



NPRS Data Quality Statement 2024

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1. Introduction

The National Perinatal Reporting System (NPRS) is the principal source of national data on perinatal events. Since the 1st January 2014, the Healthcare Pricing Office (HPO) has overseen the administration and management of this system. NPRS was first managed by the Department of Health (DoH) until 1999. From 1999 to 2013 the Economic and Social Research Institute (ESRI) oversaw the administration and management of the NPRS on behalf of the Department of Health and the Health Service Executive (HSE). The HPO is responsible for overseeing all functions associated with the operation of the NPRS database, including the development and support of the data collection, processing, data quality, management, reporting, and responding to requests for information on NPRS data. This reporting system is a valuable resource for informing policy and service planning.

2. Purpose of Data Quality Statement

The purpose of the NPRS Data Quality Statement is to inform data users and readers on NPRS data collection, key dimensions of data quality and strengths and limitations of NPRS Data Quality so data users can make informed judgements on the use of NPRS data.

3. Overview of Data Collection

Births are notified and registered on a standard four-part Birth Notification Form (BNF01)/electronic record which are used to notify local registrars of all live births and stillbirths occurring in Ireland. Part 1 of the BNF01/electronic record is sent to register birth/death records with the local Registrar and General Register Office (GRO) and the data is then forwarded to the Central Statistics Office (CSO) for vital statistics; Part 2 of the BNF01/electronic record is sent to the Director of Community Care in local HSE areas; Part 3 of the BNF01/electronic record is reviewed, coded and processed by the HPO; Part 4 of the BNF01/electronic record is saved on file with the hospital patient record or retained by the midwife. All identifying information from Part 3 of the BNF01/electronic record is removed and is sent to the HPO for the NPRS dataset.



4. Data Cohort & Scope

The NPRS data set provides a national minimum data set, which is intended to serve as a basis for the analysis of key indicators over time. The data collected by the NPRS can be grouped logically into demographic, clinical, and administrative data. The national NPRS database, held within the HPO, does not collect patient names, patient addresses, telephone numbers or medical card numbers. Information on all the data collected is available in the Perinatal Statistics Annual Reports which are available on www.hpo.ie or can be made available by making a data request to hipedata.requests@hse.ie (subject to terms and conditions of the data).

5. Data Source Description

NPRS: The NPRS system is a health information system designed to collect clinical and administrative data on all births including live births, early neonatal deaths and stillbirths in maternity hospitals and self-employed community midwives (SECMs) in Ireland.

DATA COLLECTION: With the objective of preserving confidentiality, each birth is recorded using case reference numbers unique to each hospital/maternity unit. The Software Development Team at the HPO has developed a custom designed NPRS data entry software system for use within the HPO. Data is received, either in electronic or paper format, from the hospitals/SECMs and processed using the NPRS data system. The Maternal and Newborn Clinical Management System (MN-CMS) has been introduced into a number of sites and uses a national numbering system. The HPO crosscheck the MN-CMS numbers with the sites to ensure accuracy and completeness.

COVERAGE: Coverage of the NPRS system is calculated by inputting the data from part 3 of the BNF01 forms that are sent to the HPO either in electronic or paper format, from the hospitals/SECMs. Missing records can be identified using the unique case reference number system and checking the yearly totals with hospitals and SECMs. Where a record is found to be missing, a request is made to the hospital/maternity unit to provide the birth notification form for any missing records. Similarly, SECMs are requested to submit an annual summary of all births attended for a specified year, which is cross-checked against the birth notification forms received. The Maternal and Newborn Clinical Management System (MN-CMS) uses a national numbering system. The HPO crosscheck totals at the end of each year with the sites to ensure accuracy and coverage completeness.



TIMEFRAMES:

The HPO requests BNF01 forms 3 months in arrears from maternity units and one month for SECM's. Previously, SECM's had a 12 month deadline to send BNF01 forms however this has since changed to one month. The NPRS file is closed every 2 years. The HPO are working hard to produce statistics in a more timely basis.

CLASSIFICATION & STANDARDS:

A number of classifications are used to code NPRS data; details of the application of Nationality, Occupation and Cause of Death coding are outlined in the table below.

Variable	Classification
Nationality	Central Statistics Office (CSO)
Occupation	Central Statistics Office (CSO)
Infant Cause of Death	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Vols. 1-3. Geneva: World Health Organisation
Main disease or congenital malformation affecting infant	
Other diseases or congenital malformations affecting infant	
Main maternal disease or condition affecting foetus or infant	
Other maternal diseases or conditions affecting foetus or infant	

Note: The collection of the variables of diseases or congenital malformation affecting foetus/infant are collected from a data quality perspective, as an explanation for cause of death, illness, or longer length of stay. The collection of variables of diseases or congenital malformation affecting foetus/infant is not mandatory for live births.



6. Overview of Data Quality Under the Dimensions of Data Quality

6.1 Accuracy and Reliability

The Accuracy & Reliability of NPRS Data is assessed based on the following characteristics:

Coverage: The NPRS collects information on approximately 55,000 birth records each year from 19 maternity units and all practicing SECM's. The NPRS team within the HPO are responsible for inputting the data on part 3 of the BNF01 into the NPRS software in the HPO. In terms of coverage, at the end of each year when 100% of the forms received have been coded, the final number is cross checked with hospitals to ensure NPRS has 100% coverage. Note: The NPRS file does not close until all coded cases are free from errors, therefore the file closure timeline can vary , as sometimes NPRS must wait for feedback from maternity units/ SECM's.

Data Capture & Collection: Accuracy of NPRS data is required at the hospital level, case level and at national level. Hospital administration staff and all practicing SECMs are trained in filling out the BNF01 form accurately and are aware to post part 3 of the form to the HPO for data entry. NPRS staff are trained in the data entry system and manually input each form into the NPRS system. Each data field collected by NPRS is defined in the NPRS Data Dictionary. The NPRS Instruction Manual is a useful resource in understanding how NPRS data is captured. Both the NPRS Data Dictionary and the NPRS Instruction Manual are available at www.hpo.ie

Data Processing: The information from Part 3 of the BNF01 is entered onto the local NPRS system by the NPRS team in the HPO. The HPO receives data to code via part 3 of the BNF01 or from the MN-CMS system. All information from the NPRS system is verified by the NPRS coder against the information available in the form. Data entry edits are built into the NPRS software which applies guidelines at data entry stage. Checks are implemented at data field level to ensure that entered information follow specified input rules and formats. Once the data is reviewed, coded and processed the HPO undertakes data quality and validation checks before it is used for publication in the Annual Reports.



Completeness & Validity: Data quality activities are performed at a hospital level and a national level. Data quality and validation checks are run monthly and annually on hospital level data.

Separate annual data quality checks are performed on national NPRS data. Quality checks include the application of a comprehensive series of edits, which are built into the custom designed NPRS data entry software to check for completeness, validity, logic, and coding errors. Any feedback or queries arising from the validation checks are sent back to hospital/midwife for review. The HPO is introducing an additional validation check in conjunction with the New-born Hearing Screening Programme to check the home births on a monthly basis.

National data on perinatal deaths is consolidated and cross checked with the National Perinatal Epidemiological Centre (NPEC). Once the data has been validated, this forms the national data set. NPRS data is then used in publishing perinatal statistics in the annual Perinatal Statistics Reports, data analysis and data requests. The HPO has released Data Quality resources such as the NPRS Instruction Manual and the NPRS Data Dictionary which are available on www.hpo.ie. The NPRS team at the HPO carry out extensive validation directly with each maternity unit and self-employed community midwives (SECMs). The NPRS team in the HPO work with maternity units and SECM's to validate NPRS case records as necessary and to confirm the total number of births, including perinatal deaths, occurring in each maternity unit/SECM each year. The HPO is working to deliver data quality reports on NPRS data across years for each participating maternity unit. This data quality report will enable maternity units to compare their statistics to national NPRS statistics across years.

6.2 Relevance

The Relevance of NPRS Data is assessed based on the following characteristics:

Release and Use of the Data: NPRS provides a national minimum data set, which is intended to serve as a basis for the analysis of key indicators over time. NPRS provides perinatal statistics and provision of information and statistics to the Department of Health, Health Service Executive and other relevant agencies such as Vital Statistics for the CSO, NPEC and Europeristat. NPRS information has a wide range of potential uses including perinatal epidemiology, planning of maternity services and input to population health profiles at health board levels. NPRS data is available upon request and is subject to terms and conditions of data use. The HPO produces the Perinatal Statistics Report on an



annual basis. In 2022 the 2020 Perinatal Statistics Report was published. The Reports are available on the HPO's website www.HPO.ie.

Value of the Data: In 2021 the NPRS Governance Group was established. The NPRS Governance group provides strategic guidance and support to the HPO, HSE, hospitals and midwives, the Department of Health and other key stakeholders in the operation and development of the NPRS and BNF01. The Governance Group ensures the provision of high quality, timely, relevant BNF data to Ireland's health information system. This is also in line with HIQA's Information management standards for national health and social care data collections (HIQA 2017) which states in Standard 2: *"The managing organisation of the national health and social care data collection has effective governance, leadership and management arrangements in place, with clear lines of accountability to ensure that its objectives are met."*

Adaptability of the Data Source: NPRS currently follows the classification from the World Health Organisation, 2005, International Statistical Classification of Diseases (ICD-10) and Related Health Problems, 10th Revision, Vols. 1-3. The HPO makes sure to keep NPRS variables up to date and relevant with ongoing variable validity review, e.g. adding and removing variables in order to keep the file relevant. For example, in 2022, the NPRS team removed the fathers details section from part 3 of the BNF01 following consultation with the NPRS Governance Group. Any new requests for additional variables are reviewed and implemented by the NPRS Governance Group on an ongoing basis.

6.3 Accessibility & Clarity:

The Accessibility & Clarity of NPRS Data is assessed based on the following characteristics:

Accessibility: NPRS information from previous years is available on request subject to terms and conditions of data use. NPRS data is only available for reporting on closed files from previous years. Details of annual NPRS data is available in the Perinatal Statistics Reports. The Perinatal Statistics Reports can be accessed on www.hpo.ie

Interpretability: The NPRS data entry edits ensure that all required fields are completed before the coded case can be stored in the NPRS system. The classifications for coding NPRS data ensure



consistent and accurate data fields are sent to the HPO. The NPRS Instruction Manual and the NPRS Data Dictionary provide specific details on the data collected. The NPRS Instruction Manual and NPRS Data Dictionary are updated regularly and are available on www.HPO.ie

6.4 Coherence & Comparability

The Coherence & Comparability of NPRS Data is assessed based on the following characteristics:

Standardisation: NPRS adheres to the World Health Organisation, 2005, International Statistical Classification of Diseases (ICD-10) and Related Health Problems, 10th Revision, Vols. 1-3, Demographic information is collected as per the CSO.

Coherence

The NPRS Data Dictionary provides a definition for each of the variables collected by NPRS. NPRS data quality is ensured at code level through the NPRS data entry system used by NPRS staff in the HPO.

Comparability

NPRS data at a national level in the Perinatal Statistics Reports is compared at an International level to allow the most recent statistics for Ireland to be compared with those for other European countries. NPRS Reports are available at www.hpo.ie

6.5 Timeliness & Punctuality:

The working deadline for NPRS data is 3 months in arrears from maternity units and one month for SECM's. The NPRS national files are made available on a two year basis following finalisation. The most up to date NPRS data available is 2021. Data users can access NPRS data through the Perinatal Statistics Reports and can also request specific information by contacting the HPO at HIPEdata.requests@hse.ie.



7. Strengths and Weaknesses

<u>DQ Dimension</u>	<u>Strengths</u>	<u>Limitations</u>
<p>Accuracy & Reliability (Accurate data refers to how closely the data correctly captures what it was designed to capture)</p>	<p>NPRS Data Quality Tools such as the NPRS Data Entry edit checks and data quality and validation checks are undertaken by the NPRS team in the HPO. The NPRS Instruction Manual and NPRS Data Dictionary are excellent resources for specific details about the data collected.</p> <p>The NPRS team undertakes numerous data quality assurance activities such as uncoded cases reports, missing case number reports, SPSS validation checks, error reports, case summary reports, and duplicate checks. The HPO communicates with relevant hospitals to correct any cases following these data quality activities.</p>	<p>There are some limitations to the physical BNF01 form that the HPO receive via post such as: Ensuring all forms are received, counted correctly and inputted correctly leaves a higher risk for human error, and missing cases to occur.</p> <p>There are also limitations with the electronic records that the HPO receive. When electronic systems such as MN-CMS are initially rolled out in hospitals it can be difficult to ensure the system is accurately capturing all of the information required for NPRS. This issue can vary from hospital to hospital. The HPO has undertaken some data quality reviews of MN-CMS data and engaged in meetings with the MN-CMS back office to try and improve this situation. Another risk associated with the accuracy and reliability of NPRS data is the documentation on the medical chart that could be misinterpreted in maternity units leading to incorrect information on the BNF01.</p>



<p>Relevance (Relevant data meets the needs of information users)</p>	<p>The establishment of the NPRS Governance Group in 2021 provides support and guidance on NPRS data. The NPRS Governance Group meet on a quarterly basis. The HPO work to keep NPRS data relevant by effectively communicating any changes to NPRS data such as reviewing, adding or removing variables in the NPRS data set and publishing annual reports.</p>	<p>NPRS data can be limited by what's available and collectable. There are limitations as to what variables are feasible for NPRS to collect. While relevant data meets the needs of data users, it may not cover specific specialities. The BNF01 can only hold so much information in its A4 format. Any changes that could be made to the BNF01 must be changed across all 4 parts of the form, therefore if NPRS want to change something on the BNF01 for part 3, it has to be agreed amongst all stakeholders who collect the BNF01 and implemented across all 4 parts of the form.</p>
<p>Accessibility & Clarity (Data is easily obtainable and clearly presented in a way that can be understood)</p>	<p>NPRS Data is easily accessible through Perinatal Statistics Reports on www.hpo.ie. NPRS data can also be requested by emailing hipedata.requests@hse.ie (subject to terms and conditions of data use).</p>	<p>The backlog in the availability in NPRS data is a limitation to the accessibility and clarity of the data and its availability to data users.</p>
<p>Coherence & Comparability (Data is consistent over time and across providers and can be easily combined with other sources)</p>	<p>The NPRS Data Dictionary & Instruction Manual are useful resources for interpreting NPRS Data. The Perinatal Statistics Reports published annually (on data 2 years in arrears) are comparable internationally and across years.</p>	<p>European comparisons on perinatal mortality rates were not available in time for the publication of the 2020 Perinatal Statistics Report for the majority of EU countries. Therefore, it was not feasible to present comparisons on perinatal mortality rates for Ireland for 2020 data. 12</p>



		<p>Previous reports in this series can be downloaded from www.hpo.ie.</p> <p>NPRS has not updated the classification from International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Vols. 1-3. Geneva: World Health Organisation. The delay in updating to the most recent classification has been to maintain consistency in data collection across years, however to ensure accurate comparability, especially international comparisons, the classification should be updated.</p>
<p>Timeliness & Punctuality Data is collected within a reasonable timescale and delivered on the promised dates</p>	<p>The implementation of the MN-CMS system across hospital sites aims to help speed up processing NPRS data. As the MN-CMS system is rolled out across more hospital sites in the future, it should have a significant impact on meeting NPRS deadlines. NPRS deadlines are crucial for timely, accurate NPRS Data available to data users.</p>	<p>Coordinating all hospitals and SECM's to send in the BNF01 to the HPO within a set deadline can be challenging as each unit has different staffing arrangements in place etc. Resource issues in the HPO have also led to a backlog in the data processing of NPRS data. External factors also impacted the timeliness of data and producing annual reports due to the COVID-19 pandemic and the HSE cyber-attack. The HPO is working to clear the backlog and produce reports one year in arrears going forward.</p>



8. References:

NPRS, Healthcare Pricing Office <http://hpo.ie/>

NPRS Data Dictionary, HPO

http://hpo.ie/nprs/nprs_documentation/NPRS_Data_Dictionary_2022_V1.4.pdf

NPRS Instruction Manual, HPO

http://hpo.ie/nprs/nprs_documentation/NPRS_Instruction_Manual_2022.pdf

Perinatal Statistics Report 2020, HPO

http://hpo.ie/latest_hipe_nprs_reports/NPRS_2020/Perinatal_Statistics_Report_2020.pdf