Document Name	NOCA Audit Process Data Quality Assessment
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Audit	National Paediatric Mortality Register (NPMR)
Purpose	This Data Quality Assessment documents the processes and controls used by the National Paediatric Mortality Register (NPMR) to ensure the quality, accuracy, completeness, timeliness and reliability of data collected and reported. The assessment is aligned with the Health Information and Quality Authority (HIQA) Data Quality Framework and evaluates current arrangements across the key dimensions of data quality. The document provides assurance regarding the quality of data collected by NPMR, identifies areas for improvement, and outlines actions to support ongoing enhancement of data quality processes. It will be reviewed periodically to ensure that the dataset, associated processes and reporting arrangements continue to meet the needs of stakeholders and support the objectives of the NPMR.
Effective from	15 June 2026
Developed by	Dr Maria Kehoe, PhD, Audit Development Manager Dr Cliona McGarvey, PhD, Paediatric Programme Manager
Date	09 June 2026
Approved by	Aisling Connolly, Head of Communications, Operations & Quality Assurance Cliona O'Donovan, Head of Data Science
Date	09 June 2026

Relevance

Relevant data meets the current and potential future needs of users.

Characteristic	Criteria	Assessment
Release and use of data	Are regular assessments carried out to determine whether all of the data that is being collected is being used?	Yes ☒ No ☐
	Has a list of key users and their use of the data been compiled, including unmet user needs?	Yes ☒ No ☐ Partially ☐
	Is this reviewed annually?	Yes ☒ No ☐ Partially ☐
Value of data	Are data users consulted to establish if the data available assists them in achieving their objectives?	Yes ☒ No ☐
	Are quality improvement plans in place to address required improvements in the data in order to ensure the data remains relevant to users?	Yes ☒ No ☐ Partially ☐
Adaptability of the data source	Are procedures in place to gather information on the potential future needs of data users?	Yes ☒ No ☐ Partially ☐
	Are data user needs prioritised as a result, of consultation undertaken with data users about how the data relates to their needs?	Yes ☒ No ☐

Additional comment

Relevance

Data elements for the NPMR notification form were defined based on a review of international datasets, amendments to legislation (Civil Registration (Electronic Registration) Act 2024 No. 27 of 2024), the General Register Office (GRO) death notification process, WHO guidelines on paediatric mortality and morbidity auditing and previous child mortality data collections (National SIDS Registry, CHI Child Death Review Pilot study). Datasets used in other jurisdictions were also reviewed such as National Child Mortality Database in England, Australian Coroners Information system, the New Zealand Child and Youth Mortality Review Committee and the USA's National Fatality Review Case reporting system to inform the final notification form.

Frontline stakeholders were involved in the co-production of the form to ensure that the data captured in the notification form provides relevant information to support those providing care for children and young people (CYP). There was consideration of the current Irish and local context. Workshops were held with a wider range of stakeholders through the NPMR steering committee at Temple St as part of a larger Quality Improvement project on child death review in the hospital with input from paediatricians from both regional hospitals and CHI, coroners, Public and Patient Interest representatives (PPIs), pathologists and statisticians in addition to input from the working group. Additional stakeholder workshops were held to illustrate the patient process flow illustrated. These identified additional data items required in the dataset to

operationalise the NPMR data collection and validation processes (e.g. notifier details for initial notification, consultant details for data verification).

Continuous engagement through working group membership is ongoing with the HSE project manager overseeing implementation of the changes to national death registration process by the HSE and the GRO. This will ensure alignment of the datasets and processes to avoid duplication. An assessment of use of data, future user need, annual review and quality improvement plans to address required data improvements will be considered at the end of phase 1 in addition to the requirements for phase 2 of the notification.

Accuracy and Reliability

The accuracy of data refers to how closely the data correctly describes what it was designed to measure. Reliability refers to whether that data consistently measures, over time, the reality that it was designed to represent.

Characteristic	Criteria	Assessment
Coverage	Are details of the reference population explicitly stated in all information releases and is the coverage of the population quantified?	Yes ☒ No ☐ Partially ☐
	Are significant coverage issues that may impact analysis and interpretation of data documented and made available to users?	Yes ☒ No ☐ N/A ☐
	Are processes in place to identify and handle duplicate and potential duplicate records within the data?	Yes ☒ No ☐ Partially ☐
Data capture and collection	Are issues with the quality of data submitted that have the potential to impact significantly on analysis and interpretation of that data addressed and documented for users of the data?	Yes ☒ No ☐ N/A ☐
Data processing	Are data validation processes applied consistently and are the processes documented for data users?	Yes ☒ No ☐ Partially ☐
Completeness and validity	Are rates of valid, invalid, missing and outlier values documented and updated routinely and reported with each data release?	Yes ☒ No ☐ Partially ☐
Revisions	Are revisions or corrections made to the data regularly analysed to ensure effective statistical use of same?	Yes ☒ No ☐

Additional comment

Accuracy and reliability
Data validation at the point of entry is included in the NPMR electronic death notification form.

Coverage
Two approaches are taken to ensuring full coverage locally in participating hospitals and at national level. NPMR will also collect information on deaths occurring outside of hospital.

The first approach involves each hospital developing a bespoke reporting system locally to ensure full coverage. The Irish National ICU Audit (INICUA) collects data in all ICUs, the Irish Paediatric Critical Care Audit collects data for paediatric ICUs and the Irish Potential Donor Audit collects information in some ICUs. Each of these data collections can identify when a patient has died in the ICU. NPMR audit coordinators can work locally with the audit coordinators for these audits locally to assess data coverage for the ICU context. Where this is not feasible, audit coordinators can access independent reports from clinical information systems to assess data coverage. A similar approach can be adopted using other systems for other areas of the hospital (such as the information system in the Emergency Department, a flagging system using the Integrated Patient Information Management Systems (IPIMS), or other local approaches e.g. medical social worker / mortuary databases obtained locally) whereby routine reports are submitted to the NPMR audit

coordinator at an agreed frequency (e.g. quarterly / biannually) depending on the number of deaths in a given hospital. Patients who die outside of the hospital and do not present to ED but who are admitted to the hospital for a post-mortem can be identified using IPIMs or the Hospital Inpatient Enquiry (HIPE) database as a medical record number is created for them for the purpose of the post-mortem. Each hospital must submit a coverage report at the end of phase 1.

The second approach involves checking the total number of submissions in a given year against the figures available through the CSO. Due to the delayed registration of many child deaths, accurate annual occurrence data is not timely; 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. Yearly summary data is published by the CSO at the end of Q4, followed by annual reports of revised occurrence data in the following year. NOCA is provided access to CSO microdata files that permit NPMR personnel to view national death registration data without the need to wait for published data. Details of 100% of CYP deaths registered in Ireland are contained in the CSO dataset. Completeness of the dataset is no less than 99.4% for all variables included.

Data capture and collection
A data capture form was developed with carefully sequenced conditional branching as a mechanism for data validation at the point of data entry and minimising the need for data collection on unnecessary items. A data dictionary was developed to ensure accurate interpretation of the questions.

Accuracy and Reliability
The accuracy of data refers to how closely the data correctly describes what it was designed to measure. Reliability refers to whether that data consistently measures, over time, the reality that it was designed to represent. Data definitions are embedded into the online questionnaire on an item-by-item basis to provide quick reference to the related definition. The online tool has in-built data validations. Conditional questions are prompted based on other entries e.g. those specific to neonates or children <5yrs. This approach further maximised validity at the point of data entry. Additional data validation checks will be performed after data capture. Many data points were tested using an earlier version of the form. Variables with a high degree of error were reviewed as part of the NPMR Child Death Notification Form pilot study. Each NPMR audit coordinator receives training and ongoing support around interpretation of the definitions to ensure accuracy. Accuracy of the NPMR data will be required and checked at case level, hospital and national level. Hospital staff will be trained in the process for filling out the NPMR form, validating and submitting accurately. This will extend to all audit co-ordinators, department heads, medical staff, and included in Non-Consultant Hospital Doctor rotation training as required.

Validity and completeness
Consultants will review any discrepancies identified during data processing and either confirmed data were correct or revise it accordingly, these are flagged directly in the system. Findings on completeness and validity will be reported in the publicly available report.

Reliability
Steps to mitigate factors that may impact the results include the development of a dataset, clear and mutually exclusive data definitions, training, development of data verification rules with immediate feedback and triangulation of data with existing national or local data sources will reduce inter-rater variation and variation over time. Processes for completion and submission of the NPMR form will be included on hospital checklists of tasks used by staff when a child dies.

There will be an assessment of consistency and pattern of responses selected across hospitals. These should be logical based on the profile of patients seen in the hospital. This will be feasible due to the small numbers of deaths. Data will be examined routinely for outliers and missing values.

Timeliness and Punctuality

Timely data is collected within a reasonable agreed time-period after the activity that it measures. Punctuality refers to whether data are delivered or reported on the dates promised, advertised or announced.

Characteristic	Criteria	Assessment
Submission timeliness	Are procedures in place to ensure the effective and timely submission of data from providers?	Yes ☒ No ☐
	Are agreements in place with data providers, which detail planned dates for submission of data?	Yes ☒ No ☐
	Are follow-up procedures in place to ensure timely receipt of data, including procedures to address necessary improvements?	Yes ☒ No ☐
Processing timeliness	Are data processing activities regularly and systematically reviewed to improve timeliness and has an associated action plan been developed and implemented?	Yes ☒ No ☐
Release timeliness and punctuality	Has a data release policy and procedures document, which includes targets for timeliness, been developed, published and implemented? Does the policy describe revisions for key outputs that are subject to scheduled revisions?	Yes ☒ No ☐ Partially ☐
	Do planned releases occur within a specified period of time from the end of the reference period?	Yes ☒ No ☐
	In the event of delays affecting a planned release, are delays and causes documented and made available to data users?	Yes ☐ No ☐ Partially ☐
	Is an up-to-date release calendar publicly available?	Yes ☒ No ☐

Additional comment

Timeliness and punctuality

Submission timeliness

One of the objectives of NPMR is to collect, complete, standardised and timely data from multiple sources on the magnitude and characteristics of CYP deaths in Ireland. Furthermore, the Civil Registration (Electronic Registration) Act (2024) will require a patient's death to be notified to the HSE and GRO within 5 days by a doctor. Doctors and NPMR audit coordinators are advised to collect data as soon as possible following a patient's death so that their data remains up to date and accessible to them. In line with this a reporting metric was developed to incentivise timely submission. This data will be available within the IT tool as follows:

- Number (%) of notifications <1day
- Number (%) of notifications 1-5 days
- Number (%) of notifications > 5 days to 4 weeks

- Number (%) of notifications > 4 weeks

Release timeliness and punctuality
It is important to frontline stakeholders to be able to access data in as close to real time as possible so that early actions can be taken to prevent avoidable deaths. Preliminary real-time reports will be available through the NPMR electronic data collection tool on basic report metrics. These reports will be based on preliminary, i.e., not fully validated data. This final national report will provide validated information suitable for benchmarking in the future.

Coherence and Comparability

Coherent and comparable data is consistent over time and across providers and can be easily combined with other sources.

Characteristic	Criteria	Assessment
Standardisation	Is data collected in line with national and international standards and classifications?	Yes ☒ No ☐ Partially ☐
	Is a data dictionary available?	Yes ☒ No ☐
	If yes, is it publicly available?"	Yes ☒ No ☐
Coherence	Is aggregated data compared with other sources of data, for example, administrative data, that provide the same or similar information on the same phenomenon?	Yes ☒ No ☐
	Are divergences identified and clearly explained to data users?	Yes ☐ No ☒
Historical comparability	Are historical changes/trends in the data documented and publicly available for data users?	Yes ☒ No ☐ N/A ☐
	Are any changes in the data/trends that can potentially have a significant impact on interpretation and analysis of data, that is, changes to key elements of the data set, documented and available for data users?	Yes ☒ No ☐ N/A ☐
Regional comparability	Is the impact of any identified differences in data across regions documented?	Yes ☐ No ☐ N/A ☒

Additional comment

Standardisation

A number of steps were taken to ensure that historical or regional comparability would be feasible in the future. A careful review of terminology ensured that the wording is consistent with accepted contemporary clinical practice. The Data Dictionary was presented and positively evaluated by the HSE Dataset

Specification Management Process (DSMP, 2024, eHealth Ireland) group to promote comparability. The National SNOMED-CT release centre was consulted. The NPMR dataset will encompass the SNOMED reference set for "Cause of Death". Further engagement with the SNOMED-CT release centre over time will inform a Paediatric specific reference set for "Cause of Death" will facilitate further standardisation and interoperability of the dataset.

Coherence
A placeholder is reserved for when the IHI becomes available. This will allow for linkage, the valuable combining of datasets in the future and to ensure comparability around the appropriate data elements across data sources.

Comparability
Regional comparability is currently not appropriate for NPMR in the absence of a suitable risk adjustment model. Thus, hospital mortality rates and other reporting metrics should be compared to their own points of centrality (median / mean) over time through run charts or SPC charts once sufficient data is available.

Accessibility and Clarity

Data are easily obtainable and clearly presented in a way that can be understood.

Characteristic	Criteria	Assessment
Accessibility	Are data available to users in a form that facilitates proper interpretation and meaningful comparisons?	Yes ☒ No ☐
	Is ICT effectively used to disseminate data and information?	Yes ☒ No ☐
Interpretability	Are supporting documents, for example, metadata, publicly available to facilitate clarity of interpretation for data users?	Yes ☒ No ☐ Partially ☐
	Does a revision policy exist which covers all data and is it available to data users?	Yes ☒ No ☐ Partially ☐

Additional comment
Accessibility and clarity

Accessibility
Report metrics were co-developed with frontline stakeholders following a review of international approaches. A simple, standardized approach was developed for the presentation of reports. It was intended to be potentially used for international benchmarking in the future, where appropriate.
PPI representatives representing families of deceased children were involved in the coproduction of the family information leaflet and will be consulted in the presentation and summary of findings in the final report. The National Adult Literacy Agency guidelines were followed in relation to the family information leaflet.

Interpretability
A complete data dictionary is available to the public.

Data Quality Improvement plan

Improvement plans for timeframe of this Data Quality statement

Driver	Improvement action	Lead	Due by
Rationale for improvement, should reference data quality dimension	Should be action orientated	NOCA lead	Expected completion date
The development phase is intended to develop and test a suitable approach for the notification of deaths in children and young people. Real world testing of the proposed approach will inevitably provide unanticipated insights and learning as to what is **relevant** to data users and what should be included.	Maintain a list of learnings pertaining to the dataset from the phase 1. Implement and test changes to the dataset and corresponding filters and metrics following phase 1.	Audit Development Manager Once the data set is revised for national implementation (if required), ongoing dataset maintenance will be led by NPMR Audit Manager	At the end of phase 1
Further engagement with the SNOMED-CT release centre, to develop a paediatric-specific reference set for 'Cause of death' will facilitate further **standardisation and interoperability** of the dataset.	Engagement with the SNOMED CT release centre in national implementation.	NPMR Audit Manager	In national implementation
Ensure data accuracy and reliability	Regular monitoring of outliers and missing values.	NPMR Audit Manager	Periodically e.g. quarterly for all data

References

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