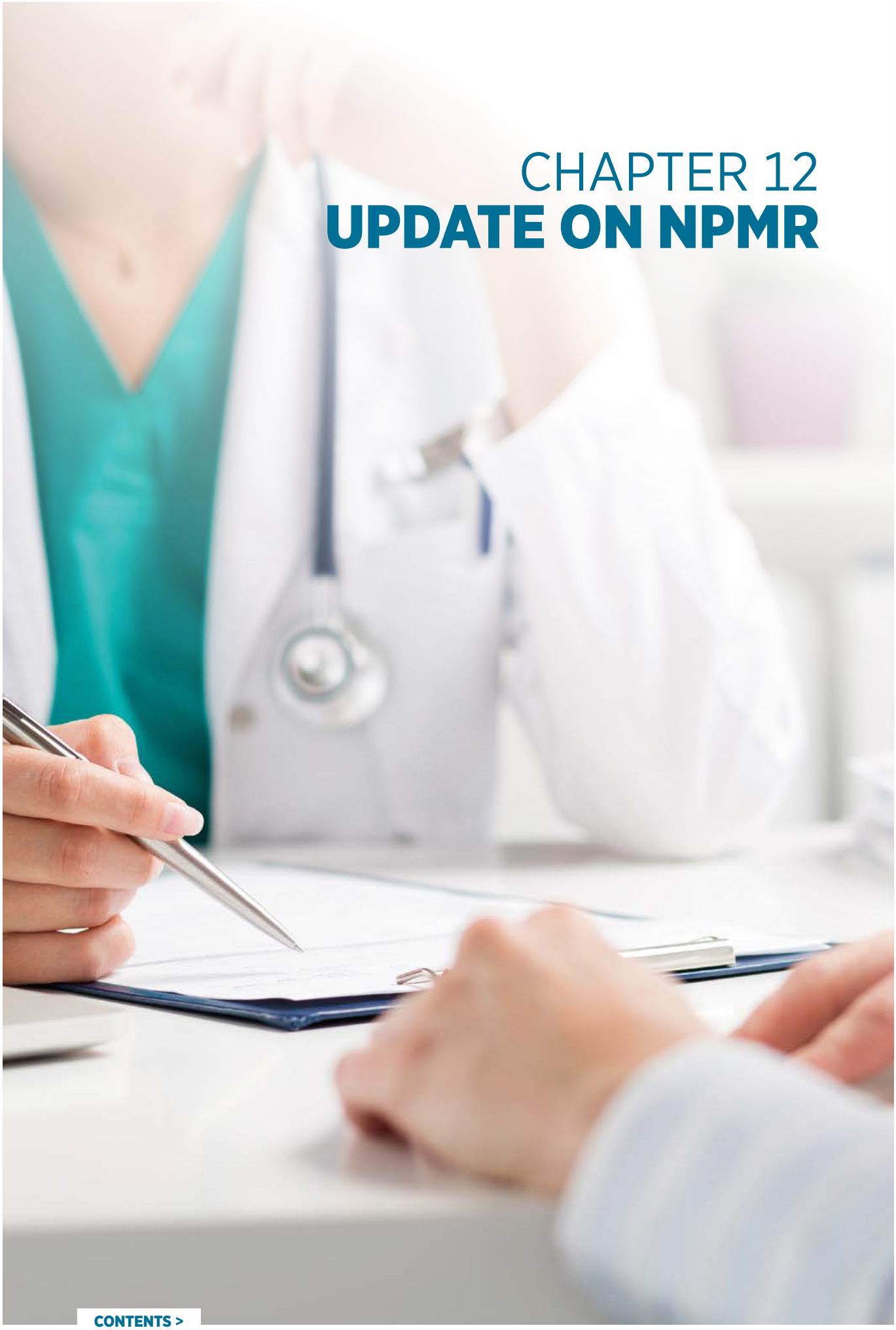
CHAPTER 11
QUALITY IMPROVEMENT

CONTENTS >

CHAPTER 11: **QUALITY IMPROVEMENT**

Accurate data on CYP mortality is required to drive improvements in the quality of care for both the child and family, including end of life care. Implementation of a standardised and timely reporting system for infant and CYP deaths across the Irish health system will enable a more accurate understanding of the causes of child death and provide the basis for quality improvements in delivery of care and better outcomes for children and young people.

- The data compiled by NPMR will produce timely and accurate mortality estimates for the CYP population in Ireland. This will enable accurate comparison with international estimates, which will assist with benchmarking the overall quality of care to children and young people in Ireland. For accuracy, comparisons in quality of care should not be made between individual hospitals. This is because accuracy of measurement is strongly influenced by other factors unrelated to quality of care that are difficult to adequately adjust for (e.g. unit case mix, concentration of cases in specialist units, or small case numbers being influenced by inter-hospital coding variations). The data would aim to describe differences between groups (i.e. vulnerability or socioeconomic status, variation in coding practices between hospitals) and also highlight areas of good practice. Mortality rates are based on HIPE discharge codes, hence the importance of reducing variability in coding between hospitals.
- The NPMR dataset will facilitate improvement in accuracy of cause of death statistics in underserved populations, particularly sudden unexpected deaths and areas of greatest potential for misclassification. Of particular value will be additional information on underlying conditions and co-morbidities associated with particular cause of death categories. This is because the current practice of categorising and reporting child deaths according to a single cause of death limits the information and opportunities for improvement because broader factors affecting mortality including underlying conditions and co-morbidities are not considered (Duke *et al.,* 2019).
- Continuous monitoring of the data will identify the most prevalent causes of death and enable population trends to be tracked accurately in a timely manner. An example of this would be availability of data that will enable distinction between deaths that occur in intensive care units vs wards, emergency departments and palliative care settings, providing more accurate data for development of targeted interventions and resource allocation.
- Through collation of post-mortem reports, the standard of post-mortem procedure for various cause of death categories, (particularly important in sudden unexpected, unexplained deaths) can be reviewed using information retrieved from post-mortem reports and measured against recommended standards.
- Any future Child Death Review Process, which is the gold standard for identifying improvement in quality of care in relation to child deaths, will be supported by standardised national aggregate data.
- 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 intention to stimulate response from report users. The intended responses may include
  - Using NOCA reports to cross reference data to validate local conformance – the intent is to ensure national findings are relevant to a local context
  - Review of Best practice guideline on topic – the intent is to inform users of current recommended practice
  - Use of QI resources – the intent is to provide practical advice on starting improvement projects.



CHAPTER 12
UPDATE ON NPMR

CONTENTS >

CHAPTER 12: **UPDATE ON NPMR**

AUDIT DEVELOPMENTS

The following is a description of recent developments relating to the NPMR:

- Data acquisition:
  - A memorandum of understanding was put in place between NOCA and the CSO to permit NOCA to access the available death registration information on all deaths in children aged under 19 years.
  - The Healthcare Pricing Office has given NOCA access to the HIPE dataset; as a result, the NPMR now receives data from the HIPE dataset on all deaths of children aged under 19 years that occur in hospital. This permits analysis and description of in-hospital deaths in relation to each patient's diagnosis on admission and on any additional diagnoses.
- Data from the pilot NPMR Child Death Notification form were used to inform the building and testing of an electronic web-based tool for the collection of death notifications. This tool will be piloted in CHI at Crumlin and another regional unit in 2023. This work will inform requirements for the national implementation of the NPMR Child Death Notification form. Following implementation of the NPMR Child Death Notification form in paediatric units, it is proposed that the child death notification process will be rolled out in all hospitals nationally before its use is extended to the community. Engaging sites and recruiting them to the notification process will be a focus of the NPMR's work in 2023. The current and proposed data flow for an operational NPMR is outlined in Figure 12.1.

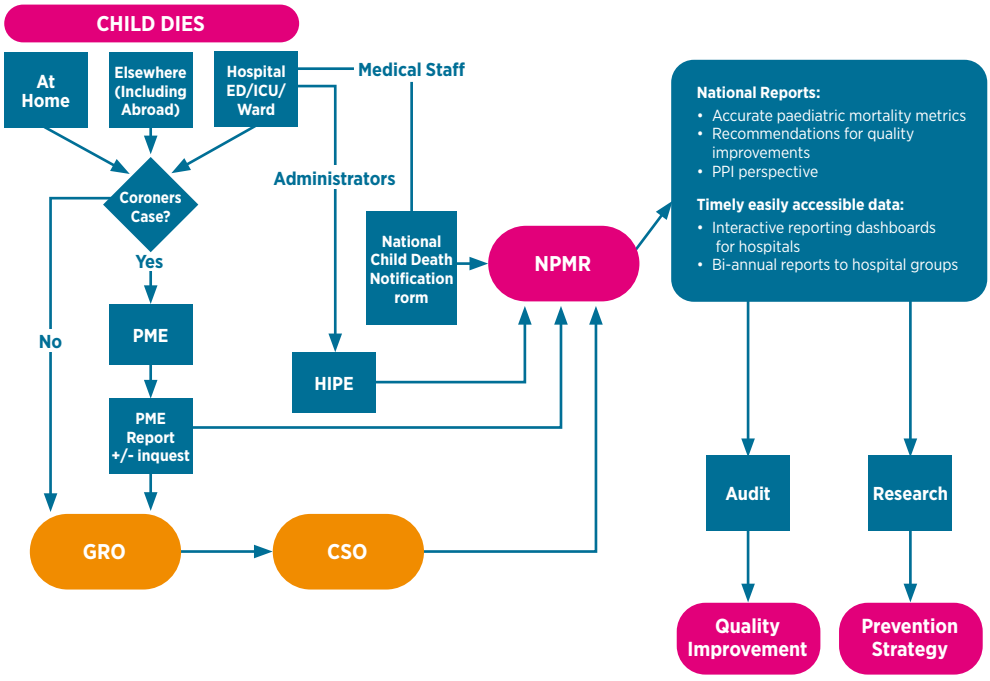


FIGURE 12.1: PROPOSED NATIONAL PAEDIATRIC MORTALITY REGISTER DATA FLOW

RESEARCH COLLABORATIONS

MD THESIS: "Why children die: paediatric mortality in Ireland 2011–2021"

Candidate: Dr Niamh Beirne
Supervisor: Dr Martina Healy
Ethics: Approved by Research Ethics Committee, Children's Health Ireland at Crumlin, June 2023.

At Children's Health Ireland, as the governing and operating body for acute paediatric services and all national paediatric services, important information relating to child death is collected at group and hospital level via iPMS, as well as at departmental level, e.g., department specific clinician-led databases at the Intensive Care Unit (PICU) and Emergency Department (ED), as well as via Post-Mortem studies and reports. This work aims to establish the process of death record / reporting at a tertiary paediatric referral centre. Additionally, where possible, it aims establish the number, demographics, and cause of death of children in a critical care setting (PICU/ED) at a tertiary paediatric referral centre over a 3-year period (2020-2022).

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 (CPC) is a national policy objective, there are issues around inconsistent referral patterns, unmet needs, lengthy hospital stays, limited CPC workforce planning and regional inequalities in CPC supply. Substantial gaps in evidence impede policy development, as well as the planning and delivery of CPC 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).

AUDIT ACTIVITY

Submission to the Department of Social Protection regarding the proposed changes to the process for notification and registration of deaths

In April 2021, the NPMR Governance Committee contributed to the consultation process on the Department of Social Protection's proposed changes to the death registration process in Ireland (Department of Social Protection: General Register Office, 2021). The resulting document highlighted the work of the NPMR, and offered support for the proposed changes to the death registration process as well as feedback from public and patient interest representatives. Legislative changes to underpin the proposed changes are pending. As a result of the consultation process, NOCA is in the process of engaging with the Health Service Executive (HSE) project team tasked with implementing electronic systems to facilitate the collection of death notifications going forward, and ensuring that these systems align with the NPMR's objectives.

Submission to the HSE regarding the review of *Standards and Recommended Practices for Post Mortem Examination Services*

In October 2022, feedback was provided to the HSE National Quality and Patient Safety Directorate consultation process on the proposed post-mortem examination services guidelines by means of an online survey. These guidelines provide clarity on individual responsibilities and make a clear distinction between coroners and hospital post mortems. The NPMR recommended that the HSE National Quality and Patient Safety Directorate should provide clear definitions for infant and child deaths, as well as explore the possibility of using one form for multiple purposes where possible.

Update to HSE resources following review of HSE Guidelines for parents and professionals on reducing the risk of SIDS

- The HSE's booklet *Safe sleep for your baby – reduce the risk of cot death* has been updated, and is now available on https://www.healthpromotion.ie/media/documents/HPM00078_hJ4sUjA.pdf.
- The HSE mychild.ie website has been updated: https://www2.hse.ie/conditions/cot-death/.
- HSE Nursing and Midwifery Education, in collaboration with the Regional Children's and Young People's Nurse Education Group HSE West/Midwest/Northwest, launched the Caring for Newborns webinar 2021 and 2022.

PUBLICATIONS

Publications from the NPMR dataset, along with other NOCA reports, can be found at the following link: https://repository.rcsi.com/search?groups=25382

CHAPTER 13
RECOMMENDATIONS

CONTENTS >

CHAPTER 13: **RECOMMENDATIONS**

The data outlined in this report provide an indication of the magnitude and main causes of mortality among children and young people in Ireland. The report also highlights the large number of potentially avoidable injury deaths across the various CYP age groups, which warrants further attention. However, the data presented are limited and not of sufficient quality to make recommendations in relation to addressing specific areas of child mortality. Hence, the following recommendations are focused on the objective of improving data quality. Preliminary considerations and learning points from the data analysis are provided at the end of this chapter for inclusion in future reports.

RECOMMENDATION 1

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 publication and enactment of legislation to mandate timely reporting of all deaths.

Rationale
• Accurate and timely data on deaths in infants and CYP are important for informing healthcare policy and the planning and delivery of services, as well as for monitoring population health outcomes.
• There is currently no dataset in Ireland that adequately captures data on the circumstances and causes of death in CYP, or on how many CYP die every year (whether in hospital or at home) and from what causes. Current reports of overall infant and child mortality rates do not provide sufficient information to allow for the identification of complex causes of death, such as when there are chronic underlying conditions which lead to death in patients of various age groups, which is not reflected in official mortality statistics. The usefulness of death registration information is limited by reliance on single causes of death for classification, use of classification systems more appropriate for adult deaths than CYP deaths, and variations and/or errors in reporting and classification practices, as well as delays in publication of annual statistics due to the late registration of many deaths, particularly when they are subject to a coroner's investigation and inquest.
• Many infant and CYP deaths are potentially avoidable, and there is a need to identify factors that contribute to these deaths so that appropriate intervention strategies can be developed and applied. Complete population-based datasets must be established in order to fully examine the impact of factors such as social deprivation on child mortality, the impact of which cannot be determined based on a local review of deaths.
Evidence Base
• The routine collection of population-based information is essential for informing policy decisions and evaluating their effectiveness, and aids in the generalisability of audit findings (Morrato *et al*., 2007).

- The effectiveness of the systematic collection and analysis of data in identifying risk factors and informing intervention mechanisms aimed at reducing mortality rates has been previously demonstrated in Ireland for the infant population via the National Sudden Infant Death Register (National SIDS Register, n.d.).

- Complete, high-quality data are required in order to provide an accurate picture of the delivery of care, including the identification of areas with high standards of care, as well as providing opportunities for informing and implementing service improvements. Conversely, poor-quality data have a substantial impact on the safety of service users. The Health Information and Quality Authority's (HIQA's) *Information management standards for national health and social care data collections* (HIQA, 2017) and *National Standards for Safer Better Healthcare* (HIQA, 2012) outline key principles for health information and seven dimensions contributing to data quality.

- A lack of national data limits the learnings from child deaths, as it prevents the universal application of system improvements due to the lack of a standardised process for the collection and reporting of data. The World Health Organization (WHO) recently published guidelines on approaches to paediatric mortality and morbidity auditing, citing the collection of accurate national mortality data as an essential element in the process (Duke *et al.*, 2019; WHO, 2018).

- The Irish Hospice Foundation's *Quality Standards for End-of-Life Care in Hospitals: Making end-of-life care central to hospital care* (Irish Hospice Foundation, 2010) outlines the need for improvement in hospital information systems in order to facilitate a national minimum dataset on deaths in hospital and other places of care outside of private homes, so that the HSE can produce a more accurate national picture of deaths across the spectrum of care settings. The Irish Hospice Foundation's Quality Standards include the standard that each hospital should have a clear procedure for the notification of death within 3 working days of the death occurring. This applies when cases are not referred to a coroner.

- National registries have the added advantage of efficiently monitoring and reporting trends, identifying high-risk groups and enabling the timely evaluation of interventions (Glicklich *et al.*, 2020).

What actions should be taken?

- The legislation to permit changes to the process by which deaths are reported (Civil Registration (Electronic Registration) Bill 2023) should be enacted in order to facilitate the timely and complete capture of mortality data in a centralised system.

- NOCA has made a submission in response to the Government consultation on the review of the process of notification and registration of deaths.

- The NPMR Governance Committee and NOCA will advocate for the publication and enactment of legislation to mandate the timely reporting of all deaths.

Who should take action?

- NOCA should advocate for the Department of Social Protection to enact the Civil Registration (Electronic Registration) Bill 2023 in order to enable changes to the current process of notification and registration of deaths to come into effect.

Who will benefit from this recommendation?
• Earlier notification and registration of deaths will support public health monitoring and enhance public service delivery. The Department of Health and the HSE will benefit from a national repository of accurate and timely data on CYP mortality that will inform policy and research relating to causes of death in infants and in CYP.
• The availability of timely national mortality estimates for comparison with international data will assist with benchmarking the overall quality of care provided to CYP in Ireland.
• The HSE and its staff will benefit from a better understanding of the causes of death in infants and in CYP, which will help improve the quality of hospital care, which in turn will promote better outcomes.
• The NPMR dataset will provide baseline information for researchers on the preventable causes of infant and CYP deaths. Future generations of children and their families will benefit from the knowledge and learnings that are gained as a result of the data provided.
When should this recommendation be implemented?
• The legislation should be enacted following the publication of the Civil Registration (Electronic Registration) Bill 2023.

RECOMMENDATION 2

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 paediatric mortality database.

Rationale
• NOCA is currently in the process of testing a web-based system for the submission of CYP death notifications. Following an initial pilot in one CHI and one regional site, this web-based system should be implemented nationally.
• The lack of timely and accurate mortality data for the Irish population during the COVID-19 pandemic prompted the HSE and the Department of Social Protection to conduct a review of the death registration process. Consequently, in order to improve the efficiency of the death registration process, and pending an amendment to the Civil Registration Act 2004, new statutory duties will be introduced that will require medical practitioners to notify all deaths to the HSE within 2 days. The time frame for completion of the Medical Certificate of the Cause of Death and registration of the death with the General Register Office (GRO) will also be reduced.
• A review of international best practice in Chapter 5 of this report identifies mandatory notification of deaths as the optimal model to enable timely, standardised and complete capture of the relevant data.
• The implementation of the NPMR Child Death Notification form in CHI at Temple Street, described in Chapter 10 of this report, demonstrated the feasibility of incorporating a child death notification process within the hospital system. It also provided insight into the data points that should be included in a minimum core dataset for a child death notification system.
Evidence Base
• Currently in Ireland, the Civil Registration Act 2004 states that all deaths must be registered within 3 months (Civil Registration Act 2004); however, this occurs in just 80% of cases. Public health management during the COVID-19 pandemic relied on access to good-quality and timely data, but these data were not available from public administrative sources (Department of Social Protection: General Register Office, 2021).
• Timely death registration processes in other countries enable the rapid reporting of mortality data and monitoring of trends. A description of international best practice is provided in Chapter 5 of this report.

What actions should be taken?
• NOCA must work with the HSE project team tasked with implementing systems for notifying deaths to the HSE to ensure that both systems are aligned in order to avoid the duplication of effort and data collection.
• In order to avoid waste as a result of duplication and the delay of data transfer, initial notifications relating to the deaths of infants and CYP forwarded to the HSE/GRO should also be made available to the NPMR in NOCA. This can be facilitated either by directly submitting the relevant notifications to both organisations, or via the HSE providing a data feed to NOCA. The learnings from piloting the NPMR Child Death Notification form and NOCA's stakeholder engagement with regard to the national implementation of a system for the timely notification of CYP deaths will be shared with the HSE in order to aid with the implementation of the revised notification and registration system.
• The partnership between NOCA and the HSE should support the NPMR objective of implementing a universal, standardised system for capturing data on all CYP deaths in a national paediatric mortality database.
Who should take action?
• NOCA should progress discussions with the HSE Office of the National Director Operational Performance and Integration (Project Evergreen Team), which was tasked with implementing the changes to the death notification system, in order to establish the pathway for aligning with NPMR systems (including during the period when both systems are operating in parallel) and the process for discontinuing the separate NPMR notification process.
• NOCA must conduct a scoping exercise in order to establish avenues for collecting notifications of infant and child deaths occurring outside of hospital and share this information with the HSE project team.
Who will benefit from this recommendation?
• The HSE will benefit from the learnings shared by NOCA with regard to collecting mortality data on infants and CYP nationally.
• NOCA will benefit from the technical support provided by the HSE for the national implementation of the data collection system.
• Healthcare staff will benefit from the availability of a standardised and electronic system for the notification of deaths.
• The general public, policy makers and the health service will benefit from a more efficient system for the notification and reporting of data on infant and child mortality. The Information derived from the data analysis will be critical to accurately informing future audits, studies, and public policies.
When should this recommendation be implemented?
• Discussions have already been initiated with the HSE Project Evergreen team to progress the alignment of the NPMR with the implementation of the revised death notification and death registration system, which will be a mandatory requirement following the enactment of changes to the Civil Registration Act 2004 (the Civil Registration (Electronic Registration) Bill 2023 is due for imminent publication at the time of writing this report).

RECOMMENDATION 3

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 must be received by NOCA in a timely fashion using electronic systems.

Rationale
• Discrepancies and delays in the publication of death registration information lead to inaccuracies in mortality data analysis and reporting. A standardised method for data collection using the same rules and definitions across sites ensures consistency and accuracy in the details provided, improving the reliability of the data and enabling comparability with data from other jurisdictions.
• The data presented in this report demonstrate that information from death certificates was insufficient to allow for the accurate estimation of the various external causes of death. For example, additional deaths attributed to head injuries without reference to the specific cause in the text or coding used to register the death means that the real proportion of deaths due to road traffic collisions (RTCs) may be substantially higher than what is reported. Furthermore, it was not possible in many cases to accurately classify injury deaths according to intent.
• A review of death registration information on infant and CYP deaths in Ireland over the 6-year period from 2006 to 2011 revealed that there was a discordance in the cause of death coding in 4% of death registration records (Shilling *et al*., 2013).
• The analysis of CSO data in Chapter 7 of this report indicates that 26% of deaths among children aged 1–14 years, and 49% of deaths among adolescents aged 15–18 years, occurred outside of hospital.
• The additional detail collected by the NPMR over and above the official death registration details will permit a more thorough analysis of infant and CYP mortality data and provide a description of child deaths that is clinically meaningful for healthcare professionals. Of particular importance will be collection of information on the presence or absence of modifiable risk factors.
Evidence Base
• This limitation of death certificate data for analysis of infant and CYP mortality statistics has also been reported in other jurisdictions: a review of child deaths in the United Kingdom (UK) identified inaccuracies in the certified cause of death in one-third of cases reviewed (Pearson *et al*., 2011b). A similar study of neonatal deaths in Australia identified a discordance between the certified cause of death and the clinical/pathological summary by a medical examiner in 42% of cases reviewed (Hunt and Barr, 2000), while child fatality review teams in the United States of America (USA) reported errors in the assigned cause of death in 13% of infant and CYP death certificates (Johansson *et al.*, 2006).
• 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 data meant that it was not possible to examine socioeconomic inequalities among the infant and child populations in Ireland.
• The use of electronic systems to submit data to the NPMR would align with *the eHealth Strategy for Ireland* (DoH, 2013) and recommendations in a recent HIQA report (HIQA, 2021).

What actions should be taken?
• The minimum core dataset for the notification of infant and child deaths using a web-based system should be piloted in at least one CHI site and one regional unit. This pilot should test dataset and collection methodology and make recommendations for national implementation. A two-phased approach to implementation has been identified as the recommended approach based on the findings of a stakeholder consultation process (which included data providers), and was subsequently approved by the NPMR Governance Committee.
• A minimum core dataset of information submitted with the initial death notification will allow for rapid notification of the fact of death, and additional details can be collected at follow-up by NOCA staff. This aligns with the model outlined in the proposed changes to the official death notification process by the Department of Social Protection and with the standards outlined by the WHO for notifying infant and child deaths, which will ensure international comparability (Department of Social Protection: General Register Office, 2021; WHO, 2018, 1979).
• Identifiable information is required to avoid problems of double counting and permit linkage with other data sources. NOCA should engage with all relevant data collection sites and conduct a gap analysis in order to identify barriers to and facilitators of the child death notification process, and to ensure that the relevant data can be collected across all sites.
• NOCA must conduct a data privacy impact assessment, complete a statement of information practices, and implement the required data-sharing arrangement with all sites in order to facilitate the national implementation of the NPMR child death notification process.
• A scoping review should be undertaken in order to establish the avenues by which the NPMR can capture deaths occurring outside of hospital. This information will be shared with the HSE (see Recommendation 2).
Who should take action?
• The NPMR Governance Committee and NOCA are responsible for defining and testing the dataset for the NPMR.
• NOCA should work with Ireland's Systematized Nomenclature of Medicine (SNOMED) National Release Centre and follow the HSE's Data Specification Management Process in order to ensure that the data points collected by the NPMR use standardised terminology that can be used for comparisons with international data.
• NOCA should work with relevant hospitals in order to secure data-sharing arrangements that will permit the NPMR notification protocol to be implemented and engage with the HSE Acute Hospitals Division in order to implement this policy in a phased approach in all hospitals throughout Ireland.
• NOCA and the NPMR Governance Committee should work with the HSE Office of the National Clinical Advisor, the National Clinical Programme for Palliative Care, and HSE Healthlink in order to develop a notification process for infant and CYP deaths that occur at home and do not present to hospital for post-mortem examination.

Who will benefit from this recommendation?
• Data users – including the HSE, the Department of Health, acute hospitals, NOCA, coroners, researchers and the general public – will benefit from the standardisation of data input processes and definitions, which will ensure that the data are quality assured, robust and fit for purpose. Standardisation of data, and high levels of data completeness will enable reliable comparisons with international data and facilitate future interoperability with other healthcare systems if required. Data providers will benefit from a lower burden of effort resulting from a reduction in the level of detail requested from the medical practitioner at the initial death notification stage, as well as from a new electronic web-based system for uploading and submitting the data.
• NOCA will benefit from the increased completeness of data enabled by a more efficient death notification and data submission process.
When should this recommendation be implemented?
• National implementation of the NPMR child death notification system should begin following the completion of the pilot in one CHI unit and one regional unit.

RECOMMENDATION 4

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.

Rationale
• A description of the currently available datasets relevant to paediatric mortality, and the limitations of each one, is provided in Chapter 4 of this report. These data sources can add to the value of the NPMR database by providing additional information, reducing the burden of data collection, avoiding duplication of information, and aiding in the validation of the dataset.
• The use of the IHI for the NPMR is the most efficient method of collating data from multiple sources and would permit the linkage of mortality data with other process and structural metrics, maximising the NPMR dataset's potential to identify areas for improvement.
• A large proportion of CYP deaths, particularly those that occur in hospital, occur in the neonatal age group (aged under 29 days) and, due to distinct patterns of mortality, should be reviewed separately from the deaths of postneonatal and older infants and children. Furthermore, gestational age is an important variable that should be taken into account when reviewing these data, although this information is currently unavailable on mortality datasets. Linkage of datasets with birth notification data included in the National Perinatal Reporting System (NPRS) would permit a more accurate and informative analysis of data on neonatal deaths.
Evidence Base
• The National Health Information Strategy 2004 and *Building a Culture of Patient Safety: Report of the Commission on Patient Safety and Quality Assurance* (Department of Health and Children, 2008) recommend the introduction of a system of unique identification within the healthcare sector in order to improve the quality and safety of patient care.
• A recent report from HIQA (2021) outlined major deficiencies in the collection, use and sharing of health information – which is being managed on different electronic systems or using inefficient paper-based records – and the associated impacts on patient safety. The lack of an operational IHI has been highlighted as a fundamental shortcoming in the Irish healthcare system, and the role that the IHI played in roll-out of the COVID-19 vaccination programme is identified as providing an opportunity to build on that success.
• The use of an individual health identifier has been a key enabler of the success of national CYP mortality databases and review processes in other jurisdictions, such as the UK and USA (see Chapter 5 of this report for a more detailed discussion).

- 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 the final registered cause of death. A study in the UK has shown that linkage of death registration information with a child's hospital records can give accurate statistics and information on mortality (Hardelid *et al*., 2014). This approach estimated that most CYP deaths in a particular cohort of children were due to neurological conditions; however, the most common cause of death was deemed to be cancer when based on underlying cause of death alone, which highlighted subgroups of patients at greater risk of death. Hardelid *et al*. concluded that many of the shortcomings in death registration information can be overcome (at relatively low cost) by linking data sources (Hardelid *et al*., 2014).

- The Health Identifiers Act 2014 defines who may access the National Register of Individual Health Identifiers and for what purpose as follows: "a specified person may access the National Register of Individual Health Identifiers for a relevant purpose" (Health Identifiers Act 2014).

What actions should be taken?

- A scoping exercise should be undertaken to determine the requirements, timelines and permissions required in order to make the IHI available to and accessible by NOCA for the purposes of the NPMR.

- The NPMR dataset should include a placeholder for the IHI, and, until the IHI is implemented, the Personal Public Service Number of the deceased child should be collected in the interim.

Who should take action?

- The Chair of the NPMR Governance Committee, the NPMR Clinical Lead, and NOCA should collectively consult with the Access to Information and Health Identifiers Programme Division of the HSE's Office of the Chief Information Officer to determine if the collection of data by the NPMR satisfies the criteria/requirements for use of the IHI as outlined in the Health Information Act2023 (DoH, 2023).

Who will benefit from this recommendation?

- Individual health identifiers promote patient safety by allowing accurate identification and linkage of patient information, reducing the risk of data input errors.

- Healthcare staff will benefit from the efficient availability and accessibility of patient information.

- Audit coordinators and NOCA staff will benefit from the improved efficiency and accuracy of the dataset, which eliminates problems as a result of accidental double counting and accurately links the data.

- Data users will benefit from the increased reliability and accuracy of the data.

When should this recommendation be implemented?

- The feasibility of using the IHI should be explored prior to national implementation of the NPMR child death notification form, but following the publication of the Health Information Bill and the endorsement of the first NPMR report by the NOCA Governance Board.

RECOMMENDATION 5

In line with international best practice, the NPMR 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.

Rationale
• The child death review process aims to gain a better understanding of the factors and vulnerabilities that contribute to child deaths. The review of individual cases by multidisciplinary panels can identify systemic problems and provide insights and learnings for quality improvement and interventions in order to reduce the number of preventable deaths and improving quality of end of life care for children with life-limiting conditions.
• Child death review is implemented at national level in many countries and is a statutory requirement in some (e.g. England and New Zealand; see Chapter 5 of this report).
• As of 2023, the child death review process in Ireland extends only to children who die while they are in the care of a government agency. In 2007, the Ombudsman for Children made a recommendation to the Minister for Health and Children that a mechanism to systematically review all child deaths in Ireland should be established; this was followed by the publication of the *Child Death Review Options Paper* for consideration in 2009 (Ombudsman for Children, 2009). A similar recommendation was made in the *Report of the Independent Child Death Review Group* relating to the deaths of children in the care of a government agency (Shannon and Gibbons, 2012).
• The WHO recently published guidelines for auditing mortality in children and young people that provide guidance on the classification and coding of cause of death, as well as approaches to classifying modifiable factors and documentation management and recordkeeping to inform the child death review process (WHO, 2018).
Evidence Base
• The United Nations Committee on the Rights of the Child has indicated that, where appropriate, government agencies should include the investigation and reporting of child deaths in death registration documentation, along with cause of death (in line with Article 6 of the United Nations Convention on the Rights of the Child, which requires that government agencies recognise the inherent right to life of every child and ensure the survival and development of the child to the maximum extent possible) (United Nations, 1989).
• The merits of a child death review process are outlined in Chapter 5 of this report.
• Examples of positive policy changes and public health initiatives arising from child death reviews in the USA include: public education on safe sleep; stronger policies and training for healthcare providers on reporting child abuse and neglect; suicide prevention initiatives; tougher penalties for drunk drivers; the introduction of standardised procedures for the investigation of sudden and unexplained infant death; the revision of information detailed on death registration certificates; revised policies on home visitation; and folic acid awareness programmes (Ornstein *et al.*, 2013; Palusci *et al*., 2010).

- The National Review Panel for the investigation of serious incidents known to the child protection system – including the deaths of children in care – was set up in 2010 as part of the *Report of the Commission to Inquire into Child Abuse, 2009: Implementation Plan* to review deaths and serious incidents involving children in care. The National Review Panel is commissioned by (but remains independent of) Tusla, the Child and Family Agency. The National Review Panel submits reports to the Chair of the Board of the Child and Family Agency and to HIQA, but it is now having trouble obtaining records from organisations that are not under the control of Tusla. The National Review Panel operates under The *Guidance for the Child and Family Agency on the Operation of The National Review Panel* (HIQA, 2014).

What actions should be taken?

- NOCA should engage with the Department of Health and HSE Office of the Chief Clinical Officer in order to advocate for the establishment of a child death review process.

Who should take action?

- NOCA should submit the NPMR report to the National Quality and Patient Safety Directorate of the HSE and to the Department of Health in order to support future calls for the establishment of a national child mortality review panel.
- NOCA should participate in the Child Death Review Working Group of the International Society for the Study and Prevention of Perinatal and Infant Death and share findings with the NPMR Governance committee in order to ensure awareness of international standards and developments in this area.

Who will benefit from this recommendation?

- A child death review improves the experience of professionals and bereaved families involved in the death of child.
- The standardisation of the child death review process ensures that the data captured are comparable across units and contributes to the universal applicability of the findings.
- Learnings from the child death review process are used to help prevent deaths due to similar causes.

When should this recommendation be implemented?

- NOCA will engage with the Department of Health and the HSE following publication of this NPMR report.

CONSIDERATIONS AND LEARNING POINTS

- Analysis of the available data on child mortality has shown that a large proportion of child deaths, attributable to injury and sudden unexplained deaths in infancy and childhood (SUDI/SUDC) are potentially avoidable. Additional data should be collected on CYP mortality in order to accurately establish the burden of both intentional and unintentional injury, and sudden unexpected and unexplained deaths in the Irish CYP population and to aid identification of contributory and modifiable risk factors.

- Contemporary data is needed to understand the interactions between children and their environment and how these interactions influence the risk of death. This information should be used to inform policy aimed at reducing the number of such deaths in the future. The available data highlights the following areas of injury fatality among the Irish CYP populations that warrant further attention.

1. Despite the high burden of mental health conditions among adolescents, services are currently lacking. Additional detail on the circumstances of suicide deaths among older children should be collated via the NPMR in order to provide accurate estimates of suicide rates among this age group. This data should be used to highlight awareness of the high incidence of such deaths among the Irish CYP population and support development of services and preventative initiatives.

2. Although the rate of RTC fatalities among Irish children has declined substantially, rates remain higher than best-performing countries such as the UK, Norway and Sweden. Additional data is required 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.

3. The risk of serious injury and fatality resulting from accidents occurring on farms is often obscured within overall CYP injury fatality statistics. This category of deaths warrants increased awareness. Accurate data on the various causes of CYP deaths on farms should be compiled and stratified by age. This data can potentially be derived from the NPMR dataset and accompanying post-mortem reports.

4. Drowning is one of the leading causes of injury fatality among children globally. The location and source of drownings vary according to infant age and gender. Regular review of drowning deaths should be conducted using NPMR data to help identify modifiable risk factors and inform preventative initiatives.

5. The data provided in this report indicate an increase in the number of CYP deaths due to homicide. This data should be used to increase awareness around the risk to children and support development of clear national guidelines for medical child protection assessment, based on best practice and international standards.

- The rate of deaths from sudden infant death syndrome (SIDS) has declined substantially in Ireland since the introduction of prevention campaigns based on 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 when the infant is of low birthweight or premature. Such detail is necessary to enable accurate diagnosis of SIDS cases. There is currently a gap in information relating to the epidemiology of SIDS in Ireland, particularly in relation to the location and position of the infant at time of death. Such important information on the circumstances of these deaths are not routinely collected unless documented by pathologists in the post-mortem report. The NPMR should collect details relating to the major risk factors for SIDS in all cases of sudden unexpected deaths in infancy and early childhood. This data should be used to provide accurate estimates of SIDS rates in Ireland and inform further prevention strategies.

CHAPTER 14
CONCLUSION

CHAPTER 14: **CONCLUSION**

This report outlined the rationale and evidence to support the need for a national register of CYP deaths in Ireland. Implementation of a timely, reliable system for capturing details of CYP deaths will improve the quality of data and information available for reporting on child deaths. This in turn will provide a resource for identifying gaps and will provide baseline information for the development of future research and audit. The NPMR dataset will highlight any discrepancies in the coding and classification of various cause of death categories, which in turn will lead to improvements in statistical reports. These broad comparisons will identify the gaps and inform the agenda for paediatric mortality audit.

The limitations of the existing available data sources on paediatric mortality are evident from chapters 6 to 9 of this report. The importance of this lack of information is highlighted by the observation that a large proportion of all infant and child deaths are potentially avoidable. The NPMR Child Death Notification Form Pilot study (reported on in Chapter 10) demonstrates the feasibility of implementing a direct notification system, which can be further facilitated through the use of electronic systems for the submission and collection of data. Additionally, this central database can be supported by triangulating data from other sources using a unique 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.

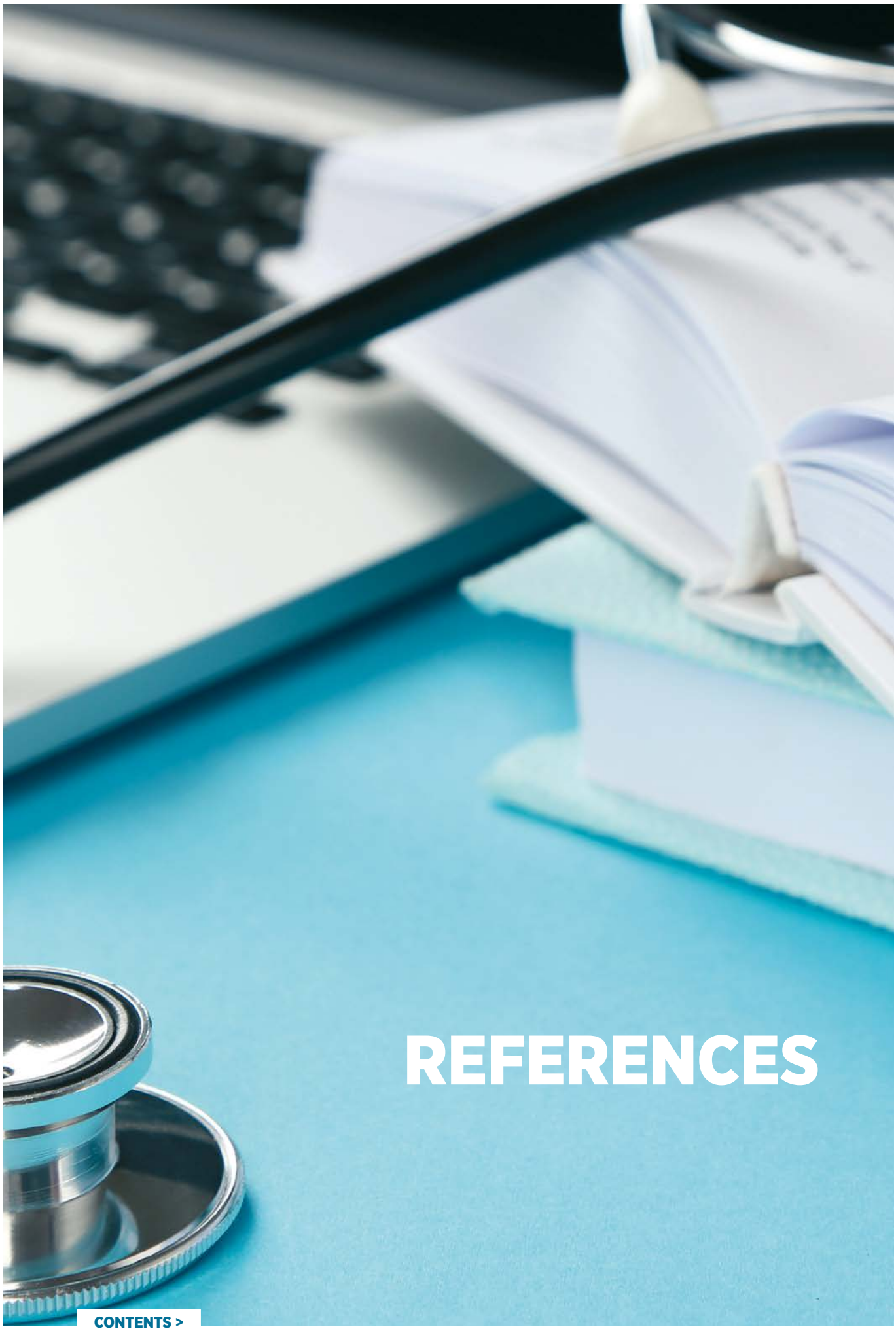
United Nations Convention on the Rights of the Child

ARTICLE 6 - SURVIVAL AND DEVELOPMENT

1 State Parties recognise the inherent right to life of every child

2 ensure to the maximum extent possible the survival and development of the child

"State Parties should include where appropriate the investigation of and reporting of child deaths along with cause of death in death registration" (in line with Article 6 of the UN Convention on the Rights of the Child (UNCRC)).



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APPENDIX 1:
NATIONAL PAEDIATRIC MORTALITY REGISTER GOVERNANCE COMMITTEE MEMBERSHIP AND MEETING ATTENDANCE, 2022–2023

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APPENDIX 2:
NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORM

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APPENDIX 3:
FREQUENCY TABLES

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APPENDIX 4:
VARIABLES PROVIDED FROM HOSPITAL IN-PATIENT ENQUIRY DATASET

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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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APPENDIX 6:
COMPLETION RATE OF VARIABLES INCLUDED ON THE NATIONAL PAEDIATRIC MORTALITY REGISTER CHILD DEATH NOTIFICATION FORM DURING THE PILOT IN CHILDREN'S HEALTH IRELAND AT TEMPLE STREET

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