

# NATIONAL PAEDIATRIC MORTALITY REGISTER 2023 SUMMARY REPORT

The National Paediatric Mortality Register (NPMR) aims to collect, analyse and report on data relating to all deaths in children aged under 19 years in the Republic of Ireland. Although mortality in children has declined globally, many deaths continue to occur, and there is an urgent need to identify factors that contribute to those deaths so that appropriate intervention measures may be applied.

The purpose of this report is to provide an overview of child mortality in the Republic of Ireland and to demonstrate the need for a universal, centralised system for the notification of deaths that will permit analysis and timely reporting of data on child mortality. This report examines the data, which is currently available, and highlights the deficits in information at national level.

**PLEASE BE AWARE THAT THE CONTENT OF THIS REPORT, WHICH DETAILS CHILD DEATHS, MAY BE DISTRESSING FOR SOME READERS.**







## A MESSAGE FROM ONE OF OUR PATIENT AND PUBLIC INTEREST REPRESENTATIVES

“When I was asked to be a Patient and Public 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 broken-hearted 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, Patient and Public Interest Representative*



## Total Child Deaths in Ireland 2019-2021 = 892

AGE	UNDER 28 DAYS 	29 DAYS TO 1 YEAR 	1 – 14 YEARS 	15-18 YEARS 
TOTAL DEATHS	46%	15%	23%	16%
BOYS/ GIRLS 	53% / 47%	51% / 49%	58% / 42%	69% / 31%
PLACE OF DEATH 	93% in-hospital 6% at home		66% in-hospital 26% at home 7% other	32% in-hospital 49% at home 19% other

Data source: Central Statistics Office (CSO) Death registration information.

# NATIONAL PAEDIATRIC MORTALITY REGISTER

# KEY FINDINGS

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



## CHILD MORTALITY ESTIMATES 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.

### 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%**.



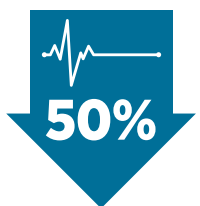
### INFANT MORTALITY IN 2021 WAS 58% LOWER THAN THAT RECORDED IN THE LATE 1990s

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.



### 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.



### 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.

## 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.



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 in the Republic of Ireland should be notified to a central national database as part of death certification. The Department of Social Protection has commenced drafting legislation relating 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 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.



## RECOMMENDATION 3

The NPMR must have a universal and standardised 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 in line with international best practice and must be received 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.



## 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.



## A MESSAGE FROM ONE OF OUR PATIENT AND PUBLIC INTEREST REPRESENTATIVES



“When joining this group as a Patient representative, I found it incomprehensible that such a database did not already exist. How could we not know how many children were dying and the circumstances of their deaths? How could we enable them to live and reduce the risk of them dying if we didn’t have such basic information? The findings of this report leave me with a deep sense of urgency that each and every one of the recommendations is implemented in its entirety. Our children, and those yet to be born depend on us to have a structured and centralised system in place for them.”

*Mary Desmond Vasseghi,  
Patient and Public  
Representative*

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