Health registries

Last reviewed
04 June 2026

What are health registries?

Health registries collect information to help improve health services, understand health conditions, and support better outcomes for people in Northern Ireland.

These registries monitor areas such as pregnancy and child health, neonatal care, cancer, long term conditions to help identify trends, improve quality of care, support research, and inform public health planning.

- **Neonatal Intensive Care Outcomes Research and Evaluation (NICORE)**
- **Northern Ireland Maternal and Child Health (NIMACH)**
- **Northern Ireland Cancer Registry (NICR)**
- **Northern Ireland Cerebral Palsy Register (NICPR)**

NICORE (Neonatal Intensive Care Outcomes Research and Evaluation)

Neonatal Intensive Care Outcomes Research and Evaluation (NICORE) has been routinely collecting data on neonatal units in Northern Ireland since 1994. We use this data to monitor a number of key quality markers and to ensure consistently high standards of care so that all babies admitted to a neonatal unit in Northern Ireland will benefit. The NICORE database is an important source of information which allows:

- neonatal teams to reflect on the standard of care and make the necessary changes to improve quality of care;
- neonatal teams to accurately inform parents regarding short and long-term outcomes for babies;
- neonatal teams to share good practice and compare performance with other neonatal units in Northern Ireland, the Republic of Ireland, the UK and internationally;

- HSC providers to make informed decisions about the future needs of sick babies in Northern Ireland
- researchers to carry out important studies and to contribute to existing knowledge.

Each year, approximately 2,000 newborn babies in Northern Ireland will need extra care and will be admitted to a neonatal unit. Most of these will need intensive or high dependency care.

Most babies in a neonatal unit have been born prematurely, are too small or have internal organs that have not formed properly. They all have complex needs and each baby must receive the right care at the right time, based on sound medical advice.

When your baby is admitted to a neonatal unit, details are coded using the mother’s and the baby’s unique references recorded onto a system that are confidential and can be accessed only by the health professionals caring for your baby. This includes details about your baby’s birth, birth weight, conditions, treatment, etc.

The activities of NICORE are overseen by a steering group which is comprised of representatives from a range of health professions involved in the care of your baby and from Queen’s University, genetics, ophthalmology and public health.

This project is a joint initiative between the Public Health Agency and Queen’s University, Belfast, and is funded by the Department of Health, Social Services and Public Safety (DHSSPS).

NICPR (Northern Ireland Cerebral Palsy Register)

The Northern Ireland Cerebral Palsy Register (NICPR) is a confidential record of children and young people living with cerebral palsy within Northern Ireland.

The NICPR is held at the Queen's University of Belfast and is funded by the Public Health Agency. Contact from parents and people with cerebral palsy is particularly welcome.

Further information can be found at www.qub.ac.uk/research-centres/nicpr

Contact the NICPR at:

Northern Ireland Cerebral Palsy Register
Room 1.36
Mulhouse Building
Queen’s University Belfast
Grosvenor Road
Belfast BT12 6BJ

Telephone: 028 9063 5045

NICR (Northern Ireland Cancer Registry)

The Northern Ireland Cancer Registry (NICR) is run under agreement between the Public Health Agency and Queen's University of Belfast.

The Registry is part of the Centre for Public Health (CPH) in the School of Medicine, Dentistry & Biomedical Sciences, Queen's University of Belfast.

The Registry has collaborative working links with the National Cancer Registry of Ireland, all other UK Registries, European Cancer Registries and the National Cancer Institute USA . The Registry's work is supported by a Steering Group and Council.

The purpose of the NICR is to:-

- Collect, analyse and confidentially store accurate, timely and comprehensive data on cancer.
- Uphold patient and carer confidentiality.
- Promote, facilitate and undertake research into cancer causes, prevention, treatments and outcomes.
- Facilitate planning of cancer services for prevention, diagnosis, cure and care.
- Undertake and assist audits of cancer treatments, services and outcomes, and recommend improvements in cancer services where appropriate.
- Provide appropriate information on cancer for ad hoc queries.
- Promote professional and public awareness about cancer.
- Publish scientific reports and papers relating to cancer.
- Link nationally and internationally to promote cancer registration and increase understanding and control of cancer.
- Monitor the Registry’s activities and programmes to ensure the provision of high quality data on cancer.

NICR publications are available at https://www.qub.ac.uk/research-centres/nicr/Publications/

Peer reviewed publications broken down by year are available at https://www.qub.ac.uk/research-centres/nicr/Publications/peer-reviewed-publications/

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For more information go to: www.qub.ac.uk/research-centres/nicr/

NIMACH (Northern Ireland Maternal and Child Health)

NIMACH (Northern Ireland Maternal and Child Health) collects and analyses data in support of Clinical Outcome Review Programmes.

The Clinical Outcome Review Programmes (previously known as confidential enquiries), are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers and policy makers to learn from adverse events and other relevant data. The programmes have a key role in supporting local, continuous improvements to service quality.

The Clinical Outcome Review Programmes are commissioned by The Health Care Quality Improvement Partnership (HQIP) on behalf of NHS England, DHSSPS Northern Ireland, the Health Department of the Scottish Government, the Welsh Government, the Channel Islands and the Isle of Man.

Further information related to the programmes may be found on the HQIP website at: http://www.hqip.org.uk/clinical-outcome-review-programmes/#.WvIDg_6Wzrc

Northern Ireland’s involvement in the national CORPs is commissioned by HQIP on behalf of the Department of Health and Social Services.

Within Northern Ireland, the programmes for maternal, newborn, infant and child health are coordinated via the Northern Ireland Maternal and Child Health Office (NIMACH) which is based within the Public Health Agency.

NIMACH collects and analyses data in support of :

- Maternal, Newborn and Infant programme: Coordinated by MBRRACE-UK
- Child Health programme: delivered by NCEPOD in collaboration with University of Cardiff

Key reports:

1. **Maternal, Newborn and Infant Clinical Outcome Review Programme**

- Perinatal Mortality Surveillance Report for births in 2021_MBRRACE-UK_published September 2023
- Perinatal Confidential Enquiry Report : A comparison of the care of Asian, Black and White women who have experienced a stillbirth or neonatal death_ published December 2023
- Saving Lives Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2019-21_MBRRACE-UK_published October 2023

Previous reports - https://www.npeu.ox.ac.uk/mbrrace-uk/reports

- Perinatal Mortality Surveillance Report | MBRRACE-UK | NPEU (ox.ac.uk)
- Confidential Enquiry into Maternal Deaths | MBRRACE-UK | NPEU (ox.ac.uk)

2. Child Health Programme - Chronic Neurodisability - Each and Every Need NCEPOD March 2018

3. Island of Ireland Perinatal Mortality report - Island of Ireland Perinatal Mortality report 2015-2016

NIMACH works collaboratively with National Perinatal Epidemiology Centre (NPEC) in the Republic of Ireland to compare surveillance data and learn more about perinatal mortality across the Island of Ireland as a whole.

The first Island of Ireland Perinatal Mortality report which represents the collaborative efforts of the Northern Ireland Maternal and Child Health (NIMACH) office of the Public Health Agency in Northern Ireland and the National Perinatal Epidemiology Centre (NPEC) in the Republic of Ireland was published in September 2017.

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