

TOO LITTLE, TOO LATE?

Why Europe should do more for preterm infants

IRELAND*

Country Snapshot

Key Data	
Total live births/year	76,021 in 2009
Preterm births/year	4,540 in 2009 (6%)
Estimated cost of preterm births	€ 66,017-€ 78,919 per case of extremely low birth weight € 24,079-€ 35,236 per case of very low birth weight € 2,362-€ 19,466 per case of low birth weight
Key Policies	
National plan	No
Guidelines	Active National Neonatal SubCommittee ensures consistency in neonatal clinical care Regional hospital guidelines, national guidelines covering 517,135 in 2006 (0.95%)
Planned actions	Appointment of the National Clinical Leads in Neonatology and Paediatrics, National Neonatal Hearing Screening Programme, National Paediatric Hospital, Specialist Training in Neonatology

The Health Service Executive (HSE) (in Irish, *Feidhmeannacht na Seirbhíse Sláinte, FSS*) is the publicly funded body responsible for the provision of healthcare and personal social services in Ireland. It was established by the 2004 Health Act and became operational in January 2005, under the responsibility of the Ministry for Health and Children. The HSE is Ireland's largest employer with over 100,000 direct employees, and another 40,000 in funded health care organisations. It has an annual budget of over €14 billion. In addition to the public health system, there is a wide range of private health-care services available in Ireland, which are, however, not funded and it is therefore up to the patients to cover all healthcare and treatment costs.

PREVALENCE & COST DATA

The Health Research and Information Division at the Economic and Social Research Institute (ESRI) is responsible for the collection, processing, management and reporting of data on all births in the country. The data is collected via the National Perinatal Reporting System which gathers information from the 20 maternity units in Ireland and from independent midwives. It is the only complete national reporting system on Irish births and it is generally considered an invaluable resource for policy-making and healthcare service planning. Relevant perinatal information and statistics are published in the ESRI annual Perinatal Statistics report.¹

Live births:

According to the Perinatal Statistics report, there were 76,021 live births in Ireland in 2009 which is equivalent to 17.0 births per 1,000 citizens.² The Irish birth rate

grew by 41% from 1999 (53,924 births) to 2009 (76,021 births), which makes it currently the highest birth rate of all 27 EU countries.³

Preterm births:

In 2009, preterm births amounted to 6% of total births. Preterm births are broken down as follows:

Weeks of gestation	Prevalence
<28 weeks	0.4%
28 -31 weeks	0.7%
32 -36 weeks	4.9%
37 – 41 weeks	90.6%
42 + weeks	3.4%

Prevalence of preterm births is increasing. Professionals explained this trend by increased maternal age, IVF treatment, multiple births, obesity and other dietary factors as well as the catchall effect of 'greater

* This chapter was developed by the Neonatal Subcommittee, a Division of the Irish Faculty of Paediatrics. The research was carried out between March and October 2011.

urbanisation'. Coupled with the steadily rising annual birth rate, this has led to a significant increase in demand for Irish neonatal services.

Neonatal mortality:

In 2009, neonatal mortality rate was estimated 2.0 per 1,000 births. Congenital malformation (lethal/severe) was the leading cause, accounting for 27.8% of all neonatal deaths. These were followed by other problems linked to maternal complications related to the pregnancy, placenta, cord, membranes, labour and delivery, such as maternal infections, abruption of placenta, abnormal contractions of uterus, etc, which accounted for 20.5 % of deaths.⁴

Cost burden:

Cost data for the public healthcare system in Ireland is evaluated by the National Casemix Programme⁵ and published by the Health Service Executive (HSE). In 2009, the cost burden linked to prematurity per patient per day was estimated as follows:

Newborn with birth weight under 750g, average hospitalisation length of 83,35 days:	€78,919
Every additional day in hospital:	€944
Newborns with a birth weight between 750g – 999g, average hospital stay of 62,07 days:	€66,017
Additional cost per hospitalization day:	€1,063
Newborns with birth weight between 1,000g – 1,249g:	€1,042
Newborns with birth weight between 1,250g – 2,499g: (depending on the level of care)	€433 - €1,405

The healthcare costs related to newborns requiring cardiothoracic surgery (any birth weight) were estimated to amount €2,045 per day, with an average cumulative cost of €104,766.⁶

The available data and estimations do not include additional costs and expenses incurred by the family in relation to the preterm birth or the costs related to follow up care after discharge from neonatal intensive care unit.

“ The EFCNI report is both welcome and timely. It raises the profile of premature babies in Ireland and the multitude of challenges that they and their families face. It brings the size of the problem to the attention of both the healthcare planners and the public. The prematurity rate is rising and now stands at 6%. The Report points out both the positive and negative aspects about Irish prematurity care. The challenge is to bring together a cohesive, effective Irish neonatal programme with a clear set of goals. The remit of the Clinical Lead in Neonatology is to advance this process ”

Dr John F. Murphy, Clinical Lead for Neonatology

GOVERNMENT HEALTH POLICY AGENDA

The organisation of the public healthcare system in Ireland is governed by the Health Act from 2004 which established a new body responsible for providing health and personal social services - the Health Service Executive (HSE). The HSE became operational on 1 January 2005. New structures are currently in the process of being established as part of the roll out programme planned in 2004. There is also a large private healthcare sector in Ireland.

In 2005, Ireland spent 8.2% of its GDP on healthcare, or €2,814 per capita. Of that, approximately 79% was government expenditure.⁷

Despite massive expenditure and policy reforms in recent years, the Irish public health system is facing crucial challenges, namely linked to too long “waiting lists”.⁸ A deep reform of the Irish healthcare system was initiated in June 2003 aimed at addressing this issue. Measures include improving cost efficiency, increasing coordination with hospital management structures and targeting interventions around particular backlogs.⁹

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The new public health policy framework is currently under development and is expected to be ready by the end of 2011. It will set up the public health policy agenda for 2012 – 2020 and is expected to focus on 4 key issues, namely wider determinants of health and health inequalities, chronic disease and lifestyle, inter-sectoral and cross-sectoral approaches to health policy and practice and protection from and responses to public health threats (e.g. alcohol and drug abuse).

NEONATAL HEALTH POLICY

There is currently no national neonatal health policy or programme in place in Ireland. However, within the Faculty of Paediatrics of the Royal College of Physicians of Ireland (RCPI), there is an active Neonatal Sub - Committee ensuring a certain level of consistency in neonatal clinical care. Some official clinical guidelines have been established to date and a number of policy recommendations have been endorsed by the Faculty of Paediatrics of RCPI, including policy on care at the threshold of viability,¹⁰ policy on vitamin D and vitamin K supplementation, management of respiratory distress syndrome, management of exposure to HIV in neonatal/perinatal period and policy on management of infants born to diabetic mothers. Nation-wide policy on management of infants of GBS positive mothers is yet to be developed.

The Directorate of Clinical Strategy and Programmes (DCSP)¹¹ and the Directorate of Quality Risk and Clinical Care, within the HSE, are responsible for strengthening clinical leadership, improving clinical performance, and optimising efficiency and quality in healthcare delivery. The Clinical Strategy and Programmes Directorate establishes national targeted programmes to achieve these goals. The Clinical Lead for Neonatology (CLN) is responsible for developing the strategy for the provision of neonatal services across the country, as part of the overall National Programme for Paediatrics (NPP), with the active involvement of the National Director for Paediatrics. It is through this governance structure, including the DCSP, NPP with its director and CLN, that clinical management guidelines will be approved.¹² In 2008, an 'Independent review of maternity and gynaecology services in the greater Dublin area',¹³

included a thorough assessment and recommendations of neonatal care management, which have largely become the general HSE practice.

The Neonatal Intensive Care Outcomes Research and Evaluation database (NICORE)¹⁴ collects relevant data independently and provides a regional picture of neonatal intensive care admissions in the Republic of Ireland and Northern Ireland¹⁵. This data is used to evaluate the performance of participating neonatal units at national level and compare their results/outcomes. It is a joined project between units in the Republic of Ireland (through the National Perinatal Epidemiology Centre, at the University College Cork) and Northern Ireland.

PREVENTION & SCREENING

In Ireland, all expectant mothers are entitled to free maternity care, covering antenatal visits, labour, delivery and postnatal care. Antenatal care is generally provided by a family doctor (general practitioner) for the first 12 weeks of pregnancy. After this, general practitioners provide 6 examinations during the pregnancy, which are alternated with visits to a hospital obstetrician at the maternity units. The first visit to the hospital antenatal clinic should take place by the 20th week. When particular risks of preterm birth have been identified, women are often redirected to hospitals with specialised neonatal units. In Ireland there is no consistent national policy on the provision of prenatal screening and diagnosis and the availability of such tests is inconsistent. The practice of sonographic and serum screening for abnormalities such as foetal aneuploidy is not clearly defined, with some centres offering routine sonographic screening and serum screening, while others perform partial screening tests or indication-based ultrasounds.

The Clinical Advisory Group of the Institute of Obstetricians and Gynaecologists, based at the Royal College of Physicians of Ireland¹⁷ was set up in 2010 to work with the HSE and the National Director for Obstetrics and Gynaecology with the aim to develop and implement national clinical guidelines on prevention, prenatal care and screening, including on issue such as ultrasound diagnosis of early pregnancy loss,

HIV, obesity in pregnancy, management of preeclampsia and diabetes mellitus in pregnancy and post natal period. Healthcare professionals consider that it would be beneficial to develop guidelines on the management of preterm labour.

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

There are 19 public and 1 private maternity units across the country. Out of these 19, 8 departments have the status of regional neonatal intensive care unit (Level III). These accept referrals from sub-regional centres (Level II) and general hospital based neonatal units (Level I). Regional centres are spread throughout the country but Dublin concentrates the highest number (3 of the regional centres are in Dublin and one each in Cork, Limerick, Galway, Drogheda and Waterford). Neonatal transfers requiring admission to regional units are secured by the National Neonatal Transport Programme¹⁸ (which operates both ground and air transportation means). Although this transfer system ensures broad coverage across the country, poor financial support limits its operation to only during day time (9 am - 5 pm). Out of these hours the sub-regional and general hospital units depend on their own resources to transport a newborn to a higher level of care centre. All the 8 regional neonatal centres also have to arrange their own transport team when they need to transfer newborns (5 pm to 9 am) to surgical departments in the country's paediatric hospitals. This is generally regarded as insufficient amongst medical professionals working in neonatal/paediatric medicine, who consider crucial to urgently extend the current transport system to a 24/7 service, as it can be a determining factor in preterm's survival.

Neonatal surgical services are only available in 2 paediatric hospitals in Dublin. The limited number of skilled neonatal/paediatric surgeons and lack of full time dedicated neonatal transportation system put significant pressure on the current paediatric surgical departments and will mean a future challenge as the number of preterm infants tends to increase. The Neonatal Sub - Committee has developed guidelines on

'Neonatal transport and neonatal consultant manpower requirements'.¹⁹

Standards and Guidelines:

Neonatal intensive care units across the country have developed local guidelines on usual clinical situations and are partially staffed by consultant neonatologists. The actual implementation of certain clinical practices depends on the individual preferences of the consultant neonatologist working in a particular unit. Other neonatal units not providing intensive care are part of general paediatric departments in general hospitals and as such are staffed by general paediatricians. Parents and neonatology staff have concerns about the current situation and consider crucial to ensure that the medical staff in neonatal units have the necessary experience and expertise in the neonatal practice.

The Clinical Lead for Neonatology, appointed by HSE/RCPI in 2011, is planning to develop guidelines on specialised neonatal care as of 2012, which could become very useful for practicing physicians, midwives and nurses, particularly in sub-regional neonatal units. Currently, there are guidelines on 'neonatal resuscitation, minimal standards of neonatal care'.²⁰

Some NIDCAP (Neonatal Individualized Developmental Care Program) practices are being progressively implemented in the 4 biggest neonatal intensive care units, the majority of which are located in Dublin, and there is an increasing awareness of these in the smaller units across the country. Kangaroo care is also applied in larger units. However, full implementation of developmental and family centred care (NIDCAP) is considered impossible due to the lack of space, funding and staffing. Professionals and parents deeply regret this situation and fear that the further nursing and medical staff cuts being applied will inevitably lead to an unacceptable limitation of patient access to adequate care and a decrease in quality of healthcare deliver.

Not only is neonatology not a recognised sub-speciality by the Irish Medical Council, but there is also currently no neonatal fellowship or sub-speciality programme in Irish university-based maternity hospitals, which leads to an outflow of neonatal trainees abroad. The lack of structured specialised training and education for future

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neonatologists is therefore a matter of concern in ensuring future improvement of neonatal care across the country. A proposal for Specialist Training in Neonatology has been submitted to the Irish Medical Council.

Moreover, because of rotation schemes, non consultant practitioners in Irish neonatal departments are in the very early stages of their neonatal training, thus lacking the necessary experience in exposure to the high-end levels of neonatal care. This impacts directly the quality of routine day-to-day care. Neonatal units in the country are currently not staffed according to British Association of Perinatal Medicine (BAPM) recommendations – see the UK chapter of this report.

There are well established systems of postnatal screening in Ireland. All newborns are currently screened for cystic fibrosis, phenylketonuria, homocystinuria, maple syrup urine disease, classical galactosemia and congenital hypothyroidism. In addition, there is a newly newborn hearing screening programme being implemented in the South–West HSE region which will soon be extended nationally.

Parent Involvement and Education:

In most Irish neonatal units, before the preterm infant is born, parents are counselled by the attending neonatologist/paediatrician. Visiting hours in the neonatal units are flexible with free parental access at any given time except when important procedures or staff handovers are taking place. Parental involvement in the direct care of premature infants (day-to-day care, handling, feeding, and skin care) is limited when the infant is in intensive care, but increases once the infant's condition improves. At this stage however, many parents are still cautious about getting involved in their infant's cares due to a combination of fear, lack of education and, poor and/or inconsistent, information and support from medical professionals within some neonatal units.²¹ Accommodation facilities for the parents in the neonatal units are generally inexistent or considered largely inadequate.

Towards the end of their child's hospitalisation the parents are encouraged to directly participate in the day-to-day care of their baby. However, the parental

experience and confidence is hampered by the lack of rooming-in facilities in maternity hospitals. Once parents take the baby home, they are also taught the basics of first aid and neonatal resuscitation. However, parents deeply regret that the overall support and education is insufficient and claim it should be improved urgently.

Vaccination:

While not mandatory in Ireland, vaccination is strongly advised by the health authorities and is carried out very consistently across the country by GP's, after parental consent and free of charge. All preterm infants born in Ireland follow the same immunisation schedule as full term children. The country wide vaccination program is coordinated by the HSE National Immunisation Office, which provides detailed guidance on all types of vaccinations and relevant issues.

AFTERCARE & LONG-TERM CARE

In Ireland, the long term follow up care of infants born before 33 weeks of gestation or weighing less than 1,500g is organised, for the first two years of life, by the hospital or the neonatal consultant. Infants are assessed from developmental, dietetic and physiotherapy points of view and the medical follow up care is generally provided by the same consultant neonatologist who looked after the child in neonatal intensive care or special care baby unit. Parents and health professionals involved in neonatal care strongly agree there is a lack of dedicated developmental physicians.

If early intervention is needed, the child is referred to specialised local teams. These are however considered insufficient, overbooked and understaffed with the consequent problems linked to long waiting periods to get a visit as well as late diagnosis and intervention as needed.

There is no structured follow up for infants born after 33 weeks and with a birth weight above 1,500g. The identification of any developmental issues often becomes therefore the responsibility of family physicians (GPs). Professionals and parents believe that

the current system fails to target a large percentage of infants. Healthcare professionals particularly point out that development of preterm infants may be seriously affected by the unacceptable waiting lists and therefore limited access to quality healthcare services.

Families who have the financial means often opt for private services to ensure that the child's developmental issues are timely diagnosed and quickly addressed thereby feeding the existing gap between the two tiered health system in Ireland²², which leads to increasing social and health inequalities.

SOCIAL & FINANCIAL SUPPORT

There is no specific social or financial support system for premature infants and their families in Ireland. Maternity leave lasts for 26 weeks, of which at least 2 have to be taken before the end of the week of the infant's expected birth and at least 4 after, according to the Maternity Protection (Amendment) Act 2004. The mother can decide how she prefers to take the remaining weeks. There is no additional maternity leave granted for mothers of premature babies.

Employers are not obliged to pay women on maternity leave.²³ Instead, maternity benefit is paid by Department for Social Protection for 26 weeks, with the amount depending on the mother's previous earnings.

For families with other children, the financial and social strain of combining caring for children at home whilst also visiting the NICU is immense and currently there are no standardised social service provisions to alleviate this. Any assistance that they receive depends largely on where in the country they are located and how sympathetic their local social officer is.²⁴

Parents of premature infants with a high degree of disability may be eligible to general support schemes, such as the Domiciliary Care Allowance²⁵, the Carer's Allowance²⁶ and Drugs Payment Scheme²⁷. However, these options remain accessible for families only with infants with serious disabilities, which in practice only cover a

limited percentage of preterm infants. A significant financial burden therefore remains, with those families with infants with mild/moderate disabilities.

OUTLOOK

Awareness about the implications of prematurity and the value of targeted action remain very low amongst public and decision makers.

Neonatal care in Ireland remains very fragmented, with significant disparities across the country and units tend to work in isolation. Parents and healthcare professionals agree that the outstanding challenge to ensure quality neonatal care is to bring together a cohesive, effective national neonatal programme with a clear set of goals. They hope that the Clinical Lead in Neonatology will play a crucial role in advancing this process, but they remain committed and look forward to joining forces and engage in the process in order to ensure successful progress. Consistent implementation of neonatal care practices and after care programmes, as well as improved transport system to 24/24, are amongst the key elements of future policy action. There is also a general fear that the current economic crisis and its tremendous impact on healthcare will obstruct decision-makers in adopting an effective neonatal health policy framework.

“ The establishment of a national neonatal health programme governing all aspects of neonatal health in Ireland is essential in the delivery of a cohesive, structured and uniform high standard of care. We welcome the remit of the Clinical Lead in Neonatology which will play a key role in advancing the process towards improved neonatal intensive care across the country ”

Mandy Daly, Family Liaison Manager, Irish Premature Babies

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Key demands from parents and healthcare professionals include the following:

- Develop and implement a targeted public policy on neonatal health, with the active engagement of healthcare professionals and parents
- Increase general awareness of prematurity (its health, social and economic implications)
- Develop and implement a National Prevention and Screening Programme for high risk pregnancies
- Take active measures to improve neonatal workforce education and neonatal units staffing in order to meet international standards
- Extend the current Neonatal Transport Programme to a 24h service to ensure adequate coverage and patient access to emergency and quality care as needed.

There is significant expectations of the newly appointed Clinical Lead in Neonatology to develop national guidelines that address the issues of levels of care in neonatology, full time neonatal transport programme

and statistical information that can be used to develop economic arguments on the need of improved neonatology policy and resources at the governmental level. This process is expected to start in 2012. Access to long term care, physiotherapy and early intervention support services also need to be addressed nationally.

Plans for a new paediatric hospital are expected to take into consideration modern approaches in family centred neonatal care including rooming-in facilities and family infrastructures. This new national paediatric institution should be in operational by the end of 2016 and is expected to provide for further training opportunities for aspiring neonatologists.

The National Newborn Hearing Screening Programme²⁸ has already been implemented in some parts of the country and will be extended nationally in 2012.

¹ National Perinatal Epidemiology Centre, University College Cork, <http://www.ucc.ie/en/npec/>

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³ The Economic and Social Research Institute, http://esri.ie/news_events/latest_press_releases/perinatal_statistics_repo_3/index.xml

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⁶ Ready Reckoner 2011, National Casemix Programme, Health Service executive, www.casemix.ie

⁷ World Health Organisation, <http://apps.who.int/whosis/data/Search.jsp>

⁸ Health Service Executive, www.hse.ie

⁹ Department of Health, <http://www.dohc.ie/press/releases/2011/20110601.html>

¹⁰ Perinatal Care at the Threshold of Viability, Neonatal SubCommittee, RCPI

¹¹ Health Service Executive, http://www.hse.ie/eng/about/Who/clinical/Clinical_Strategy_and_Programmes_Directorate.html

¹² Job specification, Clinical Lead for Neonatology, National Pediatric Programme, Royal College of Physicians of Ireland, <http://www.rcpi.ie/Faculties/Faculty%20of%20Paediatrics%20Downloads/Job%20Spec%20-%20Neonatal%20Clinical%20Lead.pdf>

¹³ Independent Review of Maternity and Gynaecology Services in the Greater Dublin Area (GDA), 2008

http://www.hse.ie/eng/services/Publications/services/Hospitals/Independent_Review_of_Maternity_and_Gynaecology_Services_in_the_greater_Dublin_area_.pdf

¹⁴ Neonatal Intensive Care Outcomes Research and Evaluation (NICORE), www.ucc.ie/en/npec/report/DocumentFile-37541-en.ppt

¹⁵ University College Cork, Ireland, <http://www.ucc.ie/en/npec/publications/presentations>

¹⁶ Prenatal Screening and Diagnosis, Caoimhe Lynch, Fergal D Malone, *Ir Med J.* 2007 Mar;100(3):405-7

¹⁷ Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland, <http://www.rcpi.ie/Faculties/Pages/ObstetriciansandGynaecologists.aspx>

¹⁸ National Neonatal Transport Programme, <http://www.nntp.ie/showpage.asp?k=aboutus>

¹⁹ Ryan CA et al., Neonatal Consultant Manpower Requirements, 09/2000

²⁰ Clarke T, Connolly KD, Counahan R, Gorman WA, Griffin E, Minimal Standards of Neonatal Care for the Republic of Ireland, 19.2.1989

²¹ Irish Premature Babies, 2011, <http://www.irishprematurebabies.com/>

²² Data from Irish Premature Babies, <http://www.irishprematurebabies.com/>

²³ Citizens Information, Public Service Information, last update 2010, http://www.citizensinformation.ie/en/employment/employment_rights_and_conditions/leave_and_holidays/maternity_leave.html

²⁴ Irish Premature Babies, 2011, <http://www.irishprematurebabies.com/>

²⁵ Department of Social Protection, last update 2009, <http://www.welfare.ie/EN/Publications/sw127/Pages/1WhatisDomiciliaryCareAllowance.aspx>

²⁶ <http://www.welfare.ie/EN/publications/sw41/Pages/1WhatisCarersAllowance.aspx>

²⁷ http://www.hse.ie/eng/services/Find_a_Service/entitlements/Drugs_Payment_Scheme/

²⁸ http://www.cuh.hse.ie/Our_Services/Clinical_Services/Cork_University_Maternity_Hospital/Services_Provided/Newborn_Care/Newborn_Care/Newborn_Hearing_Screening_Programme/NHSP_-_Welcome/