

european foundation  
for the care of  
newborn infants

## EU BENCHMARKING REPORT 2009/2010

# TOO LITTLE, TOO LATE?

Why Europe should do more for  
preterm infants.

Country Highlights - EFCNI EU Benchmarking Report 2009/2010



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**“TOO LITTLE, TOO LATE?”**

Why Europe should do more for preterm infants

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**Austria**

- Austria has the highest rate of preterm birth amongst the European countries covered by the report, followed by Germany, Belgium and Spain. The number of preterm birth has increased from 8.1% in 1991 (7,407) to 11.1% in 2008 (8,639), despite the decrease of births (77,752 births in 2008, a decrease of 17.8% compared to 1991).<sup>1</sup>
- The number of infants dying during the first year of life has decreased from 1.3% in 1982 to 0.4% of total births in 2008. There are however significant differences between the different regions across the country.<sup>2</sup>
- Parents, experts and medical professionals involved in neonatal care believe that early prevention and screening to detect particular risks of preterm birth, as well as information to pregnant mothers, should be improved.
- Neonatal care standards, medical practice and the availability of specialised healthcare staff and equipment differ considerably across the country.
- Psychological support is provided to parents from the first day after a preterm infant is born. This support, as well as follow up checks, are however not consistently available across the country.
- In general, parents stress that the economic and social status of the family still plays a role when it comes to accessing high quality care, including prevention and screening.

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**Belgium**

- There is no coherent and complete data on prematurity at the national level in Belgium. A comprehensive data collection system across the country is a priority demand from parents.
- In Flanders, an estimated 5,761 babies out of 69,470 were born prematurely in 2008, equivalent to 8.3%.<sup>3</sup>
- There is a clear decrease in the early neonatal mortality rate in Flanders over the last ten years, falling from 0.25% in 1999 to 0.19% in 2008.
- In 2007, the College of Physicians recommended the Ministry of Health to develop a national perinatal health programme.
- Parents and experts stress the need to ensure greater resources for research, psychological support, specialised care and long-term follow up, through

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<sup>1</sup> Health Statistics Yearbook 2008

<sup>2</sup> Health Statistics Yearbook 2008

<sup>3</sup> National Institute for Statistics

specialisation of the neonatal services and greater resources to implement family-centred developmental care.

- Parents are well-informed on the potential health problems and risks that may occur during the first year of a preterm baby's life. However, information is generally not provided on potential complications or special needs that may appear in the longer-term.
- There are no specific guidelines for aftercare and long-term care of the preterm infants who may suffer from chronic diseases or have socio-emotional problems. The government is considering a proposal for a structured follow-up scheme during the first 8 years of a preterm infants' life.

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### Czech Republic

- In recent years there has been an increase in the birth of both low weight and preterm infants due to a number of reasons, including in vitro fertilisation treatment (linked with multiple pregnancies) and the increasing age of pregnant mothers.<sup>4</sup> In 2007, a total of 8,690 newborns weighed under 2,500g, which is equivalent to 7.6% of total live births.
- The delay in implementation of the major reform of the healthcare system, announced in 2006, is also impacting the improvement of neonatal services.
- Czech experts have expressed their deep concern about the worsening conditions of prenatal and neonatal care and have described the situation as "critical". They have warned of a disastrous increase in mortality rates if the current conditions remain.
- Healthcare professional associations provide guidelines on screening, specialised treatment and care. Family-centred care in neonatal services is considered crucial for the optimal development of preterm infants.
- Only infants born with a weight lower than 1,500 g receive specialised follow up care. Experts have called for further financial support and extended long-term care to detect and treat complications that may appear at a later stage of infancy.
- There is no adjusted or extended maternity leave for mothers with preterm infants.

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### Denmark

- In 2008, 6.8% of all births were preterm. Amongst preterm infants, 0.5% of babies were born before the 28<sup>th</sup> gestational week, 0.9% between 28 and 31 weeks and 5.8% between 32 and 36 weeks.<sup>5</sup>
- The estimated costs of care and treatment of preterm babies ranges from €1,500 to €55,460 per birth.
- Denmark has a national maternity plan, however there are no specific guidelines on the specialised care of preterm infants.

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<sup>4</sup> Institute of Health Information and Statistics (IHIS)

<sup>5</sup> Recommendations of Pregnancy Care 2009

- Experts and parents agree on the need for very preterm infants to receive care and treatment in specialised centres with the necessary expertise.
- Parents are consistently involved in the care of their preterm infants during hospital stay and in the decisions about the care and treatment provided to the child.
- Regular checks up are carried out during the first two years of life. However, the practices vary significantly from hospital to hospital. Parents highlight the need for better coordination of follow-up and long-term care, in particular for late preterm infants, for which less serious problems such as psycho-emotional disorders may appear at a later stage.
- In the case of preterm birth, maternity leave starts at the date of hospital discharge instead of the birth date.

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### France

- There is no organised or centralised data collection system which allows for a comprehensive understanding of the impact of prematurity, linked mortality, morbidity and related costs in the long-term. The existing data are considered scarce and unreliable.
- Data from the Euro-Peristat report estimates that 6.3% of births are premature in France every year. Parent associations however strongly argue that the rate of preterm births is significantly higher across the country (around 8%).
- Since 1997, there has been a decrease in newborns dying within the first 28 days, from 0.31% in 1997 to 0.25% in 2007.
- The “*Plan Périnatalité: ‘humanité, proximité, sécurité, qualité’*”, adopted for the period of 2005 – 2007, established a number of objectives to address prematurity. However, parents and healthcare professionals regret that the plan failed to effectively address all the challenges, to provide sufficient financial support and to promote specialised healthcare staff in neonatal services.
- There are no harmonised national guidelines on the care and treatment of preterm infants, and no structured follow-up programmes.
- Following strong mobilization from parents, maternity leave in the case of preterm birth has been extended to cover the period of hospitalisation after birth.

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### Germany

- Data on prematurity is collected by local clinics on a voluntary basis. However, the information gathered across the different federal states is not consistent and comparable.
- In 2007, 7.1% of all births in Germany were preterm (48,678). In the same year, a total of 2,371 neonatal deaths were reported, representing a mortality rate of 0.35%. Among infants born before the 26<sup>th</sup> week of gestation, the mortality rate was 34.6%.<sup>6</sup>

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<sup>6</sup> Hummler et al., *Mortality and Morbidity of Very preterm infants in Baden-Württemberg Depending on Hospital Size. Is the Current Degree of Regionalization Adequate?* Z Geburtshilfe Neonatol 2006; 210:6-11,

- The independent expert study BabyCare, conducted in Lower-Saxony, estimated that the short term costs related to preterm birth exceed those of a full term birth by approximately €10,550 per child. In 2007, the extra costs associated to preterm birth were estimated to represent approximately €496 million per year. Costs could be reduced by around €129 million through the implementation of targeted prevention programs.<sup>7</sup>
- Socio-economic inequalities are still considered to play a role when it comes to access to screening and prevention programmes. There are wide differences across the country. Parents and specialists agree that equal access to adequate screenings, irrespective of the economic status and place of residence of the pregnant mother, are an urgent need.
- There is guidance for hospitals caring for preterm infants in order to ensure that low-weight preterm infants are treated in specialised neonatal units with specialised staff and equipment. Stakeholders highlight the need to guarantee the required specialisation of services and sufficient resources.
- There are no national guidelines or recommendations on parent involvement and family-centred care, and the practice varies significantly depending on the individual hospital and available resources in the neonatal unit.
- Parents regret the lack of sufficient financial resources to provide training to neonatal professionals and for the improvement of neonatal services.
- In the case of preterm birth, maternity leave can be extended for 4 additional weeks.

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### Italy

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- In 2006, the overall rate of preterm births in Italy was estimated at 6.5%. The Ministry of Health considers that socio-economic factors play an important role in the occurrence of preterm births.
- In 2005, neonatal mortality rate amounted to 0.37%.<sup>8</sup>
- In 2008, a total budget of €7 million was allocated to improving and establishing specialised neonatal intensive care units and €3 million was dedicated to improve neonatal screening of genetic hereditary and metabolic pathologies.
- There are no medical guidelines or policy guidance on neonatal prevention and screening at the national level. Healthcare professional organisations publish guidelines on prevention and screening at a regional level.
- The involvement of parents in the care of their preterm baby is considered poor, with wide variations between the different regions across the country.

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*WIdO study in a current hospital report shows: by increasing minimum numbers of premature and newborn infants with very low birth weight treated mortality can be avoided. Kinderkrankenschwester. 2009 Jun;28(6):258.*

<sup>7</sup> Baby care study, <http://www.baby-care.de/index.html>

<sup>8</sup> Certificato di Assistenza al parto, Analisi dell'Evento nascita – 2006, Ministero della Salute (Italian Ministry of Health, Analysis of the birth event, 2006),

- The number of neonatal intensive care units (NICUs) in Italy is considered to be far below current needs and recommended capacity, causing mothers and infants to be transferred to regular hospitals soon after delivery. A study by CeDAP showed that there are only 116 neonatal intensive care units (NICUs) in 554 hospitals covered in the study.
- In 2008, The Ministry of Health encouraged healthcare professionals to provide long-term care and follow up of extremely preterm infants until the age of 14 years. In general, access to follow-up programmes varies significantly across the regions.

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### Netherlands

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- In 2007, 13,121 infants were born prematurely (7.6% of the total number of births), a slight decrease compared to 2006 when the estimated share was 7.9%.<sup>9</sup>
- The same year, 532 preterm infants died during the first week of life (0.31%), out of a total of 634 deaths reported (0.37%). The mortality rate has been stable over the last few years.<sup>10</sup>
- The costs involved in follow-up care were estimated as comparable to the costs incurred by one child in a neonatal intensive care unit during one day.
- A new perinatal registry is currently being developed in order to allow for comparisons with data from other countries.
- Screenings aimed at detecting the risk of preterm birth are not in place. Equally, there are no specific educational or support measures for families at risk of preterm birth.
- Hospitals are increasingly involving parents in infant care and implementing developmental care practices.
- Neonatal care and specialised treatment are reimbursed in the Netherlands.
- In 2000, the *Gezondheidsraad* stated that the shortage and inadequate training of nurses and the lack of sufficient cots undermined the quality of intensive neonatal care. 7 years later, the Special Perinatal Care section of the Dutch Association of Obstetrics and Gynaecology reported that this situation had not changed; causing a high number of patients (17.4%) had to be transferred to another region.
- Neonatal specialists agree that follow-up care should be extended from 2 years to 4 years after birth, to improve the health of the infant in the longer-term and to save costs to the healthcare system.
- However, there are no specific support measures for preterm infants and their families. It is uncertain if the government will approve the extension of maternity leave in the case of preterm birth, which is a strong demand from stakeholders.

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### Poland

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<sup>9</sup> 2007 Yearbook Perinatal Care in the Netherlands

<sup>10</sup> 2007 Yearbook , The Netherlands Perinatal Registry, 2007,

- It is estimated that approximately 24,000 babies are born prematurely every year, which is around 6-7% of all live births. This represents a significant reduction since the late 1990s, when the rate of preterm births stood at 11%.<sup>11</sup>
- Data from 2009 estimate the perinatal mortality rate at 0.76% and the neonatal mortality rate at 0.49%.
- Although Poland took important steps in the early 1990s to decrease perinatal mortality and morbidity, no additional steps have been taken. On the contrary, for example the government ended reimbursements for birthing classes and reduced the length of free-of-charge periods in hospital for breast-feeding mothers.
- However, the current National Health Programme identifies women, newborn babies and children as one of its priorities. The programme focuses amongst other on reducing the rate of preterm births to 5.5% and the early mortality rate to 3.0 per 1.000 births by 2015. Experts are, however, critical about the practical outcomes of these policy targets and regret that due to budget restrictions, some commitments remain only theoretical.
- There is no specific body in place responsible for the coordination of the neonatal services and the monitoring of qualitative outcomes.
- Access to prevention and screening of pregnant mothers vary greatly between the regions. Depending on the place of residence, only 40-60% of all women visit a doctor during the first trimester.<sup>12</sup>
- It is generally perceived that parents receive insufficient information about the risks and potential long-term complications that may appear during a preterm infant's early years. Especially the lack of psychological support for parents, resources to implement family-centred developmental practices and structured long-term care are important weaknesses of the system in Poland.
- Access to specialised follow-up care remains very limited.

### Portugal

- In 2007, there were approximately 9,296 preterm births in Portugal, an increase from 5.9% in 2000 to 9.06% in 2007.<sup>13</sup>
- Portugal has a national framework programme in place since 1991 (the *Programa Nacional de Saúde Materno Infantil*) which has been shown to be very successful in recent years, based on continued analysis of data and priority actions. In 2009, this framework was strengthened through the creation of the National Commission for Maternal, Child and Adolescent Health.
- Experts stress the need to analyse the reasons for an increased preterm birth rate in the country, and also to understand whether neonatal policies are being equally implemented throughout the country.

<sup>11</sup> National Consultant in Neonatology Prof. dr hab. med. Ewa Helwich, oral interview (5 November 2009) and a written response

<sup>12</sup> Ministry of Health, Rozporządzenie Ministra Zdrowia w sprawie formy opieki medycznej nad kobietą w ciąży, uprawniającej do dodatku z tytułu urodzenia dziecka, 18 września 2009, Ministerstwo Zdrowia

<sup>13</sup> National Institute of Statistics

- Prevention and screening are well organised, with more than 80% of women initiating medical follow-up before the 16<sup>th</sup> week of pregnancy.
- Portugal follows the latest techniques for the care of preterm infants: 'kangaroo care' is a standard technique. The *Newborn Individualized Developmental Care and Assessment Program* (NIDCAP) practices are being increasingly implemented, although only two hospitals are known to have them fully in place.
- Parents are well informed and involved in the treatment of their preterm babies. Parent associations, however, point out that parents often do not receive information on possible long-term complications and how to detect them.
- Parents stress the need to improve social and financial support for the period when preterm babies are hospitalised and would like to see support from the government and employers in response to the specific needs of families with preterm babies.

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### Spain

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- In 2007, there were 32.921 preterm births (6.7%), representing a significant increase compared to the 17.000 preterm births registered in 1997.<sup>14</sup>
- The number of babies dying in Spain has progressively declined over the last 40 years. Data gathered by SEN1500, show a decreasing mortality trend amongst preterm infants with a birth weight lower than 1,500 g from 19.4% in 2002 to 15.2% in 2005.<sup>15</sup> No data is systematically collected for preterm infants with a birth weight higher than 1,500 g.
- There is no publicly available data on the costs linked to prematurity for families and the healthcare system.
- Although newborn health has been a focus of public health policies in Spain for some time, at both the national and regional level, there is currently no specific focus or national policy measure on the provision of neonatal care for preterm infants.
- In general, the healthcare budget for innovative equipment is widely available to neonatal intensive care units. Professionals and parents regret, however, that a greater focus on neonatal policy is still needed in practice, including increased financial support for improving space and skilled staffing resources in neonatal services.
- Family-centred care is recognised by leading experts and parent groups as a key element of quality neonatal care. Experts stress, however, the strong need for greater awareness and education amongst professionals about the benefits and practical implementation measures, as well as the need for greater financial support and specialised healthcare staff.
- There are no structured follow up programmes for preterm infants. Experts recognise the need for improved checks ups for both late and extreme preterm

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<sup>14</sup> National Statistics Institute, *Births, 2007*

<sup>15</sup> *Mortality for newborns of birth weight less than 1500g in Spanish neonatal Units (2002-2006)*, Amer J Perinatol 2007;24



infants and for better coordination between neonatal units and paediatricians in order to ensure proper follow-up during the first years of life.

- Since 2006, under the general framework to support dependent people and their families, support may be provided to families with preterm infants. The type of support may vary depending on the weight at birth and ranges from financial support to assistance at home, on the basis of the family and the baby's specific needs.

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### Sweden

- In 2008, 6,388 babies were born prematurely, representing 5.9% of total live births.
- Neonatal professionals believe that this relatively low rate is due to a number of reasons, including broad access to prenatal care (99% of the population is considered to follow prenatal follow-ups) and in vitro fertilisation with one egg to prevent multiple pregnancies.
- In 2008, the National Board of Health estimated the cost burden of premature and neonatal intensive care at €38.6 million (SEK 392 million).<sup>16</sup>
- In order to improve access to qualitative intensive neonatal services, specialised units have been centralised in a limited number of hospitals across the different regions.
- Family-centred developmental care is widely implemented in intensive units, although some variations still exist across the country.
- Recent studies have shown that family-centred care contributes to reducing the average length of a hospital stay by more than 5 days, in particular in patients with lung chronic disease, and therefore to the reduction of the healthcare-related costs.<sup>17</sup>
- In Sweden, aftercare is organised in the neonatal units by multidisciplinary teams including psychotherapists, paediatricians and neurologists. Parents are also educated on the potential long-term problems that may appear during the first years of the infant's life.

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### United Kingdom

- In England, there are approximately 54,000 preterm births every year – approximately 8.3% of the total number of live births.<sup>18</sup>
- In 2005, the neonatal mortality rate in England was estimated at 0.35%, similar to other developed countries.<sup>19</sup>
- In 2009, the NHS estimated that the national average daily unit costs for intensive care at £1,027 (€1,172), high dependency care as £788 (€899); and special care as £442 (€504).

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<sup>16</sup> National Board of Health and Welfare, *diagnose relate group costs*

<sup>17</sup> 'The Stockholm Neonatal Family Centered Care Study: Effects on Length of Stay and Infant Morbidity' (A. Örténstrand; B. Westrup. Karolinska). *PEDIATRICS* Vol. 125 No. 2 February 2010, pp. e278-e285

<sup>18</sup> Bliss, *preterm babies – definitions and statistics*,

<sup>19</sup> *Impact assessment of Principles for Quality Neonatal Care, DoH, September 2009*,

- Next to Portugal, the UK is the only other European country with a targeted national policy for neonatal health and preterm infants.
- The creation of 24 Neonatal Clinical Networks across the country in 2003 was generally considered as a crucial step forward in improving preterm infant care in England.
- The NHS Toolkit for High-Quality Neonatal Services, adopted in 2009, provided for the first time a comprehensive policy framework to ensure high quality and safety in neonatal services as well as improved long-term service management.
- The Toolkit sets out markers of good practice and audit indicators for benchmarking in a range of areas, including organisation of different levels of neonatal care, family-centred care, skilled staffing, service management and data requirements, including costs involved and resource allocation.
- Stakeholders highlight the importance of ensuring the effective implementation of these provisions, amongst other, through appropriate financial support and the adoption and implementation of NICE quality standards.
- Long-term follow up care is provided by multidisciplinary teams. Stakeholders stress the need to improve access to structured and adequately resourced follow-up care for less serious disorders.
- In the UK, there are no specific maternal or parental leave provisions or other financial support measures in the workplace for the families of preterm infants.

For more information please see <http://www.efcni.org/>

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