

Statement of Purpose:

National Paediatric Mortality Register (NPMR)

Document Name:	Statement of purpose for NPMR
Document No:	TEM 9
Version	1
Active Date:	01/12/2020
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National Paediatric Mortality Register

Title	National Paediatric Mortality Register
Year established	2010 Transferred to NOCA Governance in October 2020
Web address	http://www.noca.ie
Managing Organisation	National Office of Clinical Audit (NOCA)
Aim	To provide a national database of standardised information on all deaths in children and adolescents aged under 16yrs. The provision of validated and robust data, triangulated from multiple sources in a timely fashion at national level will identify issues and trends in child mortality and inform national policies. A scoping exercise will be initiated to include deaths in adolescents up to age 19yrs.
Objectives	<ol style="list-style-type: none"> 1. To provide a system for continuous national surveillance of all deaths in children aged 29 days to 15 completed years regardless of cause (<i>and including any children aged 16yrs and over still attending the paediatric hospital system</i>). This data collection will also capture deaths in neonates aged 0-28 days occurring in paediatric units. 2. Collect accurate, standardised and timely data from multiple sources on the magnitude and characteristics of childhood deaths in Ireland. 3. To build an epidemiological database of information on all paediatric deaths and provide a critical analysis of data to identify trends and subsequent recommendations on factors impacting on child mortality. 4. In collaboration with the paediatric hospitals conduct audit and research studies 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. 5. Liaise with senior decision makers at both policy and operational level to implement these recommendations (HSE Dept. of Public Health, HSE CDI (Clinical Design and Innovation) Office of the Chief Clinical Officer and other stakeholders).
Overall function & Purpose	Provide a centralised national system for collection and analysis of all data relating to mortality in the Irish paediatric and adolescent population (<16yrs) and provide high quality accurate information for development of policy and intervention strategy.




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Target population	Paediatric and adolescent population (<16yrs) nationally.
Data providers	<p>Paediatric units nationally, future goal to capture deaths occurring in the community. Three main sources of data feed into a minimum core dataset;</p> <ol style="list-style-type: none"> 1. Notification forms forwarded directly to NPMR at time of death. 2. Deaths registration details on children and adolescents <=16yrs from CSO 3. Autopsy reports provided by special arrangement with Coroners nationally. Feasibility of including HIPE data underway.
Governance and Managing Structure	<p>The NOCA Governance Board is an independent voluntary board, convened to oversee and guide the strategic direction of NOCA. The NOCA Board has the authority to issue directions to NOCA Management with regard to the various clinical audit streams.</p> <p>Individual NOCA audits are governed by a Governance Committee, which makes strategic decisions relation to the audit, and oversees operational plans. The Governance Committee includes relevant clinical and management stakeholders and two patient representatives.</p> <p>The NPMR Governance committee includes representatives from general paediatric and specialties in both CHI and regional paediatric units, the Coroners Society of Ireland, Public/Patient representatives, Dept. of Statistics TCD, HSCP, nursing and hospital management.</p>

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	<p>FIGURE 1: GOVERNANCE AND MANAGEMENT TEAMS FOR NOCA AUDITS</p> <p>NOCA Governance Structure ■ NOCA Management Structure ■ External reporting ■</p>
<p>Legal basis</p>	<ol style="list-style-type: none"> 1. Service Level Agreement (SLA) between Royal College of Surgeons in Ireland (RCSI) and the HSE Quality Improvement Division. This SLA sets out the administrative and operational management of NOCA including costs and deliverables per audit. 2. HSE Contract with Hospitals. NOCA is identified in HSE contracts with hospitals as an entity with which hospitals should work (Schedules 1 and 2).
<p>National Legislation & Standards</p>	<p>The National Clinical Audit complies with the following national legislation and standards;</p> <ul style="list-style-type: none"> • Data Protection Act (2018) • HIQA Information Standards for National Health & Social Care Data Collections (2017) • HSE National Consent Policy (2017)
<p>Inter-national Legislation & Standards</p>	<p>NPMR complies with the following: Inter-national legislation: European Union General Data Protection Regulation 2018</p>
<p>Source of funding</p>	<p>NOCA is funded by HSE Quality Improvement Team to implement national clinical audit.</p>

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Reference

HIQA (2018) Guidance on a data quality framework for health and social care. Available at: <https://www.hiqa.ie/reports-and-publications/health-information/guidance-data-quality-framework-health-and-social-care> Accessed on; 19th November, 2020.

<https://www.dataprotection.ie/en/legal/data-protection-legislation>