

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.

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CONTENTS

FOREWORD	02
PREFACE & ACKNOWLEDGEMENTS	03
EXECUTIVE SUMMARY	05
INTRODUCTION & METHODOLOGY	08
PREMATURITY	10
COUNTRY REPORTS:	11
Austria	11
Belgium	15
Czech Republic	20
Denmark	25
France	29
Germany	35
Italy	41
Netherlands	45
Poland	51
Portugal	57
Spain	63
Sweden	69
United Kingdom	75
KEY FINDINGS & CONCLUSIONS	80
HIGHLIGHTING BEST PRACTICE	86
POLICY RECOMMENDATIONS	88
ANNEXES	92

FOREWORD



Dr. Angelika Niebler

In recent years, the European Union's political institutions – and especially the European Parliament – have recognised the importance of addressing the health and well-being of targeted population groups. The ageing population; the youth population; and the special health care needs of men and women in general, have all been identified as major factors of individual, societal and economic wealth in the EU.

So far, however, we have ignored one of the most important and vulnerable groups of all – our newborn children.

Approximately one in ten babies in Europe is born prematurely and these children, together with their parents, experience enormous physical, emotional and financial challenges. They also represent a significant burden on our often struggling healthcare systems.

However, despite the considerable size and continuous growth of this group of future European citizens, the quiet voice of newborn infants is yet to be heard by Europe's policy makers. This absence of newborn infants from the EU's health policy agenda and the lack of properly funded national health policies is not only surprising, but also short-sighted. Europe's children represent our future prosperity. We should be investing in research, preventive care, diagnostics and treatment, which will protect and promote the health of this new generation.

I am delighted to support the publication of this European policy benchmarking report by the European Foundation for the Care of Newborn Infants (EFCNI) which, for the first time, puts into the spotlight the different policies and practices in place in Europe's member states to address the needs of preterm babies. This report will be invaluable to Europe's decision makers as we shape the future health and social policies of the European Union and of our member states.

I hope that the results of this report will be carefully studied by those responsible for setting health policy priorities in the months and years ahead and that with the evidence of the rising prevalence and costs of preterm birth in Europe, preterm infants and their families should be featured clearly among these priorities.

Dr. Angelika Niebler

Member of the European Parliament

TOO LITTLE, TOO LATE?

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PREFACE & ACKNOWLEDGEMENTS

The European Foundation for the Care of Newborn Infants (EFCNI) presents this EU benchmarking report to politicians and policy makers as a compelling picture of the impact of prematurity across Europe. For the first time in Europe, parents, medical professionals, including from the World Health Organization, have come together to provide comparative documentary evidence of this growing health and social policy challenge.

Preterm birth is the single, major, often preventable cause associated with infant mortality and morbidity in both developed and developing countries. In Europe, approximately 1 in 10 babies are born prematurely. Those who survive are at greater risk of developing both short and long-term health complications, including cerebral palsy, sensorial and motor disabilities, respiratory illnesses, learning and behavioural disorders. These may not always appear until a later stage in life and will often require specialised care.

We believe this report marks the beginning of a vital reflection process on the way in which Europe and its member states make provisions for newborn infants, particularly those born prematurely. By presenting the available data and reporting on national practices we hope that this report will provide the necessary impetus for policy change in order to achieve high standards of infant health and to reduce health and social inequalities across the European Union. While national practices do vary and comparable data remains extremely limited, the evidence gathered shows that coordinated action - at national and European level - could lead to significant improvements in the prevention, treatment and care of preterm infants.

It is only by making neonatal health a common policy priority that we can begin to provide a better future for our children and for the future generation.

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** The views expressed in this report are solely the responsibility of the authors and do not necessarily represent the views of the World Health Organization.*

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“ The Union of European Neonatal and Perinatal Societies (UENPS) welcomes this report, which contributes to greater knowledge about the current state of perinatal and infant health in Europe, one of the UENPS goals. With the collaboration of neonatal and perinatal societies, parents associations and health organisations and authorities in all European countries, we will be able to improve perinatal health care in the future. The partnership between UENPS and the European Foundation for Care of Newborn Infants (EFCNI) is crucial to meet this objective. ”

Union of European Neonatal and Perinatal Societies (UENPS)



“ The March of Dimes Foundation congratulates the European Foundation for the Care of Newborn Infants (EFCNI) on its EU Benchmarking Report. The Report draws much needed attention to the problem of preterm birth in Europe and offers a strong and comprehensive set of recommendations in response for consideration by the leadership of the European Union and individual countries. In support of these recommendations, EFCNI has made a commendable effort to collect and present what data currently exist on the extent of the problem across Europe. As the leader in research, intervention, education and advocacy on the problem of prematurity in the United States, the March of Dimes Foundation is pleased to support the recommendations of this report. In partnership with EFCNI and other organisations worldwide, March of Dimes looks forward to reducing the severe toll of prematurity in all countries. ”

March of Dimes



ACKNOWLEDGEMENTS

EFCNI would like to thank the many individuals who have been instrumental in the completion of this report. We express our warm gratitude to the national parent associations for their invaluable contributions and to Matthias Keller, Hugo Lagercrantz, Christian Poets and Ola Saugstad for their excellent contributions and editorial work as well as the whole editorial board.

We are also extremely grateful to Dr. Angelika Niebler, Member of the European Parliament, for her ongoing political support and for raising our issues with Europe’s policy makers, where we realise we have significant challenges and also opportunities ahead.

FUNDING

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EXECUTIVE SUMMARY

Preterm infants and their families constitute a sizeable - and growing - population group in Europe which is overlooked by governments in the provision of high quality healthcare and social support.

A child's risk of dying is highest in the first month of life - a time when safe childbirth and effective neonatal care are essential to their survival.¹ Four million neonatal deaths occur every year around the world - that is 450 every hour.² Prematurity - occurs when a baby born before 37 weeks of gestation - is the single, major (often preventable) cause associated with infant mortality and morbidity in both developed and developing countries. In Europe, the prevalence rate of preterm birth ranges from 5.5 to 11.4% - an average of 7.1% of all live births. This represents a figure of over half a million babies being born prematurely every year.^{3,4}

The mortality rates amongst newborns vary greatly depending on where babies are born and the socio economic status of the family. On average, neonatal deaths occur in more than one in every hundred births in the EU, representing 63% of the total deaths in children under five years old.⁵ Preterm infants who survive birth are at greater risk of developing both short and long-term health complications including cerebral palsy, sensorial and motor disabilities, respiratory illnesses and learning and behavioral disorders. Thousands of infant deaths, chronic disabilities and health conditions linked to preterm birth could be prevented through improved neonatal prevention, treatment and care.

PREMATURITY: A GROWING CHALLENGE

Prematurity poses a serious and growing threat to the health and well-being of the future European population.

- The data available provides evidence of an increasing number of preterm infants across Europe in the last 10 years (except in Sweden). In the European Union (EU), 7.1% of babies are born prematurely every year.
- Prevalence varies widely in the EU, from 6.3% (Sweden, France) to 11.4% (Austria), according to data from 2004 gathered by the European Perinatal Health Report. These figures are still considered to underestimate the current rate of preterm birth.

- In the last five years, there has been a considerable increase in preterm infants e.g. in Portugal, the prevalence rate has risen by almost a third, from 6.8% in 2004 to 9.0% in 2008.
- Neonatal mortality is decreasing in most of the European countries covered by the report. As more preterm infants survive, the number of babies suffering health complications increases.

The cost of prematurity in Europe is a considerable, yet underestimated, burden on families and health and social welfare systems.

- There is a general lack of comprehensive data in European countries measuring the real health-economic impact of preterm birth.
- Where available, data tends to be limited to direct costs to the neonatal unit in the immediate period after birth, with no assessment of the longer-term costs to the family, health and social welfare system.
- The feasibility of such cost assessment is to some extent dependent on the availability of comprehensive data on the morbidity linked to prematurity, such as subsequent disabilities, disorders and chronic diseases, which are absent.

Comprehensive data collection on prematurity in Europe is weak and requires a stronger, more coordinated approach.

- There is currently no single source of up-to-date, reliable and comparable European data on the prevalence, mortality and morbidity associated with prematurity.
- At the national level, there is a similar gap in the collection of data on prematurity prevalence, mortality, morbidity as well as the management of neonatal healthcare services and interventions.
- In a few countries, initiatives have recently been launched aimed at providing a clear picture of the health risks and implications of prematurity in the short and longer term (e.g. Czech Republic, Netherlands, UK, Sweden).
- Where they exist, data collection systems are often voluntary and based on different parameters, indicators and definitions. They frequently lack sustainable funding and are limited in scope to certain health risks, diseases or the first stages of the infant's life.

PREMATURITY: A POLICY PRIORITY?

Despite the growing prevalence and increasing costs, neonatal and preterm infant health rank low on the policy agendas of EU member states.

- Few EU countries have implemented targeted policies focused on neonatal health and preterm infants. Out of the 13 countries covered by this report, only two have developed targeted policies aimed at improving neonatal health (Portugal and UK).
- In most countries, the approach to neonatal health policy is fragmented and uncoordinated. Provisions for prematurity more often appear in the framework of other more general health and social policies. In this respect, it remains a secondary priority for action.
- Countries with the highest rates of prematurity in Europe are among those without a targeted national policy for neonatal health and preterm infants.
- In some countries, current economic pressures may prevent the development and implementation of neonatal health policies.

The absence of targeted neonatal policies and programmes prevents access to high quality healthcare and social support for preterm infants and their families.

- Prevention and follow up programmes during the first years of infancy are poorly implemented in most countries and in an unstructured manner. The scope of these programmes is often limited due to scarce resources and may vary significantly between hospitals and regions.
- Education and awareness about the risks of prematurity, warning symptoms, potential implications and the need for specialised (long-term) care appear to be poor amongst the general public, professionals and parents.
- The lack of specialised healthcare professionals and the implementation of innovative care methods, such as family-centred care, are preventing countries from delivering high quality neonatal health services.
- Social and financial support provided to families with a preterm infant (such as extended maternity and parental leave), appear to be non-existent in most countries.

PREMATURITY: A TIME FOR CHANGE

Urgent policy action is required at both the EU and national political level in order to tackle the growing burden of prematurity on Europe's health and social systems.

- The data available clearly demonstrates the growing impact of prematurity on infants and their families, as well as Europe's health and social systems.
- It is time for EU and national policy-makers to address this challenge by developing and implementing targeted strategies and policy measures.
- Countries such as Portugal and the UK demonstrate that targeted policy action, such as regionalisation and commitment to improving neonatal health, are essential (and effective) in ensuring high standards of healthcare and social support for preterm infants and their families.

There are targeted policy measures which should be implemented immediately in order to reduce the prevalence of preterm birth together with the associated morbidity and mortality.

- National authorities should develop and implement targeted policies aimed at improving prevention, treatment and long-term care. These policies should ensure significant and continued investment in research, the provision of specialised infrastructure and professional education on prevention, treatment, long-term care and optimal planning and management of neonatal and maternal services. Prevention and care programmes - including evaluation and quality control schemes for neonatal services, structured follow up and support interventions should also be considered.
- Family-centred and developmental care should be overarching elements of the policy measures and medical guidance aimed at prevention and long-term care of preterm infants. This includes, specifically, parental involvement at all stages – from the preventive interventions during pregnancy to decision-making and the provision of care after birth.
- Policy measures should be based on the particular situation in a member state and the specific challenges of their respective population, social and health systems. They should also be developed and implemented in close cooperation with the relevant stakeholders, in particular parents, the medical and scientific community.

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

- The EU has a key role to play in promoting a coordinated approach to ensure high standards of health and healthcare across EU countries –including the establishment of comprehensive data collection systems, supporting research and the exchange of best practice as well as the effective implementation of policy measures at the national, regional and local level.
 - Key factors which determine an effective and successful approach to tackling prematurity include:
 - *National neonatal health policy/programme*
 - *Formal dialogue between government, healthcare professionals and parents*
 - *Comprehensive data collection on prevalence/morbidity/mortality/cost burden based on standardised definitions and common measurement criteria (e.g. through registries)*
 - *Comprehensive data collection on neonatal intervention outcomes/neonatal service management based on common measurement criteria*
- *Access to antenatal care and prevention/screening programmes*
 - *Specialisation of intensive care units (e.g. through centralisation/regionalisation)*
 - *National transportation system for preterm babies and mothers at risk*
 - *National treatment and care guidelines*
 - *Structured after-care and long-term care/follow up programmes*
 - *Specialised education and training of healthcare staff in NICUs*
 - *Financial and social support for families of preterm infants (e.g. extended maternity/parental leave)*
 - *Investment in neonatal research*

¹ Saugstad OD. *Reducing Global Neonatal Mortality Is Possible. Neonatology in press*

² WHO. *The Lancet Neonatal Survival Series (accessed 8 March 2010).*

³ European Perinatal Health Report (2008). Based on data from 2004. www.europeristat.com

³ Beck S, Wojdyla D, Say L, Betrán AP, Merialdi M, HarrisRequejo J, Rubens C. *The worldwide incidence of preterm birth: a systematic review of maternal mortality and morbidity. Bull World Health Organ. 2010;88:31-38.*

⁵ WHO. *The Lancet Neonatal Survival Series (accessed 8 March 2010).*

INTRODUCTION

The European Foundation for the Care of Newborn Infants (EFCNI) is publishing the report: *“Too little, too late? Why Europe should do more for preterm infants”* with one very clear objective – to give a voice to one of Europe’s most vulnerable, yet overlooked, patient groups – preterm infants.

EFCNI envisages that the findings of the report will initiate a European-wide debate on the subject of prematurity in Europe and, ultimately, drive the development of public policies that will reduce the rate of preterm birth and, at the same time, improve the outcomes for infants born prematurely.

AIMS AND OBJECTIVES

By compiling the available statistical evidence and producing a comparison of the current health and social policies and practices in Europe’s member states, we hope to paint a clear picture for EU and national policy makers of the burden of prematurity – for the infants and their families, and for the health and social system. It will also highlight the gaps and inequalities which exist across Europe.

EFCNI strongly believes that the presence of a national policy or action plan is a good indication that the challenge of prematurity is taken seriously and considered as an important government priority. Such a policy or action plan also requires that specific measures are put in place at the national, regional and local level to address prematurity and are supported by appropriate government funding, quality control and management measures.

As well as highlighting the absence of such policies in Europe, this report also seeks to highlight best practice in countries where government policies have been successful in tackling the considerable health and social challenge.

STRUCTURE AND SCOPE

This report comprises of a series of individual country reports, focusing on 13 EU member states. These include the following countries: Austria, Belgium, Czech Republic, Denmark, France, Germany, Italy, Netherlands, Poland, Portugal, Spain, Sweden, and United Kingdom.

For each country, the report aims to assess the following areas of relevance to prematurity:

- Prevalence and cost
- Government health policy agenda (general)
- Neonatal health policy
- Prevention and screening
- Medical treatment and care
- After-care and long-term care
- Social and financial support
- Outlook

Based on an analysis of the policies and programmes which have been put in place (or which are absent) in these countries, the report also draws a number of conclusions and puts forward a series of policy recommendations for consideration at both the EU and national level.

METHODOLOGY

This report was conducted on behalf of the European Foundation for the Care of Newborn Infants (EFCNI) in the second half of 2009. The findings were based on the results of targeted desk research and one-to-one interviews with national policy makers and stakeholders. The final report was subject to expert review by a group of leading gynaecologists and neonatologists working in the field of prematurity. The report is not intended as a scientific or statistical report; rather it provides a description, to the best of our knowledge, of the current policy environment on the basis of the best available, factual information and relevant stakeholder opinions.

Desk Research – relevant information was gathered from each of the 13 European countries with regard to the prevalence of preterm birth, the cost of preterm birth to healthcare budgets, and the relevant policies, guidelines and practices in place at the national and, in some cases, regional level.

The information comes from a range of sources, including government and parent association websites, published scientific literature and media reports. Regarding the references to prevalence and cost data in countries, it should be noted that, at the time of publication, there were few comprehensive, comparative European data sources available. The figures quoted in this report should be used as an indicative reference only.

Interviews – building on the desk research, one-to-one interviews were carried out in each of the 13 countries with approximately three to four national stakeholders representing, inter alia, health ministries, neonatology experts, parents and families, and healthcare professionals.

The interviews were conducted according to a pre-defined questionnaire which aimed to further assess the burden and cost of preterm births and the existence of targeted policies for prevention, treatment and care, as well as support to families, and the extent of their implementation.

The information provided during interviews has not been attributed to individuals. However, in some cases, interviewees agreed to provide approved statements, which have been included in the report. A list of participating organisations is included in Annex 2. The majority of interviews were carried out in the interviewee's mother tongue.

While attempts were made to consult a range of stakeholder groups in the preparation of each country report, in some cases responses were not received from all groups, including health ministries, within the given time period. In this situation, reports were written on the basis of the best information available.

Expert Review – finally, the report was submitted to a group of European experts in the field of neonatology for a comprehensive review (see list of Editorial Board members).

Feedback - recognising that there may have been new developments in some countries since this report was carried out, or that there may be need for further explanation and clarification of some country chapters, EFCNI welcomes feedback on this report.

Please send any comments to the following email address: information@efcni.org.

PREMATURITY

Preterm birth occurs when a baby is born before the completed 37 weeks of gestation. While the average pregnancy lasts for approximately 37-42 weeks, babies that are delivered before the full term is completed are considered preterm. Those born before the 28th week are considered extremely preterm.

Severity of preterm birth	Gestational weeks
Extremely preterm	Less than 28 weeks
Very preterm	28-31 weeks
Moderately preterm	32-33 weeks
Late preterm	34-36 weeks

According to the most recent data available, the rate of preterm birth in Europe ranges from 5.5 to 11.4% - an average of 7.1% of all live births.¹ This represents a figure of over half a million babies being born prematurely every year. Where reliable trend data is available, the rates of preterm birth are also shown to be rising.²

While significant advances have been made in recent years to improve the care of preterm infants, there has been little progress in reducing the overall prevalence

of preterm birth. In about half of all cases of preterm birth, it is still not possible to establish the exact cause of the early delivery. Despite this uncertainty, however, a number of risk factors have been identified which are likely to increase the chances of preterm labour. Women at high risk include those with a multiple pregnancy (twins, triplets or more), those who have experienced preterm birth in a previous pregnancy, and women with uterine or cervical abnormalities and infections. Other risk factors are listed in the table below:

Lifestyle factors	Medical conditions	Demographic factors
Smoking	Infections (urinary tract, vaginal, STD)	Aged under 17, or over 35
Alcohol consumption	High blood pressure	Low socioeconomic status
Drug use	Diabetes	Ethnicity
High stress level & long work hours	Clotting disorders	
Late/no prenatal care	Underweight	
Lack of social support	Obesity	

Preterm birth is a major cause of infant mortality and morbidity in both the developed and developing world. Preterm infants are at greater risk of developing both short and long-term health complications. The earlier a baby is born, the less developed its organs will be, and the higher the risk of medical complications later in life. These include learning and motor disabilities, cerebral palsy, sensory deficits and respiratory illnesses (including Respiratory Syncytial Virus – RSV).³ Many of these complications impact a child's health and development well beyond the neonatal period.

The costs of preterm birth are, therefore, considerable. Not only is there a personal impact on the child and its family (psychologically, financially, and socially), there are also wider cost implications for public health, the healthcare and social welfare system (including direct and indirect medical costs), the economy and for society.⁴

¹ European Perinatal Health Report (2008). Based on data from 2004. www.europeristat.com

² March of Dimes. 2009. White Paper on Preterm Birth (pg. 6). Available at: <http://www.marchofdimes.com>

³ Marlow, N, N Engl J Med. 2005 Jan 6; 352(1):9-19

⁴ Petrou S. Early Hum Dev. 2006 Feb;82(2):75-6. Epub 2006 Feb 7

COUNTRY REPORTS

AUSTRIA

Country Snapshot

Key Data	
Total live births/year	77,752 in 2008
Preterm births/year	8,639 in 2008 (11.1%)
Estimated cost of preterm births	€26,200 per birth
Key Policies	
National plan	No
Guidelines	Austrian Society of Paediatric and Adolescent Medicine; hospitals
Planned actions	None

Austria's health system is completely decentralised, despite the country's federal structure of government. The Federal Ministry for Health and Women, established in 2003, is the main body responsible for ensuring compliance with the national health policies and legislation being implemented by the nine *Bundesländer* (regions). The *Oberste Sanitätsrat* (Supreme Health Council), set up by the Federal Ministry of Health and composed of leading experts in various medical disciplines, is the government's main advisory body in the field of health. It issues recommendations and opinions based on the latest scientific evidence or best clinical practices. Regional health councils in the respective regions also exist.

PREVALENCE & COST DATA

Live births:

In 2008, annual health statistics reported a total of 77,752 live births in Austria, representing a decrease of 17.8% compared to 1991.¹

Preterm births:

Despite the fall in the total number of births, the number of preterm births rose sharply from 7,407 in 1991 to 8,639 in 2008, representing an increase from 8.1% to 11.1% of total live births in Austria.² This is considered to be mainly due to the growing number of multiple births and older pregnant mothers (the number of twin births has risen from 0.9% to 1.7%).³

In 2008, 9.7% of births occurred between the weeks 33 and 37, while 1.4% took place before the 33rd week.⁴ The severity of preterm births is broken down as follows:

Weeks of gestation	Prevalence
33-37 weeks	7,552 (87.4% of the total number of preterm births)
29-32 weeks	767 (8.9% of the total number of preterm births)
28 weeks or less	320 (3.7% of the total number of preterm births) ⁵

Neonatal mortality:

The number of infants dying during the first year of life has decreased in recent years, from 1.3% in 1982 to 0.4% out of total births in 2008, with significant differences between Austria's regions. While the average neonatal mortality rate – defined as infants dying within their first year of life – across Austria averaged one infant per 1,000 live births, the figures for the *Burgenland* (1.4) were triple those of the Salzburg region (0.4).⁶

Newborns of less than 28 weeks or with a birth weight lower than 1000 g, represent 48% of the overall mortality rate.⁷ Among the extremely preterm infants the mortality rate increases sharply.⁸

Cost burden:

There is no consistent national data in Austria on the estimated costs of prematurity. According to a study published by The British Journal for Obstetrics and Gynaecology, the length of the hospital stay and the related costs for those hospitals, relate directly to the gestational week at the time of birth. Over the 10-year period monitored, every child born between 28 and 31 weeks of gestation is estimated to have generated costs of €26,200, while the estimated cost for infants born after 37 weeks was approximately €2,440.⁹

GOVERNMENT HEALTH POLICY AGENDA

Since the major health reform in Austria introduced in 2005, health policies in general, and maternal and infant health in particular, have not featured highly on the country's political agenda.¹⁰

The current government's priorities in the field of health relate to the financial sustainability of the healthcare system, restructuring health insurance funds and improving the education and training of health professionals.

NEONATAL HEALTH POLICY

In Austria, there is no dedicated government policy framework or institution dealing with perinatal or neonatal health. Maternal and infant health is currently monitored through the so-called Mutter-Kind-Pass (Mother Child Passport), which records all prevention measures, taken through the prenatal period and during the first years of life for each newborn infant. Beyond this monitoring, there are no additional specific policy measures on neonatal healthcare at the national level.

Germany's neonatal policies and care models are considered to be the main reference for Austrian professionals and parent groups, according to the Graz regional *Initiative für frühgeborene und neugeborene Babys* (Initiative for preterm and newborn babies).

PREVENTION & SCREENING

Healthcare professionals involved in the field of perinatal care consider the most important risk factors in determining preterm birth to be the mother's health (notably with regard to diabetes), the existence of a cervical malformation, infections, lifestyle, psychological factors, age and multiple pregnancies.¹¹

Currently, six standard screenings are carried out between gestational week 16 and weeks 35-38. While individual factors such as multiple pregnancies or the pregnant mother's health condition are taken into account, they do not necessarily lead to intensified screening during the pregnancy. In general, parents,

experts and medical professionals involved in neonatal care believe that early prevention and screening should be improved in order to detect particular risk factors and possible infections increasing the likelihood of a preterm birth.

More concretely, healthcare professionals have long been calling for a revision of the Mother-Child Passport in order to include regular (vaginal) screening, which is currently only covered by private health insurance.¹² A study by the *Universitätsfrauenklinik* (University Gynaecological Hospital) in Vienna estimated that broader access to this type of screening would reduce the number of preterm births by up to 5%.¹³ Experts also believe that free access to regular vaginal smears to determine the pH-value and additional cervical screening should be systematically guaranteed for all pregnant mothers.¹⁴

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

Neonatal and intensive care units for preterm infants are centralised in Austria in largely populated areas such as Vienna, Graz and Salzburg. As a result, standards regarding healthcare personnel and technical equipment differ considerably across the country. Parent groups have criticised the fact that the search for appropriate neonatal services is often left to the individual family.

Standards and Guidelines:

In Austria, intensive care may be provided to preterm infants born from 22-23 weeks of gestation, based on the health of the child, according to a recommendation by the *Österreichische Gesellschaft für Kinder- und Jugendheilkunde* (ÖGKJ - Austrian Society of Paediatric and Adolescent Medicine). Babies born before the 22nd week will usually receive only palliative care.¹⁵

The Austrian Society of Paediatric and Adolescent Medicine issues guidance on a number of issues related to care and treatment of preterm infants. Hospitals also develop their own guidelines. For example, the Medical University Clinic in Vienna, which has the country's largest neonatal unit, has developed guidelines on a range of aspects, from primary care, hygiene, respiration to development-inducing care, such as the reduction of light, noise, and stress as well as parent involvement in care. Nurses and doctors in neonatal care also receive

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

AUSTRIA

targeted skills training.

The Gesellschaft für Neonatologie und pädiatrische Intensivmedizin (GNPI – Society for Neonatology and Pediatric Intensive-Care Medicine¹⁶), also brings together neonatal professionals from Germany, Austria and Switzerland to discuss, on an annual basis, the latest scientific and clinical developments and to agree on revised guidelines for neonatal professionals.

Infectious and respiratory diseases, cognitive problems and unbalanced blood pressure are currently regarded by healthcare professionals, government officials and parents as the key health risks for preterm infants.

Parent Involvement and Education:

As soon as the risk of preterm birth is detected in pregnant mothers, neonatologists inform parents about the risks and potential complications. Parents also receive emotional support from a psychologist. The practice varies significantly, however, from hospital to hospital, as they are each entitled to establish their own guidelines.

In the large neonatal centres, psychological support is provided from the first day a preterm child is born. This support however is not available consistently across the country.

“ Compared to other EU countries such as Germany, parents in general are less informed and less organised in the area of preterm infants. ”

Dina Hotter-Rahman, Chairwoman of the Initiative for preterm and newborn babies in Graz

Vaccination:

The vaccination scheme in Austria for preterm infants is the same as for full term newborns. Vaccination is reimbursed in most but not all cases. It is not compulsory. The Federal Ministry of Health strongly recommends taking into account the gestational age of the newborn for vaccinations.¹⁷ This is in line with recommendations from the European Medicines Agency (EMA) stating that vaccination among preterm infants should not be discarded or delayed.¹⁸ Experts and parents have

highlighted the need for recommending and reimbursing additional vaccinations, such as vaccines against RSV, pneumococcal and streptococcus viruses for preterm infants.

AFTERCARE & LONG-TERM CARE

The Austrian Society of Paediatric and Adolescent Medicine issues recommendations to neonatal professionals on the care and evaluation of the health of preterm infants¹⁹. On the basis of their health, age and weight at birth, newborns are categorised as running a high or moderate risk of developing secondary complications during the first 18 months of life. For high risk infants, regular checks are recommended during the first two years of life.

The level of follow up care varies significantly across the country. Parents stress the urgent need for wider access to structured follow up care in Austria. In Vienna, whose clinics have the highest medical standards, specialised after-care is provided to monitor health outcomes during the first six years of life. After-care includes physiotherapy, logopaedia or occupational support where required.

SOCIAL & FINANCIAL SUPPORT

Parents of a preterm child benefit from extensions in both weekly payments provided during maternity leave and in parental leave. Payments are extended by 8 weeks²⁰ while both parents are also entitled to take extended parental leave of up to 36 months after the birth. The maximum period is reduced to 30 months in cases when only one of the parents is taking the leave.

“ A more equal reimbursement of specialised treatment and better after-care for preterm infants should be made a key health priority in Austria. ”

Dina Hotter-Rahman, Chairwoman of the Initiative for preterm and newborn babies in Graz

Health insurance provides monthly financial support of €436. The Austrian government provides no additional direct financial support to parents of preterm children during the hospital stay or in the longer-term.

OUTLOOK

No major changes in neonatal policy are expected in the next two years, including the allocation of financial resources. This is considered to be largely due to the current economic situation.

However, health practitioners and parents have insisted on the need for greater political support in order to

improve neonatal care in Austria. Increased financial support and improved screening programmes are considered to be crucial. Wider access to reimbursement in the case of specialised treatments has also been raised as an outstanding area for improvement. In general, parents consider that the economic situation of the family still plays a key role when it comes to accessing high quality care including prevention and screening.

With regard to the role of Europe in promoting EU-wide policies in the area of maternal and preterm infant health, parents and health officials believe this would be beneficial in Austria. Health professionals were more cautious, referring to the different standards across the 27 EU member states.

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² Health Statistics Yearbook 2008, http://www.statistik.at/web_de/dynamic/statistiken/bevoelkerung/demographische_masszahlen/publikationen?id=2&webcat=31&nodeld=203&frag=3&listid=31

³ Health Statistics Yearbook 2008, http://www.statistik.at/web_de/dynamic/statistiken/bevoelkerung/demographische_masszahlen/publikationen?id=2&webcat=31&nodeld=203&frag=3&listid=31

⁴ Health Statistics Yearbook 2008, http://www.statistik.at/web_de/dynamic/statistiken/bevoelkerung/demographische_masszahlen/publikationen?id=2&webcat=31&nodeld=203&frag=3&listid=31

⁵ Health Statistics Yearbook 2008, http://www.statistik.at/web_de/dynamic/statistiken/bevoelkerung/demographische_masszahlen/publikationen?id=2&webcat=31&nodeld=203&frag=3&listid=31

⁶ Health Statistics Yearbook 2008, http://www.statistik.at/web_de/dynamic/statistiken/bevoelkerung/demographische_masszahlen/publikationen?id=2&webcat=31&nodeld=203&frag=3&listid=31

⁷ Health Statistics Yearbook 2008, http://www.statistik.at/web_de/dynamic/statistiken/bevoelkerung/demographische_masszahlen/publikationen?id=2&webcat=31&nodeld=203&frag=3&listid=31

⁸ Health Statistics Yearbook 2008, http://www.statistik.at/web_de/dynamic/statistiken/bevoelkerung/demographische_masszahlen/publikationen?id=2&webcat=31&nodeld=203&frag=3&listid=31

⁹ Preterm birth: Better screening is necessary, *British Journal for Obstetrics and Gynaecology*, October 2005, <http://www.clinicum.at/dynasite.cfm?dsmid=69699&dspaid=537540>

¹⁰ The Health System of the future, ORF (Austrian State TV and Radio), <http://oe1.orf.at/highlights/130058.html>

¹¹ Risikoschwangerschaft – Frühgeburt, Österreichischen Gesellschaft für Prä- und Perinatale Medizin, ÖGPP – Austrian Society for Pre- und Perinatal Medicine, http://www.perinatal.at/sites/schwangerschaft_fruhegeburt.html

¹² Preterm birth: Better screening is necessary, <http://www.clinicum.at/dynasite.cfm?dsmid=69699&dspaid=537540>

¹³ Preterm birth: Better screening is necessary, <http://www.clinicum.at/dynasite.cfm?dsmid=69699&dspaid=537540>

¹⁴ Preterm birth: Better screening is necessary, <http://www.clinicum.at/dynasite.cfm?dsmid=69699&dspaid=537540>

¹⁵ Primary treatment of preterm infants along the border of viability, guidelines of the working group of neonatology and pediatric intensive care, Österreichische Gesellschaft für Kinder- und Jugendheilkunde (ÖGKJ – Austrian Society of Paediatric and Adolescent Medicine), http://www.docs4you.at/Content.Node/Spezialbereiche/Neonatalogie/Erstversorgung_von_Fruhegeborenen.pdf

¹⁶ Gesellschaft für Neonatologie und pädiatrische Intensivmedizin (GNPI – Society for Neonatology and Pediatric Intensive-Care Medicine GNPI), <http://www.gnpi.de/cms/>

¹⁷ Allgemeine Informationen zu Impfungen (General information on vaccinations), Federal Ministry for Health, <http://www.bmgfj-gv.at/cms/site/standard.html?channel=CH0953&doc=CMS1239275060666>

¹⁸ Allgemeine Informationen zu Impfungen, <http://www.bmgfj-gv.at/cms/site/standard.html?channel=CH0953&doc=CMS1239275060666>

¹⁹ Konsensuspapier zur Risikoeinstufung (Consensus paper on risk assessment), ÖGKJ, <http://www.docs4you.at/Content.Node/OEGKJ/Konsensuspapiere/Risikoeinstufung.pdf>

²⁰ Familienpolitische Leistungen in Österreich, Federal Ministry for Health, <http://www.bmgfj-gv.at/cms/site/standard.html?channel=CH0953&doc=CMS1239275060666>

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

BELGIUM

Country Snapshot

Key Data

Total live births/year	120,663 in 2007 ¹
Preterm births/year	5,761 out of 69,470 in 2008 (8.3%)
Estimated cost of preterm births	Not available

Key Policies

National plan	No
Guidelines	Recommendation on prevention by the Belgian Health Care Knowledge Centre (2004)
Planned actions	Development of prevention and screening guidelines by the federal Ministry of Health; Adoption of follow up and long-term care scheme during the first 8 years of the infant's life; Government review of financial schemes for neonatal services and strengthening family-centred care

Belgium is a federal state with three levels of government: a federal, regional (three regions including the Flemish region/Flanders, Walloon region/Wallonia and the region of Brussels-Capital; as well as three communities based on language and culture (Flemish, French and German-speaking) and local level (provinces and municipalities). The responsibility for health policy is shared between the federal, regional and community levels, and although all federal regulations apply to the whole country, there are additional regulations introduced by the regional and community authorities which may differ from each other.

PREVALENCE & COST DATA

At the time of this report's publication, only Flanders could present coherent and complete data, so this statistical overview is limited to this region. The regional registry for preterm infants is published by the Study Centre for Perinatal Epidemiology.²

Live births:

In 2007, the *Nationaal Instituut voor Statistiek* (NIS - National Institute for Statistics)³ reported 120,663 live births in Belgium: 16,161 in Brussels; 65,689 in Flanders; 38,813 in Wallonia; and 621 in the German community

Preterm births:

In Flanders, the overall rate of preterm infants is estimated to be 8.3% (5,761 out of 69,470 in 2008). The regional registry makes a distinction between the number of 'deliveries' (which includes single and multiple births) and 'births' (of babies with a weight equal to or above 500 g or as of 22 weeks of gestation). The available data suggests that the number of preterm births has remained relatively stable over the past 10 years (1999-2008) in this region. However the rate of women who delivered prematurely (between 32 and 37 gestational weeks) has slightly increased from 6.0% in 1999 to

6.3% in 2008. The overall rate of deliveries under 37 weeks in Flanders was 7.4% in 2008 (5,028 out of 68,199 deliveries): 6.4% in case of single deliveries and 57.2% in case of multiple deliveries.

Weeks of gestation (66,935 single deliveries - 2008)

33-36 weeks	5.6% (3,724 births)
Between 28-32 weeks	0.5% (359 births)
Less than 28 weeks	0.3% (222 births)

Weeks of gestation (1,264 multiple deliveries - 2008)

32-36 weeks	47.5% (601 births)
Between 28-32 weeks	7.0% (88 births)
Less than 28 weeks	2.7% (34 births) ⁵

Neonatal mortality:

2008 data for Flanders show a clear decrease in the early neonatal mortality rate over the last ten years, falling from 0.25% in 1999 to 0.19% in 2008⁶ when 135 infants died during their first seven days of life. Amongst preterm infants, the mortality rates are much higher: 33.1% for infants born before 28 weeks; 4.5% for newborns delivered between 28 and 31 weeks and 0.4% for infants born between 32 and 36 weeks.

Cost burden:

There is no consistent national data on the cost burden of prematurity for families and/or healthcare systems.

“ Despite the large number of preterm infants, society is not aware of the specifics of this situation and all potential consequences. I hope for increased awareness of the impact of preterm birth on the child, the parents and society. ”

Yannic Verhaest, VVOC Parent Association

GOVERNMENT HEALTH POLICY AGENDA

Ensuring and improving access to healthcare is the main priority on the health policy agenda in Belgium. The annual healthcare strategy for 2009⁷ identified a number of policy priorities for the Belgian (federal) Ministry of Health, namely improving access to healthcare, fighting cancer, simplifying administration through e-Health, keeping prices stable for patients and improving general medicine. In the framework of these priorities, child and maternal health per se is not considered as a high priority.

In 2006, 10.28% of the gross domestic product (GDP) was dedicated to healthcare in Belgium of which maternal and child care received only 0.14%.⁸

NEONATAL HEALTH POLICY

The Ministry of Health confirmed that the planning and recognition of hospitals is based on standards determined by the federal government, i.e. norms for the maximum number of services and criteria for recognition, such as architectural regulations and provisions related to the hospital staff. The (linguistic) communities from their side control and agree the planning, supervision and recognition of hospitals.^{9,10,11} Desk research shows that the federal standards are complemented by criteria related to quality assurance policy set out by the communities.

With regards to neonatal care specifically, standards for Neonatal Intensive Care Units (NICUs) and reimbursement of medication are a federal responsibility and therefore the same across Belgium, while policies related to prevention and vaccination are community responsibilities and can therefore differ.

The *College van geneesheren voor de moeder en de pasgeborene* (College of Physicians for Mothers and

Newborns)^{12,13} also plays an important role in implementing and monitoring the criteria for neonatal healthcare. With the ultimate aim of evaluating, ensuring and improving the quality of neonatology, the College makes recommendations to healthcare professionals involved in neonatal services.

In 2007, the College recommended the Ministry of Health to develop a national perinatal programme, including the following main components:

- development of a national register;
- development of operational strategies to improve the implementation of the current criteria and standards for neonatal services and active referral policy;
- creation of a consultative platform with the involvement of all stakeholders.¹⁴

At the time of publication of this report, no follow-up measures had been carried out. The Ministry of Health currently aims to strengthen cooperation between different neonatal services and maternity hospitals across the country, including ensuring adequate transfers to specialised intensive neonatal units as needed.

In general, clinical experts believe that patient access to quality neonatal care is satisfactory in Belgium, constantly subject to evaluation and benchmarking by the College of Physicians for Mothers and Newborns.

Experts identify respiratory failure of preterm infants as one of the most important health risks requiring specialised intensive care.¹⁵ They view cognitive, motor and behavioural disorders as the most common health risks during the infancy and teenage years.

PREVENTION & SCREENING

There is no official screening and prevention programme in place at national level in Belgium. However, in 2004, the *Centre fédéral d'expertise des soins de santé* (Federal Centre for Expertise in Health Care) at the Ministry of Health¹⁶ issued general recommendations on prenatal care for all women.¹⁷ In addition, each hospital has its own guidelines on prevention and screening, so practice may vary from one establishment to another. At the time of publication, the Belgian Ministry of Health was in the process of elaborating national guidelines on prevention in the field of maternal health.

Different guidance measures on prevention and healthcare during pregnancy exist at community level as

well (e.g. the Flemish *Kind en Gezin* -Child and Family¹⁸, the *Dienst für Kind und Familie* -Service for child and family from the German speaking community¹⁹ and the Walloon *Office de la Naissance et de l'Enfance* – Birth and Childhood Office²⁰).

Moreover, professional organisations, such as the *Vlaamse Vereniging voor Obstetrie en Gynaecologie* (Flemish Association for Obstetrics and Gynaecology) issue guidelines on care and treatment.^{21, 22}

There are no country-wide education or support measures in place to help families at risk of having a preterm infant.

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

1 in 25 newborns need specialised intensive care after birth.²³ There are 106 maternity units in Belgium and 19 recognised Neonatal Intensive Care Units (NICUs). Each neonatal unit decides its level of care as there is no existing national guidance on how the different types of care are provided i.e. what particular methods each NICU practices, such as family-centred care, kangaroo care or NIDCAP. In order to provide intensive care, units must admit at least 50 patients with a birth weight lower than 1,500g per year.

Neonatal experts have suggested that merging some neonatal services at the local and regional levels would contribute to optimising the available financial resources. Recently, the Government also announced its intention to review the financial mechanisms to fund neonatal services.

Standards and Guidelines:

The Ministry of Health is the main body responsible for establishing standards for NICUs and reimbursement of medication. Regional healthcare authorities play a role in the planning and supervision of healthcare in the hospitals located in their territory as well as in establishing additional criteria for quality healthcare.

Clinical experts have pointed out the need to improve current capacities and resources for neonatal care

to meet the target of one neonatologist per five cots and 2.5 nurses per cot²⁴, which is not always respected.

Particular treatments, such as those fighting Respiratory Syncytial Virus (RSV), are reimbursed under certain conditions as established by the *Rijksinstituut voor ziekte- en invaliditeitsverzekering* (RIZIV – National Institute for Health and Disability Insurance)²⁵. Nevertheless, parents consider as poor and inconsistent the awareness campaigns currently in place to prevent and treat specific diseases, such as RSV infection. During the hospital stay, parents receive information about the concrete health risks and potential problems their preterm baby may have.

Parent Involvement and Education:

Parents are increasingly involved in the care of their preterm infants, although the practice and access to NICUs vary across the different hospitals. The Belgian government recently announced its intention to strengthen family-centred care in neonatal units, although the concrete plans and timeline are still uncertain. From the moment of birth, parents are invited to visit their baby in the neonatal unit.

Healthcare professionals and experts consider emotional support to parents insufficient, and believe that a clear legal framework should be in place in order to ensure psychological support to parents and nurses during the hospital stay.

Parents are generally informed about the potential health problems and risks that may occur during the first year of the baby's life. This is however not the case for the potential complications or special needs that may appear in the longer-term, for which no information is provided to parents in the neonatal unit.

Vaccination:

Vaccination is a community responsibility in Belgium. It is not mandatory, with the exception of protection against poliomyelitis. Doctors, however, strongly recommend vaccinations and parents generally respect the recommendations. Vaccination of preterm infants follows the standard vaccination scheme, and it is free of charge.

AFTERCARE & LONG-TERM CARE

Long-term care is the responsibility of the Ministry of Health and Social Affairs in Belgium. Most preterm infants in need of such care are currently followed by dedicated centres to treat developmental disorders. While some hospitals and neonatal units have developed centres of reference for closer follow-up care for preterm infants during infancy, there are no common standards or guidelines in place, so the practice and level of access to longer-term care varies significantly. Since 2008²⁶, neonatal units are responsible for the organisation of structured follow-up of preterm infants with a birth weight lower than 1500 g or those born before 32 weeks. In 2009, a working group of neonatal and other experts developed a scheme for consistent follow up to screen and prevent potential long-term related disorders and chronic diseases. The proposal, currently under consideration by the Ministry of Health and Social Affairs, would authorise reimbursement of long-term care for up to 8 years, although parents have called for extended reimbursement of follow up care for at least up to 13 years.

At community level, support is provided for longer-term care. In Flanders, the child and family support service provides a number of specific services for parents of preterm infants, such as support in preparing for the arrival of the infant at home; providing information on follow-up care; as well as specialised help at home by nurses as needed. In Wallonia, support from social-medical workers is available during the first 6 years of the infants' life. The Walloon Birth and Childhood Office has recently developed a protocol for the follow-up of preterm infants, although this is not currently reimbursed. Walloon authorities are also analysing the feasibility of establishing reference centres for follow-up care, including for preterm infants.

SOCIAL & FINANCIAL SUPPORT

There are no particular social and financial support measures for families with a preterm infant. Social assistance at home is provided in the case of triple births. Other support, such as tax relief or learning support at home, is allowed in the case of infants with disabilities.

Generally, maternity leave can be up to 15 weeks and is reimbursed from 1 to 6 weeks before delivery until at least 9 weeks after birth. Mothers of multiple births are entitled to 19 weeks of maternity leave. 10 days of parental leave is granted within the 4 months after birth. In the case of hospitalisation of sick newborns, maternity leave may be extended during the hospital stay, up to a maximum of 24 weeks.

“ We need to ensure further research in this field, improved psychological support to both infants and families as well as follow-up care to preterm infants in the longer-term. ”

*Yannic Verhaest,
 VVOC Parent Association*

OUTLOOK

No major developments in the field of neonatal policy are expected in the coming months. The Ministry of Health has recently announced plans to strengthen family-centred care as well as to review the financial mechanisms for neonatal services, although the concrete measures and timeline are still uncertain.

The Ministry of Health is also expected to develop, with the involvement of healthcare specialists, screening guidelines at the national level, although there was no clear timeline for this at the time of publication. The government is considering a proposal for a structured follow-up scheme during the first 8 years of a preterm infants' life.

Following the creation of the Walloon Centre of Perinatal Epidemiology in 2007, data on neonatal health should be available across the whole country in the coming years. In addition, the College of Physicians for Mothers and Newborns is currently working on improving and standardising data collection methodologies across the different neonatal units in order to make it consistent with the European Neonatal Network (EuroNeoNet).²⁷

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

BELGIUM

¹ Most recent data at time of editing, 10 March 2010

² Studiecentrum voor Perinatale Epidemiologie, Flanders, <http://www.iph.fgov.be/epidemiomorbidity/Nl/Insti/SP.htm>

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⁴ WVOC - Flemish parent association of preterm infants, <http://www.wvoc.be/main.php>

⁵ Studiecentrum voor Perinatale Epidemiologie, Flanders, <http://www.iph.fgov.be/epidemiomorbidity/Nl/Insti/SP.htm>

⁶ Study centre for Perinatal Epidemiology 2008 Yearbook, http://www.zorg-en-gezondheid.be/uploondheidsindicatoren/Ziekte_en_gezondheid/Geboorte_en_bevalling/SPE_2008.pdf

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¹² College of Physicians for Mother and Newborn, https://portal.health.fgov.be/portal/page?_pageid=56,512701&_dad=portal&_schema=PORTAL

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https://portal.health.fgov.be/pls/portal/docs/PAGE/INTERNET_PG/HOME/PAGE_MENU/GEZONDHEIDZORG1_MENU/OVERLEGSTRUCTUREN1_MENU/COLLEGESVANGENEESHEREN1_MENU/NEONATHOLOGIE1_MENU/PUBLICATIES169_HIDE/PUBLICATIES169_DOCS/ACTIVITYCOLLEGENIC2000-2007.PDF

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²² Flemish Association for Obstetrics and Gynaecology guidelines, <http://www.vog.be/categorie?c=103>

²³ Studiecentrum voor Perinatale Epidemiologie, Flanders, <http://www.iph.fgov.be/epidemiomorbidity/Nl/Insti/SP.htm>

²⁴ Arrêté royal modifiant l'arrêté royal du 23 octobre 1964 portant fixation des normes auxquelles les hôpitaux et leurs services doivent répondre, 1996, <http://www.ejustice.just.fgov.be/loi/loi.htm>

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CZECH REPUBLIC

Country Snapshot

Key Data

Total live births/year	114,632 in 2007
Preterm births/year	8,690 premature newborns with birth weight lower than 2,500 g
Estimated cost of preterm births	(7,6% of total live births)
	Not available

Key Policies

National plan	No, but Perinatology Commission of the Ministry of Health provides guidance
Guidelines	Czech Neonatology Society (CNeoS) and the Perinatology Section of the Czech Gynecology and Obstetrics Society (PS CGPS)
Planned actions	Implementation of an overall reform of healthcare is long overdue, but has been delayed since 2006; a centre for complex care for preterm infants to open in Prague (2011)

The Ministry of Health is the main body responsible for shaping the healthcare policy agenda in the Czech Republic. Implementation of a major reform of the national healthcare system is still pending.

PREVALENCE & COST DATA

The Institute of Health Information and Statistics of the Czech Republic (IHIS) is the division of the Ministry of Health in charge of national health statistics. It collects data that neonatal units are obliged to collect at hospitals with regard to the hospitalisation, birth rates (both live birth and stillbirth), congenital defects of embryos or newborns and detection of infectious disease.^{1,2}

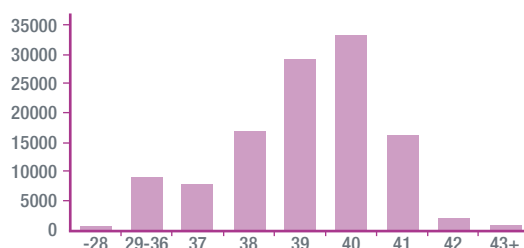
Live births:

In 2007, there were 114,632 live births in the Czech Republic. The data available show a continuous rise in live births over the past few years.

Preterm births:

In the same year, a total of 8,690 newborns weighed under 2500 g, which is equivalent to 7.6% of total live births. The data gathered by the Institute of Health Information and Statistics (IHIS) reveal an increase in low weight and preterm births in recent years³ due to multiple reasons, primarily in vitro fertilisation treatments, but also an increase in multiple pregnancies, an older average age of pregnant mothers, higher quality of available treatments and new developments in medicine.⁴ The Czech Neonatology Society⁵ has also identified socio-economic factors, in particular amongst the migrant population, as a determinant of inadequate prenatal care contributing to the rise in preterm birth deliveries in a number of cases.

Weeks of gestation⁷



Neonatal mortality:

In 2008, the National Institute of Health reported 66 newborn deaths during the first year of life.⁸ The Czech Neonatology Society and Czech Gynaecology and Obstetrics Society⁹ also collect data on mortality and morbidity in preterm infants.

Cost burden:

There is no data available on the financial burden and costs related to preterm births and neonatal care in the Czech Republic.

GOVERNMENT HEALTH POLICY AGENDA

The Ministry of Health is the main authority responsible for shaping the national health policy, including patient rights, hygiene and equipment requirements of healthcare facilities, public health insurance, hospital organisation and resources, medical professionals and mandatory statistics requirements.

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

CZECH REPUBLIC

In 2006, the government announced its plans to implement a major reform of the healthcare system aimed at resolving the chronic problem of under-funding and the resulting problems of over-crowding and low standards of healthcare services, including neonatal services. However, implementation of this reform has been delayed, and the timeline remains uncertain. Healthcare expenditure has steadily decreased since 2003. In 2007, healthcare expenditures accounted for 6.7% of GDP¹⁰, which represented a decrease of 0.17% compared to 2006. The current health priorities of the government focus on combating cancer and cardiovascular diseases with a focus on prevention.

NEONATAL HEALTH POLICY

Neonatal health policy does not rank high on the health policy agenda, and falls into the broader area of gynaecological care and the general national framework on medical care. The Ministry of Health has established the Perinatology Commission, an advisory body composed of neonatology and pediatrics practitioners as well as both the Czech Neonatology Society (CNeoS) and the Perinatology Section of the Czech Gynecology and Obstetrics Society.

There is no particular policy framework for neonatal care of preterm infants. Professional associations, namely the Czech Neonatology Society (CNeoS) and the Perinatology Section of the Czech Gynecology and Obstetrics Society¹¹ (PS CGPS) jointly provide guidance to health professionals involved in the care and management of both prenatal and neonatal care, including qualification requirements for medical professionals, clinical guidelines and recommendations on coordination and organisation of the different levels of neonatal care. The guidelines, which are developed in working groups from both professional societies, are disseminated amongst healthcare practitioners and the wider public. In addition, the Perinatology Section of the Czech Gynaecology and Obstetrics Society holds annual conferences to agree on the priorities, objectives and benchmarks of prenatal and neonatal care, based on the latest scientific evidence and clinical developments.

PREVENTION & SCREENING

Prenatal care commences as soon as the pregnancy is confirmed and it is usually delivered by gynaecologists and obstetricians. The majority of pregnant women also visit prenatal counselling clinics. Screenings are performed every four weeks up to 23 gestational weeks; every three weeks between weeks 24 to 32; every two

“ Professional societies consider the worsening conditions for the provision of prenatal and neonatal care as critical. Bed and personnel capacities are insufficient to ensure quality care and therefore it may be expected that the system of pre- and neo – natal care will disintegrate. ”

*Richard Plavka,
Chairman of the Czech Neonatology Society MD*

weeks between 33-36 weeks; and every week from week 36 until delivery. The particular screenings and tests are set up by the Perinatology Section of the Czech Gynaecology and Obstetrics Society. A bacteriological cultivation test of the cervix as well as an ECG test are run when a preterm birth is expected.¹²

Intensified screening and visits to prenatal clinics may be compulsory when a particular health risk or risk of preterm delivery is identified. In these cases and when the fetus is considered to be viable, prenatal transfers “in utero” to intermediary or perinatology centres may also be organised as from gestational week 24.

During the prenatal care, health professionals and clinics provide general information to parents on healthy lifestyles and how to prevent health risks and problems during the pregnancy.

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

Since 1995, neonatal care is organised into three levels according to the particular health conditions and risks of the infant. Hospitals and specialised centres are responsible for providing the different levels of care as set out below:

- **Level 1:** is usually provided to healthy and full-term infants in the hospital pediatric unit.
- **Level 2:** is provided in intermediary centres, to preterm infants with a birth weight lower than 2500g and from the 32nd gestation week. It is usually delivered in the hospital pediatric section with specialised equipment.

- **Level 3:** is provided in perinatology centres with intensive neonatal care units for newborns with birth weights lower than 1500g, generally between the 24th and 32nd gestation weeks. Anaesthesiology and resuscitation units also exist in these centres. Care is provided by skilled specialists, including surgeons, neurosurgeons, radiologists, ophthalmologists, anaesthesiologists educated in newborn anaesthetics, cardiologists, child orthopaedists, child neurologists, psychologists, social workers, rehabilitation and neonatal nurses. The ratio of nurses per patients varies: two nurses per patient are allocated in critical conditions and one nurse per 1-2 patients when the infant's health conditions are considered stable.

There are currently 117 basic centres, 6 intermediary centres and 12 perinatology centres across the country. In addition, there is one specialised centre for the provision of extra-corporal membrane oxygenating for newborns in the treatment and care of respiratory disease for infants weighing more than 2000g and older than 34 weeks of gestation.

Both the Czech Neonatology Society (CNeoS) and the Perinatology Section of the Czech Gynaecology and Obstetrics Society (PS CGPS) have expressed their deep concern about the worsening conditions of prenatal and neonatal care and have defined the situation as critical.¹³ Neonatal stakeholders agreed on the urgent need to improve bed and personnel capacities of neonatal units, in particular specialised technical equipment and improved access to neonatal specialists at the regional level. Professionals believe that should the current conditions remain, the mortality rate amongst preterm infants might increase disastrously. Improved access to quality neonatal services across the country, backed by sufficient financial support and skilled staff is considered crucial by professionals.^{14, 15}

Standards and guidelines:

The Czech Neonatology Society (CNeoS) and the Perinatology Section of the Czech Gynaecology and Obstetrics Society¹⁶ (PS CGPS) provide guidelines on neonatal care and treatments. During the last two decades, new care and treatment methods have been implemented across the country, including the use of antenatal steroids, transport "in utero", application of positive and expiratory pressure, controlled positive pressure ventilation, minimisation of oxytherapy and decreased artificial lung ventilation.¹⁷ Standards on resuscitation, intensive care unit bed capacities and skilled healthcare staff were last reviewed in 2000.

Healthcare professionals have called for an update and an improvement in the minimum standards for equipment and unit capacities, as well as skilled staffing policy.¹⁸ The Czech Gynaecology and Obstetrics Society is currently exploring the possibilities to implement less invasive screening methods for both diagnostics and therapy.

Parent Involvement and Education:

Parents are involved in newborn care as much as possible. Direct contact and family-centred care is considered to be crucial for the optimal development of infants. Parental access to the neonatal units is also increasingly flexible. The practice is however not uniform across the country and varies from one neonatal unit to another.

Parents believe that psychological support to families during and after the hospital stay is often inadequate and should be improved and available across the country. Non-profit organisations provide psychological support and practical advice to parents. The capabilities and practical impact of these organisations vary widely, as they do not receive any financial support from the government and therefore depend on private sponsorships or their own revenues.

Vaccination:

Vaccination against major infectious diseases is compulsory and reimbursed, as established by the Ministry of Health. Generally, preterm infant vaccination follows the same scheme as for full-term newborns. Particular vaccines, such as the ones against Hepatitis B and tuberculosis, are often postponed in the cases of infants with a birth weight lower than 2000g, over concerns that immediate vaccination could possibly entail adverse effects on the immune system. Flu vaccination is recommended for both babies and parents.¹⁹

In addition, preterm infants are provided with additional immunoglobulin doses during the first 12 hours of life at the very least.

AFTERCARE & LONG-TERM CARE

Following hospital discharge, follow up care for both full and preterm infants is provided by primary care practitioners. Only infants born with a weight lower than 1500g receive specialised follow up care in consulting clinics, where nutrition, growth, respiratory functions, psychomotor and neurological developments are monitored and rehabilitation is provided by specialised

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

CZECH REPUBLIC

neurologists as needed. Nevertheless, some differences exist from hospital to hospital. Annual check-ups and long-term care may be extended up to the age of 18. Perinatology centres also provide follow up care to infants with special health problems or needs, including psychological, social care and pedagogical consulting. In case of serious disabilities, these services may be delivered at home at the request of the parents. These services are however considered by experts to be poorly organised, and there are significant differences in the level of access and quality care amongst perinatology centres.

The Czech Gynaecology and Obstetrics Society has called for further financial support and extended long-term care coordinated by the perinatology centres in order to ensure adequate follow up care during the infancy including adequate screening, treatment and care of complications that may appear at later stages of the infant's life.²⁰

Data concerning long-term problems related to preterm births are scattered and inconsistent. Information to parents about potential health risks or problems which may appear later in infancy is not provided consistently and relies very much on the parents to seek the necessary information.

“ If current conditions remain, higher mortality and worsening of other indicators of care for mother and newborn can be expected. ”

*Richard Plavka
Chairman of the Czech Neonatology Society MD*

SOCIAL & FINANCIAL SUPPORT

There is no particular financial support to help families with preterm infants, unless a concrete disability is detected. The expenses and costs linked to visits during the infant's hospital stay are not reimbursed by basic public insurance.

Equally, mothers of preterm infants do not benefit from additional or adjusted maternity leave.

OUTLOOK

Both the Czech Neonatology Society and the Perinatology Section of the Czech Gynaecology and Obstetrics Society consider that the worsening conditions of prenatal and neonatal care in the Czech Republic are critical and should be addressed urgently in order to avoid increased mortality rates amongst preterm infants. Professionals have called for improved quality and access to prenatal, neonatal and follow up care in all units across the country.^{21, 22} Despite this, there are currently no specific plans to review neonatal healthcare services and a major reform of the Czech healthcare system has been postponed.

“ The government, founders of big hospitals together with financial regulations of health insurance companies should act upon this. However, despite the attempts of professional societies they do not show real will to solve this critical situation. ”

*Richard Plavka
Chairman of the Czech Neonatology Society MD*

In 2009, the perinatology centre of the General University Hospital Prague planned to set up a centre for complex care of preterm infants, which should be fully functional by February 2011. It will aim to deliver complete services to both preterm infants and their families, including psychological support.

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- ⁴ Births and Deaths, Institute of Health Information and Statistics of the Czech Republic, 2007, http://www.uzis.cz/download.php?ctg=10&search_name=Narozen%ED%20a%20zem%F8e!%ED®ion=100&kind=1&mnu_id=5300
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- ¹³ Czech Neonatology on Top. What's Next?", Czech Neonatology Society, 2007, http://www.neonatologie.cz/fileadmin/user_upload/Odborne_akce/Ceska_neonatologie.pdf
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- ²² The Concept of Neonatology , Czech Neonatology Society, 2001, <http://www.neonatologie.cz/cneos/>

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

DENMARK

Country Snapshot

Key Data

Total live births/year	67,400 in 2008
Preterm births/year	6.8% ¹
Estimated cost of preterm births	€1,500 - €55,460 per birth

Key Policies

National plan	No
Guidelines	National Board of Health recommendations, Danish Paediatric Society
Planned actions	Development of further guidance on neonatal healthcare by the National Board of Health

The National Board of Health is the main healthcare authority in Denmark, responsible for assisting the Ministry of Health and Prevention in the management and organisation of healthcare services.

PREVALENCE & COST DATA

In Denmark, data on preterm infants is widely available and consistently gathered by neonatal units and the National Board of Health.^{2,3}

Live births:

In 2008, according to the data of the National Board of Health, 67,400 infants were born in Denmark which is equivalent to a 10.71% birth rate.⁴

Preterm births:

The estimated rate of preterm births⁵ in Denmark is 6.8% of all live births. Data from the last few years show an increase. Amongst preterm infants, 0.5% of babies were born before the 28th gestational week.⁶ The degree of prematurity in 2008 can be broken down as follows:

Weeks of gestation	Prevalence
32-36 weeks	5.8 %
28-31 weeks	0.9 %
27 week or less	0.6 % ⁷

Neonatal mortality:

In 2008, the neonatal mortality rate was estimated at 3.8 per 1000 live births.⁸ The majority (70%) occurred in the child's first seven days of life.⁹ Of those, 19% were born between the 28 -36th gestational week and 49% were born before the 28th week.¹⁰ Of those dying within the first 7-28 days of their lives, 12% were born

between the 28th and 36th week and 40% were born before the 28th week.¹¹

In Denmark the use of softer lung treatment and respiratory assistance is generalised. While this has proven to have positive effects in reducing the incidence of secondary brain damage and lung problems, compared to other countries, some neonatal professionals believe this also explains the higher mortality in Denmark.

Cost burden:

The National Board of Health gathers data on the costs related to preterm births in Denmark, including hospitalisation. According to the latest figures, the estimated cost of premature treatment to the national healthcare system ranges from €1,500 to €55,460 per birth.¹²

GOVERNMENT HEALTH POLICY AGENDA

Healthcare ranks high on the Danish policy agenda with a focus on a number of areas including the restructuring of healthcare services, chronic diseases, prevention and healthy lifestyles.

A recent reform of the entire healthcare system has led to an increase in the number of hospitals, the establishment of specialised hospitals and increased investment in healthcare and innovative equipment.

In the period 2009-2018, the budget allocated to healthcare amounts to DKK 40 billion (€ 5.4 billion).

In 2007, 9.8% of the Danish GDP was allocated to healthcare-related expenses.¹³

NEONATAL HEALTH POLICY

Maternal and infant health is an important focus of the health policies in Denmark although there is currently no national policy plan, programme or working group dedicated to neonatal healthcare.

In 2009, the National Board of Health published a series of recommendations to healthcare professionals on the prevention and care of pregnant mothers and newborns.¹⁴ One of the objectives of these recommendations is to reduce the number of preterm births in Denmark; however they contain no specific guidance on the care of preterm infants.

The recommendations are expected to be reviewed every ten years, on the basis of scientific evidence and new developments. In general, Danish health authorities monitor guidance and policy developments in the international arena and from other countries, such as guidance from the British National Institute for Health and Clinical Excellence on neonatal services.

Danish midwives believe that the latest recommendations should be accompanied by increased financial support from the Ministry of Health and Prevention to ensure full implementation.

PREVENTION & SCREENING

The National Board of Health's recommendations on pregnancy care include a number of provisions on the prevention of health problems for the pregnant mother and her foetus. These recommendations will apply as from 2010.

Healthcare and screening during pregnancy is the responsibility of the regional health authorities and hospitals. As from the 6th gestational week or after the pregnancy is confirmed, pregnant women receive basic professional counselling from general practitioners and, as from the 13th week of pregnancy, also from midwives. More counselling is provided if necessary and intensified screening is recommended when particular risks of preterm birth have been identified.¹⁵ In those cases, women are also redirected to hospitals with specialised neonatal units.¹⁶

The National Board of Health also runs regular campaigns on the prevention of risks and promotion of healthy lifestyles amongst pregnant mothers.^{17,18}

The risk factors for prematurity are considered to be similar to those in other industrialised countries, namely smoking, mother's young age, low social status, working conditions which involve standing or walking, a previous preterm delivery or spontaneous abortions, cervical insufficiency and multiple pregnancies.¹⁹

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care

There are currently 33 maternity units in Denmark. Amongst them, 17 have dedicated neonatal units. In addition to this, four nominated hospitals are responsible for the care of extremely preterm infants from across the country - these include Skejby Hospital (near Aarhus, Jutland), Odense University Hospital (Funen), Rigshospitalet (Copenhagen) and Aalborg hospital (Northern Jutland).

“ The treatment of preterm infants with very serious problems (often extremely preterm infants) should be centralised in a hospital which has a necessary experience and know-how on how to treat preterm infants. ”

Birgit Peitersen, neonatal doctor and expert, Hvidovre Hospital

Standards and Guidelines:

Individualised care, such as kangaroo care and NIDCAP are generally practised in neonatal units. The National Board of Health recommendations from 2009 include general provisions on the care of newborn infants. It has also published other specific guidelines on the care of preterm infants. However, there are significant differences regarding the level of implementation and the actual clinical practice across the different regions in Denmark.

Some health professional organisations, such as the *Dansk Pædiatrisk Selskab* (Danish Paediatric Society) have also issued guidance on neonatal care and

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

DENMARK

particular treatments.^{20,21,22} Professionals involved in neonatal care expect to receive in the coming years further guidance on neonatal care from the National Board of Health in the context of the on-going reform and centralisation of the Danish healthcare system.

The most important complications related to a preterm birth are considered to be infectious and respiratory diseases, brain damage and neurodevelopment problems, including cognitive problems which may appear later during infancy.

Parent Involvement and Education:

Parents are consistently involved in the care of their preterm infants during the hospital stay and receive guidance on how to handle the baby at home following discharge. In many hospitals, parents are invited to visit the neonatal units and discuss prematurity with medical professionals before birth. Most Danish hospitals also allow parents to stay during the infant hospitalisation in order to facilitate their daily involvement in care as well as direct contact with the newborn. Alternatively, they are also allowed to visit the maternity wards at any time.²³

In the framework of the on-going healthcare reform, there are plans to increase the number of neonatal units with these capabilities over the next five years.

Parents also play a role in making decisions about the care and treatment provided to their child. Healthcare professionals have, however, the obligation to provide the necessary treatment and care to keep the babies alive, even against parental wishes.

“ Too many of our children are getting very little assistance and too late, which is frustrating since early intervention is so crucial. We need better cooperation between the medical personnel, the professionals working in the municipalities, as well as those in the field of education. In addition, the level of care should not depend on where the family lives; it should be based on the needs of the child. ”

*Elizabeth Pöckel, President of the parent association
Dansk Præmatur Forening*

In hospitals, parents of children with life-threatening illnesses or brain damage can receive professional psychological support, although this is not standardised. After discharge, they may also receive support from health nurses.

Vaccination:

Vaccination is voluntary and free of charge in Denmark. The scheme which applies to preterm infants is currently the same as for full term newborns. However, as recommended by the National Board of Health, the vaccination should be discouraged or delayed in case of a specific illness or an acute sickness (which might be the case for premature newborns).

AFTERCARE & LONG-TERM CARE

The National Board of Health and professional organisations have issued recommendations covering after and long-term care for preterm infants. The follow up interventions are generally defined on the basis of the particular health conditions of each preterm infant.^{24,25}

Most hospitals actively monitor health conditions and outcomes of infants born before the 32nd gestational week during the first two years of life. A pre-school check-up is offered to infants who were born between the 23rd and 32nd week of gestation. In the case of infants with specific problems or complications, the follow up care is continued as necessary. The practice may vary however from hospital to hospital. Following the first regular checks during the first year of life, general paediatricians are responsible for later follow up and for referring infants to specialists as appropriate.

While parents are generally satisfied with the long-term care and treatment of preterm infants with serious health problems or diseases such as motor skill disorders, cerebral palsy, and epilepsy, they are more concerned that infants with less serious health problems such as sensory integration and psycho-emotional disorders do not receive adequate care. They stress the need for better coordination between paediatricians and local health authorities in order to ensure a proper follow up for secondary complications such as sensory integration and socio-emotional disorders.

Presently, aside from the general support provided to children with disabilities there are no specific educational support programmes in schools targeted at children with complications arising from a preterm birth.

SOCIAL & FINANCIAL SUPPORT

In Denmark, professionals at the local municipality are responsible for providing social and financial support to families with preterm infants after the hospital discharge.

Additional support in the form of extended maternity and parental leave can be provided for in Denmark. The local authorities are responsible for the related costs, not the employer.²⁶ In general, all women are entitled to 4 week leave before the expected due date and 14 weeks following the birth. Fathers are entitled to 2 weeks after the delivery. In addition, parents have the right to 32 weeks of parental leave that they can share between themselves.²⁷ In the case of preterm infants, maternity leave starts at the date of the hospital discharge.

OUTLOOK

In the context of the ongoing health reform, neonatal services²⁸ have recently become a focus in terms of planning and specialisation of health services. Although there are currently no major changes planned in the area of neonatal care, the services are expected to become increasingly centralised. As part of this trend, the National Board of Health is also expected to adopt

further guidelines focused on the care of preterm infants - the timeline and particular issues to be covered are however still uncertain. Some officials involved in neonatal health-related issues believe that specialised medical staffing and information to parents should be covered by future guidelines.

Parents have stressed the need for improved coordination and access to follow up and long-term care, in particular for secondary problems that may appear later during early childhood or the teenage years, such as educational support and special environments.

Some professionals note that there are still difficulties with the implementation of the common guidelines across the country and stress the need for a greater focus on prevention of the secondary problems and complications. This would entail an increased number of specialised staff in all neonatal units and local municipalities in order to identify and treat particular risks, which ultimately would contribute to a higher quality of neonatal care for all preterm infants and could limit health related costs in the longer term.

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⁴ Recommendations of pregnancy care, 2009", page 19-22 + 24-25, http://www.sst.dk/~media/Sundhed%20og%20forebyggelse/Graviditet/Anbefalinger%20for%20svangreomsorg/Svangreomsorg_2009.ashx

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TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

FRANCE

Country Snapshot

Key Data	
Total live births/year	828,309 in 2008
Preterm births/year	6.3-8% of total births, depending on the source
Estimated cost of preterm births	Not available
Key Policies	
National plan	National Perinatal Plan 2005-2007
Guidelines	Ministry of Health, High Authority for Health, National Technical Committee on Ultra Sound Scans and Prenatal Screening, CNGOF – National College of Gynaecologists and Obstetricians, National Institute for Prevention and Health Education
Planned actions	Ministry of Health study on perinatal health (2009), outcome of expert working group on parent information French Neonatology Association recommendations on ethical issues and reanimation and palliative care (2010)

The Ministry of Health is the main body for shaping the health policies in France, while the High Authority of Health is responsible for the functioning and management of the healthcare system across the country, with the involvement of the regional authorities. In 2009, the French government proposed a major reform of the healthcare system aimed at achieving greater access to healthcare and improving the organisation of healthcare services in general, hospitals and regional healthcare services.

PREVALENCE & COST DATA

In France, there is no data collection system in place which allows for a comprehensive understanding of the impact of prematurity on infant mortality and morbidity, as well as other related implications for the health and welfare system and the affected families. Existing data are considered scarce and often unreliable¹ by stakeholders including healthcare professionals. The national Perinatal Plan 2005-2007 recognised the need for improved data collection systems through the development of electronic record systems at the regional level, which were however not in place at the time of publication².

Live births:

France ranks amongst the EU member states with the highest birth rate along with Cyprus and following Ireland. This is partly viewed as a result of specific policies aimed at increasing natality. *The Institut National de la Statistique et des Etudes Economiques* (Insee – National Institute of Statistics and Economic Studies) estimates that the total number of births in 2008 was 801,000³, which was equivalent to 12.57 births per 1,000 inhabitants.

Preterm births:

The available data reveal a steady increase in preterm births in France over the past years. The most recent national data publicly available on the prevalence of preterm birth dates from 1997. According to a study conducted by the *Haute Autorité de Santé* (HAS – French National Authority for Health) in 9 regions, mortality varied as follows: 84-63% in babies born between 22 and 24 gestational weeks, 34-42% in newborns between 25-26 gestational weeks, 20-13% between 27-30 gestational weeks, and 8% between 31-32 gestational weeks⁴.

The *Plan Périnatalité: humanité, proximité, sécurité, qualité 2005-2007* (National Perinatal Plan: humanity, proximity, safety and quality)⁵ refers to data from 2003 gathered in the OECD PERISTAT study, which set the prematurity rate in France at 6.9%. In 2008, the national statistics institute, Inserm, took into account data from the EURO-PERISTAT report, which estimated that 6.3% of births are premature in France every year⁶. Parent associations however estimate that the rate of premature newborns is significantly higher, currently amounting to up to 65,000 preterm infants every year. This shows an estimated increase of 20% between 1991 and 2001,

and a continued increase from 7.5% in 2005 to 8% in 2009 in continental France (11% in French overseas departments)⁷. Parents estimate that around 15,000 babies every year are born with a birth weight lower than 1,500 grams⁸.

Stakeholders explain this growing trend as a result of the increased average age of pregnant women, unhealthy lifestyles (e.g. work life and stress, alcohol and tobacco consumption⁹), increased use of fertility techniques and increased induced births as a result of improved screening of possible complications¹⁰. The National Perinatal Plan outlined a series of recommendations aimed at revising the clinical guidelines on assisted conception and understanding better the health risks linked to this issue¹¹.

There is no consistent data on the secondary health complications linked to preterm birth in France. Some healthcare professionals and researchers estimate that amongst preterm infants born before 32 gestational weeks, about 10% have serious motor disorders by the age of 5; 12% are diagnosed with intellectual disorders by the same age; and between 20-40% suffer from neurosensory, behavioural and respiratory problems¹².

Neonatal mortality:

The number of newborns who die within the first 28 days of life has significantly decreased in the past decade, from 0.31% in 1997 to 0.25% in 2007.¹³ In 2007, the birth mortality was 9.3/1000 births and mortality after 28 days and within the first year was 1.3/1000 live births.

Cost burden:

There is no official data about the costs related to prematurity and neonatal services in France. Some experts estimate the total costs of prematurity as €1.4 billion in France¹⁴. The parent association *SOS Préma* estimates the costs incurred during the stay in the intensive neonatal unit (NICU) at approximately €1,500, which would result in a total of €97 million every year. This estimation however does not include the costs involved in care and treatment after hospital discharge and those eventually incurred during the first years of the infants' life.

As in Spain, various stakeholders note some reluctance to quantify officially the costs related to specific healthcare areas or group of patients, including preterm infants.

GOVERNMENT HEALTH POLICY AGENDA

In 2009, the French government introduced a major reform of the healthcare system aimed at achieving greater access to healthcare and improving the organisation of healthcare services in general, hospitals and regional healthcare services.

The current health priorities of the government include cancer, Alzheimer's, palliative care, youth health, over the counter medicines and the improvement of health insurance coverage for the poorest citizens.¹⁵ Women and children are generally paid special attention in a number of policy initiatives in the field of health, such as the *Plan national de nutrition et santé* (PNNS 2 – Second National Plan on health and nutrition¹⁶).

The *Plan Périnatalité* : '*humanité, proximité, sécurité, qualité*' (National Perinatal Plan: 'humanity, proximity, safety and quality') was adopted in 2004 for the period 2005-2007. Since then, maternal and infant health have only been secondary topics on the health agenda. Stakeholders and in particular parents, however, expect increased focus in this area, following an encouraging statement from President Nicolas Sarkozy in November 2009 recognising the issue of prematurity as a public health matter¹⁷.

Of the total €1.15 billion budget dedicated to healthcare in 2009, €127.4 million was allocated to financing the provision of care¹⁸.

NEONATAL HEALTH POLICY

The French Ministry of Health developed the *Plan Périnatalité*: '*humanité, proximité, sécurité, qualité*' 2005-2007 as an effort to improve maternal health and reduce perinatal mortality.¹⁹ The Plan acknowledged that some disabilities and health problems are the result of preterm birth and established a number of objectives to address this issue:²⁰

- Improved training of neonatal professionals
- Follow-up of preterm infants
- Extended maternity leave and adequate combination with parental leave
- Development of a cohort study on preterm babies (Epipages study)

A dedicated committee in addition to a number of agencies and parties are responsible for the implementation

of the Plan, with a dedicated budget of €270 million. However both parents and healthcare professionals regret that the Plan did not succeed in addressing neonatal health in an effective and consistent manner, failing to reflect the real magnitude of the issue, ensure sufficient financial support and sufficiently skilled healthcare professionals.²¹

Healthcare professionals associations issue recommendations and guidance on various aspects of neonatal care. The Société Française de Néonatalité (SFN - French Neonatology Association), a branch of the *Fédération Nationale des Pédiatres Néonatalogistes* (National Federation of Neonatal Paediatricians) aims at exchanging practices, promoting skill training for healthcare professionals and raising awareness amongst decision-makers on a number of specific areas, such as research, ethical issues, communication to parents, etc.

Generally, neonatal stakeholders stress that there is low awareness of risk factors leading to premature deliver, particular healthcare needs and potential diseases or disorders linked to prematurity. Motor, visual neurological and respiratory problems are generally perceived as the most common health complications.

PREVENTION & SCREENING

In France, pregnant women undergo systematic ultra sound scans at least three times during pregnancy, usually at 12, 22 and 32 gestational weeks. Access to screening is believed to be widely available. The Ministry of Health estimates that in 2005, 97.6% of pregnant women underwent at least 3 screening tests during pregnancy.² Intensified screening and care is provided to women at risk of preterm birth or with previous premature delivers.^{23,24} In particular, the National Perinatal Plan sought to put in place systematic consultations following the first pregnancy term to assess and provide specific advice on eventual health risks. Some stakeholders however regret that this objective is not consistently respected across the country and it relies on the initiative of individual practitioners.²⁵

Healthcare authorities have undertaken a number of initiatives aimed to raise awareness about healthy lifestyles during the pregnancy, targeted at both pregnant women and healthcare professionals.^{26,27} This is also stressed in other health initiatives, such as the National Plan on Health and Nutrition.²⁸ The High Authority for Health guidelines from 2005 also include recommendations on the screening of specific infections to prevent preterm births.²⁹ Parent associations also play

an important role in raising awareness about health risks and implications of preterm birth amongst both the general public and decision-makers. Parents have also stressed the need for greater general awareness amongst paediatricians about prematurity and specific healthcare needs and potential complications. To address this lack of awareness, the parent association has published a dedicated toolkit for medical practitioners.³⁰ The National Perinatal Plan 2005-2007³¹ also sought to raise awareness about the risks of preterm birth and to improve prevention, by focusing on the impact of socio-economic inequalities on preterm birth prevalence and access to proper care and screening.

The *Comité technique national sur l'échographie de dépistage prénatal* (National Technical Committee on Ultra Sound Scans and Prenatal Screening) is a public body gathering together representatives of healthcare authorities and professionals. It develops recommendations on screening and optimal ultra sound tests, which are then formally endorsed by the Ministry. In its recommendations from 2005, it recognised ultra sound screens as one of the most efficient ways to diagnose pregnancies at risk of preterm birth.³² The *Collège national des gynécologues et obstétriciens français* (CNGOF – National College of Gynaecologists and Obstetricians) developed clinical recommendations on screening, including pregnancies at risk of preterm birth in 2002.³³

The National Perinatal Plan foresaw the establishment of a working group composed of gynaecologists, obstetricians, perinatal doctors, paediatricians and midwives to reflect on the information that regional awareness campaigns should communicate to future parents about the pregnancies and potential health risks.³⁴ In July 2009, the Ministry of Health announced its plans to study perinatal health with a focus on health risks during the pregnancy, care practices and outcomes.³⁵

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

The total number of NICUs is estimated to be around 270-300 in France. Neonatal services are structured in 3 categories, depending on the level of care provided:³⁷

- **Type 1** – obstetric services only; no structure to take preterm births into care (in 2000, 2.2% of the deliveries in these services were premature).
- **Type 2** – neonatal care unit (in 2000, 3.9% of the deliveries in these services were premature).
- **Type 3** – intensive neonatal care service and reanimation unit (in 2000, 6.3% of the deliveries in these services were premature).

The number of deliveries requiring type 2 and 3 level of care is increasing (now up to 70% of preterm births). Pregnant women are directed to the most appropriate unit depending on their particular health needs, with specifically equipped transfers, arranged as necessary.^{38,39} Despite these measures, it is estimated that 30% of premature deliveries are not dealt with in properly equipped services. This is due to the lack of time to organise the transfer as well as the lack of available places in the unit with the appropriate level of care.

The National Perinatal Plan acknowledged that, despite previous efforts, resources were insufficient including specialised healthcare professionals and equipment of neonatal units⁴⁰. The *Agences Régionales d'Hospitalisation* (ARH – Regional Hospitalisation Agencies) are responsible for the budget allocation amongst the different hospitals and services. Healthcare professionals generally welcome this decentralised approach as it allows for service management and planning according to the local needs and available resources. Parents however regret that it has led to significant disparities in the actual management, organisation of neonatal units and the care provided between the different regions.

Standards and Guidelines:

In general there are no harmonised national recommendations or guidance on the care and treatment of preterm infants. When these exist, they are not respected or implemented consistently. Some professional organisations may adopt guidance on particular issues. For example, the *Société Française de Néonatalogie* (SFN - French Neonatology Association), is expected to publish recommendations to healthcare professionals on ethical issues, reanimation and on palliative care in March/April 2010.⁴¹

Parent Involvement and Education:

The 2004 National Perinatal Plan aimed to “humanise” perinatal care by reinforcing the involvement of parents and providing them with adequate support (e.g. 24/7 service, availability of a psychologist, parental participation in the decision-making related to the care of their child, NIDCAP care and adequate follow-up care for the preterm baby)⁴². Parents and sometimes other family members also have facilitated access to visit the NICU and to stay at hospital.⁴³ The actual practice however varies greatly across the units, depending on the level of care provided, resources and management. Stakeholders note that type 2 and 3 services often provide psychological support to the parents; only type 3 services provide comprehensive guidance and support to parents. Parents note that Kangaroo care,

reduced noise and light may be provided in some units. Yet, these two practices are not consistent across the country and are considered rather rare. Mothers are also encouraged to breastfeed although the support provided is not always sufficient (e.g. lack of breastfeeding chairs, no possibility to borrow a breast pump free of charge, etc).

“Preterm babies are the most vulnerable human beings. It is our duty to protect them.”

Charlotte Bouvard, Director SOS Préma

Doctors are by law obliged to disclose all relevant health information. Parents consider that they are generally provided with the necessary information about the health challenges their premature child may have to face. They feel however that this practice is not consistent in the case of less seriously premature newborns, for whom possible health risks are often neglected. They have strongly stressed the need to raise awareness amongst both health professionals and parents about the potential needs and health problems that even the less seriously preterm babies may present.

There is currently no structured education to parents on how to provide care to their preterm infant. In some units, specialised nurses may provide this information. Some healthcare professionals note the lack of confidence amongst parents to take care of their preterm infants and highlight this as a challenge to overcome. The French parent association *SOS Préma* disseminates basic information to parents through targeted communication tools such as the booklet “*Votre bébé est arrivé en avance*”, as well as psychological and medical advice through a dedicated hotline.

Vaccination:

Preterm babies follow the standard vaccinations, with the same level of reimbursement as for full-term babies. The *Institut national de prévention et d'éducation pour la santé* (Inpes – National Institute for Prevention and Health Education) analysed the particular challenges and risks of vaccination in preterm babies in its “*Guide de Vaccinations*” (Guide to Vaccinations). Amongst others, it recommends starting vaccinations at the age of two months. Parents regret the lack of awareness amongst paediatricians in this regard and especially how to better calculate the age for vaccination of a premature baby. Some preterm infants are considered to need particular vaccines, for example against flu and bronchiolitis. Parents regret that since 2006, the Ministry of Health has been challenging the reimbursement for

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

FRANCE

bronchiolitis which an estimated 4000 to 5000 preterm babies receive every year.

AFTERCARE & LONG-TERM CARE

There is neither organised follow-up care of preterm infants in France, nor planned measures to put dedicated long-term care schemes in place. The *Centre d'Action Médico Sociale Précoce* (CAMSP – Centres for Premature Medical and Social Action) are responsible for providing a number of services when a particular need is detected at the primary care level. These services may include physiotherapy and psychology support. The number of these centres is still limited and therefore access to these services is not widely available, being restricted to children up to age of 6.

There have been some attempts by doctors to put in place a network of neonatal professionals and paediatricians across the country in order to ensure and improve follow-up care of preterm infants after hospital discharge. The practical impact of these measures remains however very limited and inconsistent across the whole population.

“ We must work towards equal opportunities from birth. ”

Charlotte Bouvard, Director SOS Préma

SOCIAL & FINANCIAL SUPPORT

There are no particular support schemes for families with preterm infants. General birth-related healthcare costs are fully reimbursed in France. In the case of extremely preterm infants only, parents may have access to additional reimbursement of healthcare costs related to the development of their baby. A daily allowance is granted to parents in charge of infants with diagnosed disabilities or illnesses.⁴⁵ Parents note the need to improve general awareness and guidance to parents on the social benefits and support schemes in place.

As a result of stakeholder and in particular parent mobilisation, since 2006 maternity leave has been prolonged in the case of preterm birth and subsequent hospitalisation, in order to cover the period between the

actual and the due birth date, in addition to the 16 weeks generally granted.⁴⁶ Parents have also worked closely with individual companies in order to promote family friendly environments and adequate working conditions for pregnant workers.⁴⁷

OUTLOOK

Despite repeated efforts in the 90's and in 2005 to improve neonatal healthcare, stakeholders agree on the need for more effective implementation of existing measures as well as greater human and financial resources to support them. In general, existing policy initiatives are considered to be fragmented and therefore fail to address comprehensively the challenges posed by preterm birth.

Stakeholders identify the main remaining challenges in France the need for the establishment of comprehensive data collection and analysis to inform policy-making, increased skill training for healthcare staff, improved follow-up care, education and support to parents during pregnancy and after hospital discharge. Addressing regional disparities in prevention, quality care, treatment and follow-up of preterm infants also remains an important need.

The National Perinatal Plan foresaw the establishment of a working group composed of gynaecologists, obstetricians, perinatal doctors, paediatricians and midwives to reflect on the information that regional awareness campaigns should communicate to future parents about the pregnancies and potential health risks.⁴⁸ In July 2009, the Ministry of Health announced its plans to study perinatal health with a focus on health risks during the pregnancy, care practices and outcomes.⁴⁹

At the time of writing, no further policy initiatives were planned with the aim of improving neonatal health. A recent statement by French President Sarkozy and continued parent advocacy may however contribute to changing this situation in the next few months.

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TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

GERMANY

Country Snapshot

Key Data

Total live births/year	684,862 in 2007
Preterm births/year	48,678 in 2007 (7.1%)
Estimated cost of preterm births	€10,550 more than full term births (short term costs related to treatment and care up to 2 years after birth)

Key Policies

National plan	No. National Action Plan for a child-oriented Germany (2005-2010)
Guidelines	Common Federal Commission
Planned actions	Development of action plans on infant health and prevention

Healthcare services are highly decentralised in Germany. Each of the 16 federal states or 'Länder' shares the responsibility for the building and upkeep of hospitals with the Federal Ministry of Health (Bundesministerium für Gesundheit)¹, while the state-regulated health insurance providers are also responsible for running costs. The Gemeinsamer Bundesausschuss (G-BA - Common Federal Commission)² is the permanent authority responsible for decision making in the field of healthcare. It gathers together representatives from the national associations of healthcare professionals from various disciplines, clinics and health care insurances, and it issues binding guidance on different health matters.

PREVALENCE & COST DATA

Since the early 90s, local clinics in Germany have collected data on neonatal health, including preterm births and neonatal care on a voluntary basis. The Federal Office for Statistics gathers and analyses information on birth and mortality rates, on the basis of birth weight rather than gestational age at birth.^{3,4} There are, however, differences in the way data is collected and therefore the information of different federal states is not consistent and comparable. The deviations from one federal state to another can be quite large.⁵ In order to avoid this, from 1 January 2010, new consistent standards on data collection are expected to apply across the country.⁶

Live births:

In 2007, the Federal Office for Statistics reported an estimated total of 684,862 births in Germany.⁷

Preterm births:

In 2007, 48,678 babies were estimated to be born prematurely in Germany, the equivalent of 7.1% of all births. Since the 1980s, the rate of preterm births has increased in Germany due to a variety of reasons, namely the increasing age of women bearing their first child; the growing number of women having fertility

treatments leading to multiple pregnancies, and the worsening health of pregnant mothers.⁸

The BabyCare study, an initiative to promote prevention of preterm births was conducted in Lower-Saxony, where the number of pre-mature births reflects the national average. The study included 1,111 births in 2006. Preterm births recorded for the BabyCare study in 2006 are broken down as follows:^{9,10}

Weeks of gestation	Prevalence
33 weeks or later	81 (7.3%)
25-33 weeks	22 (2.0%)
25 weeks or less	1 (0.1%)
Total preterm births	104 (9.4%)

The survival rate after a preterm birth varies across the different federal states, as shown in the *Arbeitsgemeinschaft der Wissenschaftlich Medizinischen Fachgesellschaften (AWMF - Consortium of the Scientific Medical Societies Guidelines)*.¹¹ Among infants born after the 27th week, the survival rate is as high as 95%.¹²

Common morbidity causes include: Intracranial bleedings or intraventricular haemorrhage (IVH), periventricular leukomalacia (PVL), necrotic enterocolitis (NEC), bronchopulmonary dysplasia (BPD), retinopathia praematorum

(ROP), and congenital dysplasia. Other important health risks identified by experts include respiratory syncytial virus (RSV) infections, cognitive and motor problems. Data on morbidity is not consistently gathered across the country. For all the federal states, except for the areas of Berlin, Hamburg and Schleswig-Holstein, the available information only focuses on immediate complications or health problems after birth.

Neonatal mortality:

In 2007, a total of 2,371 neonatal deaths were reported in Germany, representing a mortality rate of 0.35%.¹³ The mortality rate for preterm children is considered to depend on the gestational age at birth as well as the workload and specialisation of the neonatal units.^{14,15} Among infants born before the 26th week of gestation, the mortality rate was 34.6%.

Common mortality causes in preterm infants include respiratory failure, circulation collapse, sepsis, necrotic enterocolitis (NEC), intracranial and intraventricular haemorrhage.

Cost burden:

According to the independent expert BabyCare study, conducted in Lower-Saxony, the costs related to preterm birth exceed those of a full term birth by approximately €10,550 per child. This estimation only relates to short term costs such as antepartal, obstetric and postnatal hospital care, given within the first two days after birth at hospital. In 2007, the extra costs associated to preterm birth were estimated to represent a total of approximately €496 million per year. The authors also concluded that costs could be reduced by around €129 million through the implementation of targeted prevention programs such as those outlined in the BabyCare study.^{16,17}

GOVERNMENT HEALTH POLICY AGENDA

Ensuring the sustainability of the healthcare system has been the key priority of Germany's health policy in the past few years. In 2007, a major reform was agreed with this aim. The key elements of the reform include guaranteeing access to healthcare insurance, reorganising care services, the establishment of health insurance fund and the revision of the role of private health insurances.

In addition to this, German public health policy is focused on disease prevention and addresses horizontal issues such as promoting healthy lifestyles.

In 2003, 11.1% of the gross domestic product was invested in the health care system in Germany.

Promoting children's health is a recent priority of the German government. In 2008, it published a dedicated action plan, (*Strategie der Bundesregierung zur Förderung der Kindergesundheit*) under the National Action Plan of the Federal Government for a child-oriented Germany 2005-2010 (*Nationaler Aktionsplan der Bundesregierung für ein kindgerechtes Deutschland 2005-2010*). Under this framework, the Ministry of Health is expected to launch a number of programmes on infant health with a particular focus on prevention.¹⁸

“ Medical care for preterm infants is a delicate task requiring a suitable clinical setting with specialised, well-trained personnel. Preterm infants should be treated in specialised perinatal centres only. ”

Prof. Christian Poets, Universität Tübingen, Germany

NEONATAL HEALTH POLICY

Neonatal policy in Germany is generally defined according to the guidance issued by the Common Federal Commission, which is responsible for the organisation of neonatal care. When defining Germany's neonatal policy, Sweden and the best US clinics are often referenced.¹⁹

“ Information on how to prevent a preterm birth is still not easily accessible in Germany. ”

Silke Mader, Ex-Chair of the Executive Board, “The preterm child e.V.” (Das Frühgeborene Kind e.V.),

PREVENTION & SCREENING

The *Bundeszentrale für gesundheitliche Aufklärung*²⁰, (BZgA - Federal Centre for Health Education), a government agency, is responsible for promoting health education, including on women's health during pregnancy.²¹

There are wide differences across the country when it comes to access to screening and prevention programmes. Socio-economic factors and other factors such as smoking, are considered to play a key role in determining the risk of preterm birth in Germany.^{22,23} Recently, the BabyCare programme, supported by a variety of health insurances at the national level, provided a range of prevention measures including personalised counselling on various aspects such as nutrition as recommended by the German Society for Nutrition (*Deutsche Gesellschaft für Ernährung e.V.*).^{24,25} Only some health insurance providers reimburse additional screenings for pregnant women, such as vaginal pH tests, aimed at identifying risks and preventing preterm births.^{26,27}

Parents and experts agree on the need to raise public awareness and to improve parent information about the risks and how to prevent preterm birth, as well as to promote equal access to adequate screenings, irrespective of the economic status and place of residence of the pregnant mother.

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

According to the guidance issued by the Federal Common Commission, hospitals are divided into four different categories according to the level of neonatal care they provide:

- Perinatal centres LEVEL 1, which are responsible for the care of infants at highest risk
- Perinatal centres LEVEL 2, responsible for the intermediate care of infants at high risk
- Clinics with a perinatal focus, responsible for newborns requiring special postnatal care in a neonatal unit
- Birth clinics, responsible for full term births and babies who do not present any health risk

Since 2005, every two years all German hospitals are required to report data on morbidity, mortality and number of infants treated in each unit to the office for quality control at the Common Federal Commission.

In recent years, there have been an increasing number of neonatal units established in perinatal centers, responsible for preterm newborns at risk. Experts

believe that the increasing number of neonatal units has led to a lack of expertise and experience, which is resulting in increased mortality, secondary complications and health complications in preterm infants. A number of studies have shown that the mortality and morbidity rate of preterm babies correlates with the number of babies treated in a Neonatal Intensive Care Unit (NICU) per year.^{28,29} In 2008, the *Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen* (IQWiG – Institute for Quality and Cost-effectiveness in Health Care)³⁰ also published evidence on this correlation.³¹ As a result, since 2009, the Institute's guidance allows for level 1 care to be provided only by neonatal units which treat at least 14 preterm infants with a birth weight lower than 1250g per year.³²

Leading experts in neonatology and parent organisations are still demanding that the minimum number of treated infants should be increased to 50 infants with a birth weight lower than 1500g per year.^{33,34} This change would entail a regionalisation of specialised neonatal care, which is considered by experts as crucial in order to ensure high-quality care for extremely preterm infants and to optimise spending linked to neonatal services, as infants would be allocated to the most appropriate units on the basis of the particular health conditions and risks.^{35,36,37} This is, however, questioned by some professional organisations, such as the *Bundesärztekammer* (Federal Association of Medical Doctors) and the *Deutsche Krankenhaus Gesellschaft* (German Hospital Society), which call for the level of equipment and required experience to become the main criteria for evaluating the most adequate level of care that a particular neonatal unit may provide.^{38,39}

Standards and Guidelines:

The Common Federal Commission has issued binding guidance for hospitals on the care and treatment of preterm infants. According to this guidance, preterm infants with a birth weight lower than 1,500g must be treated in special perinatal centres with neonatal intensive care units (NICUs), which need to fulfil special staffing, equipment and space requirements.⁴⁰ The guidelines also recommend avoiding post-natal transfers after birth by transferring pregnant mothers to the most appropriate units before delivery. Medical service of the health insurances (*Medizinischer Dienst der Krankenkassen MDK*) is responsible for ensuring that healthcare services meet the quality standards of care.⁴¹

Neonatal professionals may also follow international guidelines for particular care methods, such as the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and the recommendations from the German Consortium of the Scientific Medical Societies on particular aspects, such as the prevention and treatment of RSV infection.⁴² Experts and parents regret, however, that most German hospitals do not have the staffing and equipment capabilities to follow these standards (e.g. not a single hospital in Germany is part of the NIDCAP network). While some hospitals apply some quality standards for kangarooing or breast feeding, this is not consistent and other key aspects, such as light or noise reduction standards are not consistently addressed.

“ No hospital operates according to NIDCAP. They do not have the capacity to get their staff trained and change their every day practice. ”

Silke Mader, Ex-Chair of the Executive Board, “The preterm child e.V.” (Das Frühgeborene Kind e.V.),

Parent Involvement and Education:

There are no national guidelines or recommendations on parent involvement and family centred care in Germany, and the practice varies significantly depending on the individual hospitals and available resources in the neonatal unit. Hospitals and neonatal professionals are responsible for providing parents with complete information about medical treatment, complications, likely complications or health risks, such as RSV infection, and education on aftercare. Parents are also involved in a number of decisions related to care, such as transfers to regional clinics in order to be as close to home as possible.

Vaccination:

Vaccination is reimbursed by Germany’s health insurance system, but vaccinations are not compulsory in Germany. As a result, the vaccination rate in some federal states does not meet the targets set up by the World Health Organization.^{43,44} In the framework of the National Action Plan on children’s health, the central government and the federal states will jointly discuss the development and implementation of vaccination campaigns across the country.⁴⁵ Recommendations for

vaccination of preterm infants are currently the same as for full term newborns.

AFTERCARE & LONG-TERM CARE

Hospitals are responsible for organising aftercare of preterm infants as required. There are currently no standards or guidelines at the national level, and the practice, as well as the level of aftercare provided, varies widely across the country.⁴⁶ Parent organisations work with neonatal clinics to provide support and education to parents after hospital discharge, including particular issues such as common complications, physical & psychological development and nutrition in preterm infants.

Since quite recently, aftercare and long-term care (e.g. psychological support for parents with preterm children, non-standard long-term therapies, care for siblings) are reimbursed in Germany. There are non-profit organisations dedicated to aftercare, which form the quality network *Qualitätsverbund Bunter Kreis e. V.*⁴⁷ The network organisations help families to reach the best quality of life possible for preterm infants and parents by providing psychological and medical support.⁴⁸

In general, children with particular needs go to special schools, according to the conditions set up by the federal states. In some cases, children with disabilities are integrated into common schools with the support of a social worker.^{49,50}

SOCIAL & FINANCIAL SUPPORT

Long-term care insurance providers are responsible for additional support measures such as housekeeping, respite care and nursing allowance.⁵¹ Families with preterm infants may also benefit from additional social and financial support allocated to people with disabilities, in the case where a disability has been identified.⁵²

In general, pregnant mothers are entitled to maternity leave from 6 weeks before the birth up to 8 weeks after birth. For preterm births, maternity leave can be extended for 4 additional weeks. Under certain circumstances, maternity leave can also be extended to up to 3 years. Parental leave is also encouraged. Parents however have strongly urged the government to

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

GERMANY

ensure that the same facilities and financial support is provided for in the case of preterm infants.⁵³

OUTLOOK

There are no particular measures currently planned in Germany in the organisation of neonatal care and the prevention, care and treatment of preterm infants.

In general, neonatal professionals and experts regret that there is still little guidance across the country on the treatment and care of preterm infants. Experts and parents also stress the need for improved education and support to parents before and after the hospital stay, as

well as the need to reassess the requirements and level of care provided by neonatal units in order to ensure broad access to high-quality care.

Under the National Action Plan of the Federal Government for a child-oriented Germany 2005-2010, the Ministry of Health launched an initiative to promote infant health with a focus on prevention. The consequent implementation of the federal recommendations is the responsibility of the local governments and health care providers.

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² Der Gemeinsame Bundesausschuss, <http://www.g-ba.de>

³ Quality report 2006, Federal Office for Quality Standards, <http://www.qualitätsreport.de>

⁴ Statistics of the Federal Office for Statistics, <http://www.destatis.de/jetspeed/portal/cms/Sites/destatis/Internet/DE/Navigation/Statistiken/Bevoelkerung/GeburtenSterbefaelle/GeburtenSterbefaelle.psm1>

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⁶ Bundesgeschäftsstelle Qualitätssicherung GGMBH, Federal Office for Quality Standards, <http://www.bqs-online.com/>

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⁸ Kirschner et al., Kosten der Früh- und Nichtfrühgeburten und die Effektivität und Effizienz von Präventionsprogrammen am Beispiel von Baby Care. Prävention und Gesundheitsförderung, 2009, 4:41-40, <http://www.springerlink.com/content/768756x0m57x762/>

⁹ Friese K, Kirschner W (2003) Das BabyCare-Projekt – Konzept, erste Ergebnisse und Erfolgskriterien. Gynäkologe 36: 403–412, <http://www.springerlink.com/content/g49v72dl61qyq36/>

¹⁰ Kirschner et al., Kosten der Früh- und Nichtfrühgeburten und die Effektivität und Effizienz von Präventionsprogrammen am Beispiel von Baby Care. Prävention und Gesundheitsförderung, 2009, 4:41-40

¹¹ AWMF Guidelines (Arbeitsgemeinschaft der Wissenschaftlich Medizinischen Fachgesellschaften – Consortium of the Scientific Medical Societies); Pohlandt F. Ergebnisse der Neonatallerhebungen der Bundesländer zur Sterblichkeit von Frühgeborenen (22 0/7 bis 25 6/6 Wochen) 2002-2004, <http://www.uni-duesseldorf.de/cgi-bin/AT-leitliniensearch.cgi?mode=simple&search=Frühgeburt%0D%0A>

¹² Genzel-Boroviczény et al., Mortality and major morbidity in preterm infants less than 31 weeks gestational age in the decade after introduction of surfactant. Acta Obstet Gynecol Scand. 2006;85(1):68-73, http://journals.lww.com/obstetricanesthesia/Citation/2006/09000/Mortality_and_Major_Morbidity_in_Premature_Infants.45.aspx

¹³ Data derived from the Statistisches Bundesamt (Federal Office for Statistics), <http://www.destatis.de/jetspeed/portal/cms/Sites/destatis/Internet/DE/Navigation/Statistiken/Bevoelkerung/GeburtenSterbefaelle/GeburtenSterbefaelle.psm1>

¹⁴ 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, <http://www.thieme-connect.com/DOI/DOI?10.1055/s-2006-947220>

¹⁵ WldO 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, http://www.ncbi.nlm.nih.gov/pubmed/19579501?ordinalpos=11&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum

¹⁶ Baby care study, <http://www.baby-care.de/index.html>

¹⁷ Kirschner et al., Kosten der Früh- und Nichtfrühgeburten und die Effektivität und Effizienz von Präventionsprogrammen am Beispiel von Baby Care. Prävention und Gesundheitsförderung, 2009, 4:41-40, <http://www.springerlink.com/content/768756x0m57x762/>

¹⁸ Strategie of the Federal Government to promote Childrens Health (Strategie der Bundesregierung zur Förderung der Kindergesundheit), http://auf-nummersicher.de/pdf/2008Strategie_Kindergesundheit.pdf

¹⁹ The care of preterm infants in Berlin and the question of minimal rates (DIE VERSORGUNG VON FRÜHGEBORENEN IN BERLIN UND DIE FRAGE NACH MINDESTMENGEN) Berliner Ärzte, 12/2007; p.15, http://www.berliner-aerzte.net/pdf/bae0712_014.pdf

²⁰ Federal Centre for Health Education, <http://www.bzga.de/?uid=c5263d201755ad6c9e131f385245f2cc&id=profil>

²¹ BzGA website on pregnancy and family planning, "<http://www.schwanger-info.de/>

²² Bergmann et al., Perinatale Einflussfaktoren auf die spätere Gesundheit, Gesundheitsbl.-Gesundheitsforsch-Gesundheitsschutz. 07/2007.

²³ Reime et al., The role of mediating factors in the association between social deprivation and LBW in Germany. Social Science&Medicine 62, 2006, 1731-1744, http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-4HBSH4Y-1&_user=10&_rdoc=1&_fmt=&_orig=search&_sort=d&_docanchor=&view=c&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=5562b84fa7f29a694b1c54c3e08914fe

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²⁵ D-A-CH-Referenzwerte für die Nährstoffzufuhr (2009), <http://www.dge.de>

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- ³⁰ The IQWiG, <http://www.iqwig.de/>
- ³¹ IQWiG report: Zusammenhang zwischen Leistungsmenge und Ergebnis bei der Versorgung von Früh- und Neugeborenen mit sehr geringem Geburtsgewicht, <http://iqwig.de/index.681.html?random=d45f99>
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- ³⁴ Das Frühgeborene Kind e.V., <http://www.fruehgeborene.de/>
- ³⁵ DRG and deduction system for the care of preterm infants (Excel file)
- ³⁶ The DRG system has been introduced in 2003. Hospitals are reimbursed with case based lump-sums, irrespective of the amount of time, labour or material spent on the patient.
- ³⁷ 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, <http://www.thieme-connect.com/DOI/DOI?10.1055/s-2006-947220>
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- ⁴¹ Medical services of the health insurances, <http://www.mdk.de/>
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TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

ITALY

Country Snapshot

Key Data

Total live births/year	517,135 in 2006 (0.95%)
Preterm births/year	6.5% in 2006
Estimated cost of preterm births	Not available

Key Policies

National plan	No
Guidelines	Ministry of Health, Regional authorities
Planned actions	Publication and implementation of 2009-2011 Health Plan

Italy's healthcare system is jointly managed by national, regional and local authorities. The Ministry of Health is responsible for setting the main policy priorities and objectives of the healthcare system. The regional governments are main authorities responsible for implementing healthcare policies, issuing treatment guidelines and guaranteeing the delivery of healthcare services through local health units.

PREVALENCE & COST DATA

Live births:

In 2006, there were 517,135 newborns in Italy. In the same year, the estimated average birth rate was 0.95% with higher rates in the southern regions.

Preterm births:

The overall rate of preterm births in 2006 was estimated to reach 6.5%. The Ministry of Health considered that the available data show a slight increase in the number of preterm births over the past five years and that socio-economic factors play an important role in the occurrence of preterm deliveries. In 2008, the Ministry of Health estimated that the rate of extremely premature newborns (born between 22-25 weeks of gestation) was 0.1-0.2%.¹

Weeks of gestation ²	Prevalence
Between 32-36 weeks	5.6%
Less than 32 weeks	0.9%

Neonatal mortality:

The neonatal mortality rate amounted to 0.37% in 2005, with wide differences amongst the different Italian regions.³

Cost burden:

There is no available data about the cost burden of preterm births to the healthcare system or to families.

GOVERNMENT HEALTH POLICY AGENDA

The *Piano Sanitario Nazionale* (National Health Plan)⁴ established the national policy priorities in the field of health. The plan 2009-2011 was not yet published at the time of writing this report. The national government and the regions have however agreed on the main health priorities for 2009, including improvement of primary care, palliative care and care & prevention of chronic diseases.

Public healthcare costs represent approximately 6.5% of the Italian GDP (total healthcare spending amounts to 8.7% of the GDP). In 2008, a total budget of €7 million was allocated to improving and establishing new neonatal intensive care units (NICUs) and €3 million was dedicated to improving neonatal screening of genetic, hereditary and metabolic pathologies.

NEONATAL HEALTH POLICY

The current health plan outlines a series of outstanding challenges for neonatal services in Italy, namely the need to decrease the hospitalisation rate amongst children, to reduce the number of maternity wards responsible for the care and treatment of less than 500 births per year and to ensure 24-hour neonatal emergency services. Parent associations also view these objectives as crucial.⁵

While the 2009-2011 Health Programme was being developed by the Ministry, the national government

and the regions agreed that improving prenatal and neonatal assistance and reducing the number of specialised neonatal units treating less than 500 births per year are key priorities for 2009-2010, with a focus on reducing the neonatal mortality rate.

PREVENTION & SCREENING

There are no medical guidelines or policy guidance on neonatal prevention and screening at the national level. At the regional level, healthcare professional organisations publish guidelines on prevention and screening to prevent and/or detect risks of preterm births.

The website of the Ministry of Health contains a dedicated section on women's health, including pregnancy with key information about women's health during pregnancy, risk factors and information about reimbursement of treatment and care. The Italian Ministry of Health runs general awareness campaigns to prevent health risks and complications during pregnancy. For example, the recent campaign "7 Azioni Per La Vita" ("Seven actions for life") outlines recommendations about how to promote their own and their babies' health during and after pregnancy. These recommendations include quitting smoking, the promotion of breast feeding and vaccinations.⁶

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

Neonatal intensive care units (NICUs) and operational neonatal units (UONs) are located throughout the country. NICUs are present in 116 of the 554 hospitals covered by the CeDAP study. UONs are present in 198 hospitals. Of these, 124 were estimated to be responsible for at least 1,000 deliveries per year⁷. 85% of preterm deliveries are found to be concentrated in bigger hospitals. The number of NICUs in Italy however are considered to be far below current needs and recommended capacity meaning that mothers and infants are being rapidly transferred to regular hospitals after delivery due to capacity constraints in specialised neonatal units.

The Italian Society of Neonatology⁸, however, notes that many Italian regions actually lack the financial resources to develop appropriate NICUs, despite the need for highly specialised care and treatment of these infants. In its opinion this situation has serious repercussions on the health of both the mother and the baby, often

jeopardising the survival of the preterm babies⁹. Neonatologists have recommended closing NICUs that treat less than 500 births per year in order to concentrate the trained personnel in bigger centres and ensure quality specialised care. The Italian Health Ministry seems supportive of such an initiative, and some small centres have already started to close. Professionals also believe that there is a need to reinforce NICUs with specialised trained doctors and nurses.

In February 2008, a number of neonatologists and gynaecologists from different clinics across the country signed the so-called 'Rome Charter', which stresses the right of preterm babies to receive appropriate treatment and care¹⁰. The Charter has divided the neonatal professional community in Italy with some doctors underlining the need for healthcare professionals to strike the right balance between therapeutic treatments and providing palliative care when infants are not viable due to severe health problems. Some doctors have warned against 'extreme resuscitation' for extremely preterm babies who are born with less than 22 weeks of gestation. They have underlined the importance of involving parents in care and treatment decisions at this stage and in providing adequate information about the health risks and long-term consequences for babies who are born extremely prematurely.¹¹

Standards and Guidelines:

The only document that establishes guidelines for the NICUs is the *Progetto Obiettivo Materno Infantile* (POMI – Guidelines for neonatal health), as established by the national government and the regions in 2000.¹² This guidance establishes a number of targets and recommendations on how to optimise maternal and neonatal treatment and care, by setting out specific organisational, structural and technological requirements for neonatal units. These guidelines are not binding, but the Ministry of Health believes that they have been implemented in a significant number of regions. Regional authorities may also issue guidelines, although the practice is not consistent across the country.

Parent Involvement and Education:

Parents consider that the psychological and emotional support provided during the hospital stay is insufficient and most of the time in-existent reflecting wide variations between Southern and Northern regions in the country. The involvement of parents in the care of their infant is generally considered poor, again with wide variations across different regions and hospitals.

TOO LITTLE, TOO LATE?

Why Europe
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ITALY

Vaccination:

Italy has a compulsory and fully reimbursable vaccination scheme for all children under 24 months against diphtheria, poliomyelitis, tetanus and hepatitis B. Preterm infants follow the standard vaccination scheme. In the framework of recent awareness campaigns, the Ministry of Health has strongly recommended that families ensure that preterm babies receive the same vaccinations as full-term newborns.¹³

According to the Ministry of Health, other vaccines are also reimbursed in all regions. Nevertheless, several regional bodies have adopted additional guidelines on vaccinations that vary among the regions. Parents consider RSV infection one of the most common infections in preterm infants.

AFTERCARE & LONG-TERM CARE

Follow up care for premature infants depends on their level of prematurity and, where in place, is fully reimbursed by all regions. There are however significant differences across the regions in terms of guidelines and the organisation of the follow-up process.

In March 2008 the Ministry of Health issued a recommendation to healthcare professionals regarding prenatal and postnatal care in the case of extremely premature babies (22-25 weeks of gestation). In this context, the Ministry of Health encouraged professionals to provide care and follow-up of extremely premature babies until the age of 14 years.

SOCIAL & FINANCIAL SUPPORT

The regulation of paternity and maternity rights in the workplace in Italy is covered by over 20 decrees and legislative acts.¹⁴ Maternity leave is allowed for

up to 5 months: 2 months before delivery and 3 months after birth (on an exceptional basis, one month before delivery and 4 months after birth). The leave may be extended in the case of a mother's health problems before delivery. In the case of preterm births, mothers can recover the leave not taken before a preterm infant's delivery after the birth (up to the 5 months limit). Post-birth leave starts from the date of hospital discharge, not at the date of delivery, a practice that has been recognised in Court, but not by law.

Officials from the Ministry of Health believe that a further extension of maternity leave by up to 3 months in the case of preterm infants with less than 32 weeks of gestation would be helpful.

There is no particular financial support in place for families with preterm infants.

OUTLOOK

Improved organisation of maternity wards, emergency transfer services, increased specialised healthcare staff and wider prenatal and neonatal screening are considered key outstanding needs by stakeholders in Italy. The quality of medical treatment, care and follow-up varies substantially depending on the regions which have the main responsibility for addressing these issues. There are, however, no clear plans or a timeline for improving the situation.

¹ Italian Ministry of Health, http://www.salute.gov.it/imgs/C_17_pubblicazioni_771_allegato.pdf

² Certificato di Assistenza al parto, Analisi dell'Evento nascita – 2006, Ministero della Salute (Italian Ministry of Health, Analysis of the birth event, 2006), http://www.salute.gov.it/imgs/C_17_primopianoNuovo_255_documenti_itemDocumenti_0_fileDocumento.pdf

³ Certificato di Assistenza al parto, Analisi dell'Evento nascita – 2006, Ministero della Salute (Italian Ministry of Health, Analysis of the birth event, 2006), http://www.salute.gov.it/imgs/C_17_primopianoNuovo_255_documenti_itemDocumenti_0_fileDocumento.pdf

⁴ Italian National Health Plan 2006-2008, <http://www.salute.gov.it/normativa/sezNormativa.jsp?label=psn>

⁵ Italian National Health Plan 2006-2008, <http://www.salute.gov.it/normativa/sezNormativa.jsp?label=psn>

⁶ Italian National Health Plan 2006-2008, <http://www.salute.gov.it/normativa/sezNormativa.jsp?label=psn>

⁷ Italian Ministry of Health, http://www.salute.gov.it/imgs/C_17_pubblicazioni_771_allegato.pdf

⁸ Italian Society of Neonatology, <http://www.neonatologia.it/>

⁹ Media article, June 2009, http://www.superabile.it/web/it/CANALI_TEMATICI/Salute/News/info-1087283676.html

¹⁰ Rome Chart, http://www.medicinaepersona.org/resources/argomento/N118417379254ddd8cb5/N118417379254ddd8cb5/la_carta_di_Roma.pdf

¹¹ Media article, February 2008, <http://ricerca.repubblica.it/repubblica/archivio/repubblica/2008/02/04/medici-spaccati-sulla-carta-di-roma-non.html>

¹² Guidelines on neonatal health, Ministry of Health, 2000, http://www.salute.gov.it/imgs/C_17_normativa_1548_allegato.pdf

¹³ Campaign, <http://genitoripiu.ulss20.verona.it/setteazioni-accessibile.html>

¹⁴ Legal framework for maternity and parental leave, 2001, <http://www.camera.it/parlam/leggi/deleghe/01151dl.htm>

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

NETHERLANDS

Country Snapshot

Key Data

Total live births/year	172,281 in 2007
Preterm births/year	13,121 in 2007 (7.6% of total number of births)
Estimated cost of preterm births	Not available

Key Policies

National plan	No.
Guidelines	Yes, Ministry of Health; Association of Obstetrics and Gynaecology; Royal Organisation of Midwives; Paediatric Association
Planned actions	Pregnancy and Delivery Project Board recommendations to the Ministry of Health (end of 2009). Guidelines on interventions for extreme preterm infants (2010). Stakeholder recommendations on long-term follow up care.

The Ministry of Health is the main authority for setting Dutch health policy. The Health Council is the government's main advisory body in the field of health.

PREVALENCE & COST DATA

The four main professional organisations involved in perinatal care are the *Koninklijke Nederlandse Organisatie van Verloskundigen* (KNOV – Royal Organisation of Midwives in the Netherlands)¹, the *Nederlandse Vereniging voor Obstetrie en Gynaecologie* (NVOG – Dutch Association of Obstetrics and Gynaecology)², the *Landelijke Huisartsen Vereniging* (LHV – National Organisation of General Practitioners)³, and the *Nederlandse Vereniging voor Kindereneeskunde* (NVK – Paediatric Association of the Netherlands)⁴. They collect data on perinatal care^{5, 6, 7, 8} which the *Stichting Perinatale Registratie Nederland* (PRN – the Netherlands Perinatal Registry)⁹ centralises.

Live births:

The Perinatal Registry recorded 172,281 live births in 2007.¹⁰

Preterm births:

In 2007, 13,121 infants were born prematurely representing 7.6% of the total number of births. This represents a slight decrease compared to 2006 when the estimated share was 7.9%. Of the total number of preterm infants 2,526 (1.5%) were born before the 32nd gestational week in 2007, the same share (1.5%) as in 2006. In 2007, a total of 2,451 preterm babies were born with a birth weight lower than 1,500g.¹¹

Neonatal mortality:

In 2007, 532 preterm infants died during the first week of life (0.31%), out of a total of 634 deaths reported (0.37%). Over the last few years the neonatal mortality rate in the Netherlands has been stable, but the lower the weeks of gestation, the higher the mortality rate. The level of foetal mortality during pregnancy and neonatal mortality remains high compared to other European member states.¹²

Weeks of gestation	ENM*	TNM**
Between 37-41 weeks	0.08 %	0.10 %
Between 32-36 weeks	0.54 %	0.71 %
Between 22-31 weeks	18.26 %	21.02 %

* Early neonatal mortality (first week of life)

** Total neonatal mortality

The Registry also gathers data on morbidity in preterm infants and prematurity risk factors, including the age of the mother, lifestyle (e.g. smoking) and multiple births. The ethnic origin of the mother and lower socio-economic conditions are also considered potential risk factors.

Cost burden:

There are no comprehensive data on the total cost burden of preterm births for families and the healthcare system in either the short or long-term. Data gathered

by the National Institute for Public Health and the Environment on the “Cost of illness in the Netherlands”¹³ revealed that in 2005 a total of €150 million were dedicated to cover costs related to preterm births. The Paediatrics Association’s working group on neonatal care has estimated that the costs involved in care during the first 8 years of a preterm infant’s life are similar to the ones incurred by one child in a neonatal intensive care unit during one day.

GOVERNMENT HEALTH POLICY AGENDA

The Ministry of Health has the main responsibility for shaping the healthcare agenda in the Netherlands. Increasing the quality of healthcare by 2011 compared to 2006¹⁴ is currently the main focus of the policy agenda, together with long-term care, prevention, patient safety and innovation, as outlined in the 2010 health policy plan.¹⁵ The Ministry is expected to allocate €60 billion for healthcare expenditure in 2010 which represents an increase of €2 billion compared to 2009.

In 2005, national healthcare expenditure amounted to €68.5 billion, which represented 13.5% of the Gross Domestic Product (GDP). In the same year, €1.5 billion (2.1% of the total healthcare budget) was dedicated to infant care during the first year of life. Most of this budget covered general costs which were not related to care and treatment of diseases.^{16, 17, 18}

NEONATAL HEALTH POLICY

Due to the high perinatal mortality rates in the Netherlands, maternal and neonatal care rank high on the health policy agenda.¹⁹ In 2000 the *Dutch Gezondheidsraad* (Health Council of the Netherlands)²⁰, an independent scientific advisory body to the government and the Parliament in the field of health, stressed that the shortage and inadequate training of nurses and the lack of sufficient cots undermine the quality of intensive neonatal care.²¹ Perinatal care is currently defined by the legislative framework set out in the “*Wet bijzondere medische verrichtingen*” (WBMV – “Law on special medical operations”)²² and the “*Planningsbesluit bijzondere perinatologische zorg*” (Planning Decree on special perinatal care)²³, which was revised for the last time by a 2001 Planning Decree based on recommendations from the Health Council. Those recommendations call for the centralisation of neonatal care for high risk pregnancies and preterm

infants in ten specialised neonatal units across the country. The 2001 review also aimed at increasing the capacities of these ten intensive care units, facilitating earlier transfers and allowing for specialised staff trainings, in particular for nurses.

Data from the Perinatal Registry show that in 2007, due to financial, treatment and space constraints, in order to receive neonatal intensive care 17.4% of patients had to be transferred to another region. This share represented a slight increase in comparison to 2006.

In October 2007 the Special Perinatal Care section of the Dutch Association of Obstetrics and Gynaecology reported that the important goals set out in 2001 had not been met, namely the increase in the number of cots and improved staff training. The number of transfers of pregnant women and sick newborns also remained too high prompting a call from professionals for stricter implementation and sufficient financial support to achieve the 2001 objectives by 2011.²⁴

Parents are often consulted by the Ministry of Health on the shaping of policy measures which impact neonatal care. Generally, the neonatal stakeholders consider the 2001 Planning Decree a positive development in neonatal health policy, and parents are concerned by any governmental plans to change the current framework to adapt it to the current system based on multiple health insurance providers, healthcare services and hospitals²⁵. Some experts and decision-makers have however called for a new review of the neonatal system in the Netherlands, aimed at reducing the neonatal mortality rate and optimising the quality of care. This new review would also cover improved budget allocation amongst the different neonatal units and greater cooperation among the various healthcare specialists involved in prenatal and neonatal services.^{26, 27} By the end of 2009, the Pregnancy and Delivery Project Board, composed of professional organisations involved in obstetric and perinatal care, is expected to issue recommendations to the Ministry of Health on how to improve the neonatal services, with a focus on greater quality and a more efficient organisation of obstetric and perinatal care across the country.

Parents consider cognitive, motor problems and behavioural disorders as the major health risks for preterm infants. Respiratory diseases are also perceived as important health risks.²⁸

“**Parents claim a uniform policy for the care and treatment in the case of extreme preterm birth, which aims to provide equal opportunities for all children regardless to their place of birth.**”

Gert J. van Steenbrugge, Director Dutch Association of Parents for the Care of Newborn Infants

PREVENTION & SCREENING

The National Institute for Public Health and the Environment is the body responsible for the national coordination of pregnancy screening.²⁹ The Health Council has issued a number of advisory reports focused on improving prenatal and perinatal prevention and screening in the Netherlands.³⁰ In 2007, the Council recommended that the Ministry of Health publishes and implements medical guidelines developed by healthcare experts and practitioners, with the aim of providing advice on a number of issues including nutrition, healthy lifestyles, working conditions, the use of medicines during the pregnancy and health risk factors. Other advisory reports focus on screening and therapy.^{31, 32}

Antenatal care usually begins at 10 weeks of gestation. Clinical experts believe that adequate antenatal care should commence earlier when particular health risk factors are identified, such as hypertension, other diseases or genetic conditions of the pregnant mother, as well as other risks related to lifestyle or age of the mother. They however regret that intensified screening is not widely available due to insufficient financial resources.

Current screening includes blood tests to detect infectious diseases; Down's Syndrome; and, since 2006, ultrasound scans at 20 weeks of gestation to identify spina bifida and other potential birth defects.

Special screening aimed at detecting the risk of preterm birth does not exist. Equally, there are no particular educational or support measures in place for families at risk of preterm birth. General information about healthy

lifestyles is provided to parents during the regular clinical check-ups during pregnancy. For instance by 2010 the government aims to increase by 70% the consumption of folic acid around conception.³³

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

By centralising neonatal care, the government aims to improve the quality of specialised neonatal services, which is monitored by the Netherlands Healthcare Inspectorate. The *Nederlandse Federatie van Universitair Medische Centra* (NFU – Dutch Federation of University Medical Centres)³⁴ and the *Zorg verzekeraars Nederland* (ZN - Providers of care insurance in the Netherlands)³⁵ are responsible for the practical implementation of the Planning Decree and in particular for the improvement of intensive care capabilities. The Ministry of Health remains the main body responsible for the proper functioning and funding of the system and adapting policy guidelines as necessary.

Neonatal care is organised in different levels depending on the patient's overall health and the presence of risk factors.³⁶

- **Level 1:** neonatal care provided by midwives and GPs;
- **Level 2:** neonatal care provided by obstetricians (in 98 hospitals) and paediatricians (in 67 hospitals);
- **Level 3:** specialised neonatal services, delivered in perinatal centres, with obstetric high-care units and neonatal intensive care units. There are currently 10 hospitals with neonatal intensive care units, where level 2 care may also be provided.

Neonatal care and specialised treatments, such as preventive treatment for babies at increased risk of severe RSV-related chronic diseases, is reimbursed in the Netherlands.

Standards and Guidelines:

Clinical guidelines are developed by healthcare professional associations in the Netherlands.³⁷ The Dutch Association of Obstetrics and Gynaecology has

issued guidelines on perinatal care³⁸ and treatment and on minimum quality standards for gynaecologic care.³⁹ The Royal Organisation of Midwives has its own code of conduct and guidelines for treatment and care. Guidelines are generally revised every five years. The Paediatric Association of the Netherlands has also published guidelines which include provisions on neonatal care.⁴⁰ Guidelines on interventions in the case of extreme preterm infants are expected to be published in 2010, following the initiative of the Ministry of Health.

Parent Involvement and Education:

Parents are generally encouraged to participate in their infant's care. Hospitals are increasingly introducing certain practices of developmental care. Nevertheless, the quality of and access to family-centred care varies widely across the different hospitals in the country. While kangaroo care is a general practice in neonatal units, individualised developmental care (NIDCAP) is only practiced in two centres. The "*Vereniging van Ouders van Couveusekinderen*" (Dutch association parents of newborn infants), is currently developing a quality mark for neonatal care services, including practices in individualised care, family-centred care and parent involvement.⁴¹ This is being done in collaboration with the "*Stichting Kind en Ziekenhuis*" (Foundation Child and Hospital), which previously developed a quality mark for paediatric care.

Parents receive general education about potential complications that may appear only during the first years of the infant's life. On the basis of the particular health conditions of the child, parents are given further information about potential long-term problems. Parents however believe there is a strong need for improving information and education about how to detect eventual disorders and special needs and how to seek adequate after-care.

Views about the quality of emotional support provided to parents vary amongst different stakeholders. While neonatal professionals believe that adequate support is provided by psychologists and medical social workers, parents would like to see improved access to structured support services during and after the hospital stay. Parent associations currently play an important role in

providing emotional support, by facilitating contacts with other parents, and education to parents.

Vaccination:

Vaccination is not compulsory in the Netherlands. It is, however, strongly recommended by doctors and followed by parents. Vaccination of preterm infants follows the standard vaccination scheme and is free of charge.

AFTERCARE & LONG-TERM CARE

Hospitals are responsible for delivering follow-up care up to the second year of life. Regular check-ups are also done at the local children welfare centres. Afterwards, the local paediatrician provides follow-up care as appropriate. Parents regret that there is a general lack of expertise and professional awareness about prematurity-related issues in these centres and therefore believe that follow-up care has limited value. The Paediatric Association's multidisciplinary working group on neonatal follow up care has issued guidance to healthcare professionals on check-ups at 6, 12, 24 months, 5 and 8 years old.⁴² The costs involved in this follow up care were estimated as comparable to the costs incurred by one child in a neonatal intensive care unit during one day. For this reason, it is generally considered that further financial support is required in order to ensure proper follow up care as set out by this guideline.

Neonatal experts agree that the extension of hospital follow-up care by 2 years would contribute to both improving the health of the infant in the longer-term and in saving costs to the healthcare system. Parents have called for longer-term structured follow up care including greater education to parents and sufficient financial support. A specific working group with the involvement of all stakeholders including parent representatives is currently developing recommendations on the structure, organisation and objectives of long-term follow up care.

SOCIAL & FINANCIAL SUPPORT

No specific support measures for preterm infants and their families are in place. In the case of special learning

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

NETHERLANDS

needs at school, preterm infants follow the general support scheme set up for infants with disabilities.

Current maternity leave allows for a home stay of up to 6 weeks before delivery and at least 10 weeks after birth, 16 weeks in total. In recent years the extension of maternity leave for mothers with preterm infants has been discussed in the Netherlands. Parents have called on the Ministry of Social Affairs to extend the leave by up to 10 weeks after hospital discharge in the case of preterm infants. It is still uncertain whether such reform will be pushed forward by the national government, and parents hope for developments at EU level to provide for this extension.

OUTLOOK

By the end of 2009, the Pregnancy and Delivery Project Board, composed of professional organisations involved in obstetric and perinatal care, were expected to issue recommendations to the Ministry of Health on the ways

to improve neonatal services, with a focus on reducing the national neonatal mortality rate and upgrading the quality and organisation of obstetric and perinatal care. A specific stakeholder group is also preparing recommendations on long-term follow-up care. At the time of publication, it was still uncertain whether this will lead to a review of the current neonatal policy in the Netherlands in 2010.

A new Perinatal Registry is being developed by the four main healthcare professional organisations in order to establish data collection standards and methodology in line with international practices. This reform would enable the exchange and comparison of healthcare information between different countries.⁴³

Guidelines on interventions in the case of extreme preterm infants are expected to be published in 2010, following the initiative of the Ministry of Health.

- ¹ Royal Organisation of Midwives in the Netherlands, <http://www.knov.nl/home/>
- ² Dutch Association of Obstetrics and Gynaecology, <http://www.nvog.nl/>
- ³ National Organisation of General Practitioners, <http://lhv.artsennet.nl/>
- ⁴ Paediatric Association of the Netherlands, <http://www.nvk.pedinet.nl/index.htm>
- ⁵ National Registry for Midwives, <http://www.perinatreg.nl/>
- ⁶ National Registry for Obstetricians, <http://www.perinatreg.nl/>
- ⁷ National Registry for General Practitioners, <http://www.perinatreg.nl/>
- ⁸ National Neonatology Registry, <http://www.perinatreg.nl/>
- ⁹ The Netherlands Perinatal Registry, <http://www.perinatreg.nl/>
- ¹⁰ 2007 Yearbook Perinatal Care in the Netherlands, http://www.perinatreg.nl/uploads/150/116/Jaarboek_Perinatale_Zorg_2007.pdf
- ¹¹ 2007 Yearbook Perinatal Care in the Netherlands, http://www.perinatreg.nl/uploads/150/116/Jaarboek_Perinatale_Zorg_2007.pdf
- ¹² 2007 Yearbook, The Netherlands Perinatal Registry, 2007, p.102, http://www.perinatreg.nl/uploads/150/116/Jaarboek_Perinatale_Zorg_2007.pdf
- ¹³ Cost of illness in the Netherlands", National Institute for Public Health and the Environment, 2005, p. 80, <http://www.rivm.nl/bibliotheek/rapporten/270751019.pdf>
- ¹⁴ Health Ministry budget, <http://www.minvws.nl/dossiers/prinsjesdag-2009/default.asp>
- ¹⁵ Ministry of Health 2010 policy plan, <http://www.minvws.nl/folders/staf/2009/beleidsagenda-2010.asp>
- ¹⁶ National Institute for Public Health and the Environment, <http://www.rivm.nl/>
- ¹⁷ The National Institute for Public Health and the Environment pregnancy related healthcare costs, http://www.rivm.nl/vtv/object_class/kvz_diagnose_zwangerschap.html
- ¹⁸ The National Institute for Public Health and the Environment healthcare costs for 0 years old, http://www.rivm.nl/vtv/object_class/kvz_leeftijd_0.html
- ¹⁹ Perinatal section Ministry of Health, <http://www.minvws.nl/dossiers/zwangerschap-en-geboorte/default.asp>
- ²⁰ Health Council of the Netherlands, <http://www.gezondheidsraad.nl/en>
- ²¹ Advisory report Perinatal intensive care, <http://www.gezondheidsraad.nl/en/publications/perinatal-intensive-care>
- ²² Law on special medical operations, <http://www.healthlaw.nl/wbmv.html>
- ²³ Planning Decree on special perinatal care, http://www.minvws.nl/images/2192509_tcm19-116856.pdf
- ²⁴ Article "Derdelijns verloskundige zorg: doelstellingen van het Planningsbesluit bijzondere perinatologische zorg uit 2001 nog niet gehaald", van Eyck e.a., Nederlands Magazine van Geneeskunde, June 2008, <http://www.nvlg.nl/node/315672/print>
- ²⁵ Report "Euro Health Consumer Index 2009 report", Health Consumer Powerhouse, September 2009, <http://www.healthpowerhouse.com/files/Report-EHCI-2009-090925-final-with-cover.pdf>
- ²⁶ Article "Onnodige sterfte van baby's", de Volkskrant, 21 October 2009, http://www.volkskrant.nl/binnenland/article1305821.ece/In_Nederland_sterven_onnodig_babys
- ²⁷ Article "PvdA: onderzoek naar babysterfte", de Volkskrant, 22 October 2009, http://www.volkskrant.nl/binnenland/article1306270.ece/PvdA_onderzoek_naar_babysterfte
- ²⁸ Dutch association of parents of newborn infants, <http://www.couveuseouders.nl/modules/content/content.php>
- ²⁹ National Institute for Public Health and the Environment information on pregnancy screening, http://www.rivm.nl/vtv/object_class/atl_ziekteprev.html
- ³⁰ Advisory report, "Pre-conception care – for a good start", Dutch Health Council, 2007, <http://www.gezondheidsraad.nl/sites/default/files/200719.pdf>
- ³¹ Advisory report, "Foetal screening and therapy", Dutch Health Council, 2008, <http://www.gezondheidsraad.nl/nl/adviezen/foetale-therapie-update-van-de-stand-van-de-wetenschap>
- ³² Advisory report, "Screening for pregnancy immunisation by red blood cells", Dutch Health Council, 2009, <http://www.gezondheidsraad.nl/nl/adviezen/zwangerschapsimmunisatie-door-rode-bloedcellen>
- ³³ Parliamentary paper on the Dutch Ministry for Health's Task Force Folic Acid, <http://www.minvws.nl/kamerstukken/vgp/2006/foliumzuur.asp>
- ³⁴ Dutch Federation of University Medical Centres, <http://www.nfu.nl/index.php?id=3>
- ³⁵ Providers of care insurance in the Netherlands, <http://www.zn.nl/index.asp>
- ³⁶ 2007 Yearbook Perinatal care, http://www.perinatreg.nl/uploads/150/116/Jaarboek_Perinatale_Zorg_2007.pdf
- ³⁷ Treatment and care guidelines of the Dutch Association of Obstetrics and Gynaecology, http://nvog-documenten.nl/index.php?pagina=richtlijn/pagina.php&fSelectTG_62=75&fSelectedSub=62&fSelectedParent=75
- ³⁸ Quality standards of the Dutch Association of Obstetrics and Gynaecology, http://nvog-documenten.nl/index.php?pagina=richtlijn/pagina.php&fSelectTG_62=75&fSelectedSub=62&fSelectedParent=75
- ³⁹ Guidelines of the Royal Organisation of Midwives in the Netherlands, <http://www.knov.nl/voor-verloskundigen/richtlijnen-gedragscodes-en-werkafspraken/knov-standaarden/>
- ⁴⁰ Guidelines of the Paediatric Association of the Netherlands, http://www.nvk.pedinet.nl/index.htm?vereniging/ver_doels.htm
- ⁴¹ Foundation Child and Hospital "smiley" criteria, <http://www.kindenziekenhuis.nl/professionals/criteria-voor-een-smiley/>
- ⁴² protocol National Neonatal Follow-up, http://www.kenniscentrumprematuuren.nl/upload/docs/neonatale_werkgroep_follow_up_hele_artikel_.pdf
- ⁴³ Health Level Seven, <http://www.hl7.org/>

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

POLAND

Country Snapshot

Key Data	
Total live births/year	414, 000 live births in 2008
Preterm births/year	Approx 24,000 per year (6.77% in 2008)
Estimated cost of preterm births	€ 8,000- € 30,000 per infant
Key Policies	
National plan	No. National Health Programme for 2007-2015
Guidelines	Ministry of Health is expected to publish updated standards on obstetric care, parturition care, postnatal care and neonatal care
Planned actions	Implementation of the National Health Programme for 2007-2015 Updated common standards for perinatal care to be published soon

The recently recreated Mother and Child Department at the Ministry of Health is the main body responsible for neonatal healthcare in Poland. However neonatal health policy in Poland is mainly driven by the National Consultant in Neonatology who works closely with the Ministry in an advisory and oversight role. The Consultant also works closely with the Mother and Child Institute (Instytut Matki i Dziecka)¹, the Polish Society of Perinatal Medicine (Polskie Towarzystwo Medycyny Perinatalnej)² and the Polish Neonatal Society (Polskie Towarzystwo Neonatologiczne).³

PREVALENCE & COST DATA

The main source of statistical data in Poland is the Central Statistics Office (*Główny Urząd Statystyczny - GUS*)⁴. However, specific data on preterm infants are gathered by regional health departments and are compiled by the Institute of the Mother and Child⁵ where the National Consultant in Neonatology heads its Neonatology and Neonatal Intensive Care Clinic.

Live births:

While the number of live births in Poland fell by a half from 1984 to 2003, a gradual increase has been observed since 2005, reaching 389,713 live births in 2007.⁶ According to preliminary data for 2008, there were 414,000 live births in Poland.⁷

Preterm births:

It is estimated that approximately 24,000 babies are born prematurely every year in Poland – around 6-7% of the total number of live births.⁸ While in the late 1990s there was a significant drop in the rate of preterm births (from more than 11% to 7%), over the last couple of years the rate has remained quite stable. In 2008, the rate of preterm births has been estimated at 6.77%.⁹

This can be broken down as follows:

Weeks of gestation	Prevalence
32-36 weeks	5.77 %
28-31 weeks	0.6 %
25 week or less	0.4 % ¹⁰

Neonatal mortality:

According to 2009 data, the perinatal mortality rate is currently estimated at 0.76% and the neonatal mortality rate at 0.49% which indicates a slight decrease in comparison to previous years.¹¹ The relatively high rate of neonatal mortality in Poland might be explained by the fact that in Poland serious attempts are undertaken to save the smallest preterm infants i.e. with a body weight of 500g (approximately 22nd – 23rd week of gestation). Their survival rate is however only 2%.¹² In addition, the Polish tradition and restrictive abortion law make the use of abortion very limited which results in a high rate of preterm infants born with serious congenital diseases and therefore susceptible to neonatal mortality.¹³

The main reasons for neonatal mortality in Poland are preterm births and related to that, low birth weight of

newborns.¹⁴ As underlined by the National Consultant in Neonatology, there is a very close link between preterm births and neonatal mortality – “80% of all infants who die before 28 days are preterm infants”. The low rate of abortion in Poland, due to the restrictive legislation and cultural traditions, are considered to be one of the causes leading to high rates of preterm infants born with serious congenital diseases and therefore more susceptible to die.¹⁵

Cost burden:

There is no publicly available data on the estimated cost of preterm births in Poland. According to a member of the Polish Neonatal Society, several months of hospital treatment for a preterm infant with ‘exceptionally low-birth weight’ (500-999g) costs between 70,000 and 120,000 PL zloty (€18,000 - €30,000) and for a preterm infant born with weight between 1000g – 2499g between 30,000 and 70,000 PL zloty (€ 8,000 - €18,000).¹⁶

GOVERNMENT HEALTH POLICY AGENDA

Since 1989, the Polish healthcare system has undergone several significant reforms with the introduction of the National Health Fund (2003) seen as a major improvement. However, with the system undergoing constant reform and with a limited healthcare budget a good deal of criticism is directed at the functioning of the current system (long waiting lists, equipment deficiencies, lack of reimbursement for some crucial treatments). On the professional side, low salaries and insufficient access to modern technology are seen as the main reasons for significant emigration of Polish doctors and nurses to other EU member states.

At the time of writing, the discussion on the national budget for 2010 was still ongoing. However, according to the recently adopted draft, PL zloty 6,5 billion out of 297 billion (approximately 0,5% of the total budget) will be devoted to healthcare.¹⁷ There is currently no available information on the percentage of this budget dedicated to maternal and infant care.

The Ministry of Health and its Mother and Child Department (re-created in June 2009) are responsible for antenatal, maternity and post-natal care. The Ministry of Health works in close cooperation with the National Consultant in Neonatology (appointed by the Health Minister after approval by the Polish Neonatal Society) who has an advisory and oversight responsibilities.

This post has been held for the last 7 years by the same healthcare professional.

NEONATAL HEALTH POLICY

In the early 1990s, the Ministry of Health asked a team of medical professionals to develop a “Programme for enhanced perinatal care in Poland” (*Program poprawy opieki perinatalnej w Polsce*) with the main aim of decreasing perinatal mortality and morbidity. The precise objective of the Programme, implemented in 1994, was to introduce a three-tiered system of perinatal care in Poland. There is general agreement that the creation of the new system marked a crucial step forward in improving preterm infant care in Poland, despite the recognised need for improvements in the way the system functions.

The general opinion is that in the 1990s neonatal healthcare was moving in the right direction, but the trend is now reversed: the Polish Ombudsman stated that “the 21st century started with several very negative political decisions for maternal and neonatal health”,¹⁸ referring for example, to the decisions to stop reimbursements for birthing classes and to reduce the free-of-charge period in hospital for breast-feeding mothers.¹⁹

The current National Health Programme for 2007-2015,²⁰ as its predecessor in 1996-2005,²¹ identifies healthcare targeted at women, newborn babies and children as one of the priorities for the Ministry of Health. By the end of 2015, the Programme aims, inter alia, to reduce the rate of preterm births to 5.5% and the early neonatal mortality rate to 3.0 per 1000 births.

These objectives are to be achieved by:

- improving the three-level system of perinatal care ;
- improving antenatal care of a pregnant women;
- improving prevention programmes, screening and vaccination schemes;
- introducing pre-conception health promotion enhancing the quality of perinatal care;
- upgrading the care of women and children with a low socio-economical status, introducing modern epidemiological studies of mothers and children,
- creating a sustainable monitoring system of all undertaken activities related to mother and child health.²²

Neonatal health policy in Poland is mainly driven by the National Consultant in Neonatology working closely with the Mother and Child Institute (*Instytut Matki i Dziecka*)²³, the Polish Society of Perinatal Medicine (*Polskie Towarzystwo Medycyny Perinatalnej*)²⁴ and the Polish Neonatal Society (*Polskie Towarzystwo Neonatologiczne*).²⁵ The parental organisation *Fundacja Wcześniak Rodzice – Rodzicom* ('Pre-born Foundation - Parents for Parents') focuses mainly on the daily support of parents via, inter alia, the creation of local networks of parents with preterm infants ('Mentor' programme), local supporting groups, an internet forum for parents and an on line shop with articles for preterm children. In addition, since 1993 the *Wielka Orkiestra Ąwiåtecznej Pomocy* (Great Orchestra of Christmas Charity), one of the biggest charity organisations in Poland, has been successfully raising money for infants with birth defects and preterm babies.²⁶

“ Even though neonatology is considered as the priority in Poland, in reality this does not mean much for practitioners. ”

Prof. dr hab. med. Maria Katarzyna Kornacka, Local Consultant in Neonatology, member of the Polish Neonatal Society

Research indicates that while newborn and infant health has been high on Poland's policy agenda for more than a decade, due to constant restrictions on the healthcare budget, some commitments remain purely theoretical. This is also the perception of stakeholders representing both parents of preterm infants and medical professionals. The main areas of concern include:

- the insufficient number and poor access to 3rd level, highly specialised perinatal centres (only 39 out of the 421 neonatal wards registered in Poland), equipment deficiencies in both neonatal wards including incubators, infusion pumps, cardio-monitors and in perinatal centers involving mainly respirators and monitors;
- shortages in staff, mainly fully qualified neonatologists and nurses;
- inadequate psychological support for parents of preterm children.

PREVENTION & SCREENING

The current National Health Programme recognises that pre-conception care, screening and early referral

to specialist care play an important role in preventing or reducing the risks of preterm births. As the current functioning of the three-tiered perinatal care system is still not satisfactory, its improvement is one of the key priorities of the Programme.

In general, antenatal care begins immediately after the pregnancy is confirmed. However, current data show that depending on the region, only 40-60% of all women visit a doctor during the first trimester which makes the monitoring of pregnancy and prevention very difficult.²⁷ With the hope of mobilising women to make appointments at an earlier stage, a new law adopted in September 2009 makes the birth payment (the so-called 'becikowe') conditional on a doctor's supervision from at least the 10th week of pregnancy.²⁸

Mothers that are identified as being at risk, depending on the complications, are referred either to the second or third level of the perinatal healthcare system where they are placed under specialised supervision. Neonatal stakeholders stress however, the need to increase the number of highly specialised perinatal clinics in Poland.

There are currently no guidelines, structured education of support programmes for families at risk of preterm births. Education and support may be provided by the responsible general practitioner, obstetrician or nurse.

All newborns are screened for phenylketonuria (PKU), hypothyroidism and cystic fibrosis.²⁹ A pilot screening programme of rare metabolic malformations is ongoing in selected regions of Poland.³⁰

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

Poland has a three-tiered system of perinatal care which is organised according to the following three levels:

- **Hospital care level 1** - for fetus/newborn and women with normal pregnancies and healthy born neonates (no pathology) – in total there are 286 hospitals in Poland;
- **Hospital care level 2** - for fetus/newborn and women with a limited (medium) pathology of pregnancy – in total 96 hospitals in Poland;
- **Hospital care level 3** – highly specialised perinatal centers for the most severe pathology, including preterm births – in total 39 in Poland.³¹

Generally, preterm infants are directed after birth to a neonatal intensive care unit and afterwards to neonatal

wards. Neonatal intensive care units (NICU) are mainly linked to the third and sometimes second level hospital perinatal care. This means in practice that a number of preterm newborns must be transferred to these units after birth.

“ Even though the three-level system of perinatal care was officially implemented, there is no supervising body which would control and coordinate its functioning. ”

Prof. dr hab. med. Ewa Helwich, National Consultant in Neonatology

Polish medical professionals recognise the importance of individualised care and promote practices such as kangaroo care. Parental organisations report, however, that this practice is not fully implemented in all hospitals in Poland notably due to specialised staff shortages.

As the number of neonatologists in Poland is decreasing, the Polish government is currently trying to encourage young doctors to specialise in neonatology by creating a larger number of residential neonatology posts and by offering a slightly higher monthly allowance (paid directly by the Ministry of Health and not by the hospital of employment).

With regard to hospital equipment, while all stakeholders recognise that the equipment currently available is of a high technological standard, they also recognise deficiencies and the need for constant repairs. Negotiations with the Ministry of Health are currently being led by the National Consultant in Neonatology on the implementation of a 5-year programme for the modernisation of NICU equipment.

Standards and Guidelines:

The National Health Fund is responsible for setting minimum standards for the organisation of neonatal wards (with regard to both equipment and employed staff). In 1999, the “Recommendations in the area of perinatal medicine” (*Rekomendacje postępowaf w medycynie perinatalnej*) were published by the same medical team who worked on the “Programme for enhanced perinatal care in Poland” which is considered to be a good source of information for medical practitioners. The specialised perinatal clinics (3rd level) use their own detailed internal recommendations.

In October 2007, the Minister of Health appointed a special team of experts which is currently working to define common standards for perinatal care (*Zespół do opracowania standardów opieki perinatalnej*).³² The team has developed four separate standards addressing obstetric care, parturition care, postnatal care and neonatal care which are now the subject of a public consultation. Once completed, the standards will be published.

Parent Involvement and Education

The level of parental involvement varies across the country as it depends on the individual hospital unit and/or the practitioner. It seems, however, to be better organised in the specialised perinatal clinics than in standard neonatal wards. The general perception among parents is that they do not receive enough information about potential longer-term complications that might appear during a preterm infant's early years.³³ In order to respond to this need, the parental organisation ‘Fundacja eŃniak Rodzice – Rodzicom’ (‘Preterm Foundation - Parents for Parents’) translated into Polish the American guide “Preemies. The Essential Guide for Parents of preterm babies” which provides information on preterm child care until the 6th year of life.³⁴ An educational campaign was recently launched by the Polish Neonatal Society.³⁵ In the framework of this campaign, the Society aims to publish a special guide for parents of preterm babies as well as to organise training for both nurses and doctors.

Psychological support provided to parents seems to be one of the weakest points in the current system of neonatal care. While some hospitals (mainly the specialised 3rd level clinics) have dedicated staff (e.g. psychologists), others refer parents to support schemes, such as the general social support scheme aimed at vulnerable families in general. The parental organisation ‘Fundacja WczeŃniak Rodzice – Rodzicom’ (‘Preterm Foundation - Parents for Parents’) organises emotional support groups at local level.

Vaccination:

All preterm infants in Poland are expected to follow the standard vaccination schedule, which is reimbursed by the National Public Fund. Non-mandatory vaccines must be paid for by the parents. While there is no automatic adjustment of the vaccination calendar for a premature child, in practice, neonatologists may decide to make this decision independently.

AFTERCARE & LONG-TERM CARE

The aftercare and long-term care of preterm children is an integral part of the three-tiered system of perinatal

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

POLAND

care. In general, all specialised neonatal clinics (3rd level of perinatal care) have specialised aftercare and long-term care departments which monitor the development of the preterm infant up to 24 months. For various reasons mentioned above, access to these specialised perinatal centers is still limited. In some cases, the aftercare and long-term care is provided either by a local neonatologist (although there are a limited number available), paediatrician or a regular family doctor.

In 1998, the Mother and Child Institute introduced a comprehensive examination of all infants born before their 33rd week of gestation. In 2008, a monitoring programme (*Polska Sieć Neonatologiczna* ('Polish Neonatal Network')) of infections occurring in neonatal intensive care units was launched.³⁶ Unfortunately due to the financial difficulties these activities have been recently reduced.

Representatives of the parental organisation "*Fundacja Wcześniak Rodzice – Rodzicom*" ('Preterm Foundation - Parents for Parents') indicated that the eventual creation of a clinic for preterm infants could be a solution for better monitoring of preterm infant development.³⁷ Insufficient access for preterm infants to rehabilitation facilities was also highlighted by the same organisation with specific reference to the lack of transparency and inconsistency of the selection criteria.

“Very often parents
are left alone.”

Parental Organisation *Fundacja
Wcześniak Rodzice – Rodzicom*

SOCIAL & FINANCIAL SUPPORT

There is currently no special social or financial support for parents with preterm babies. As for normal child births, the parents of a preterm baby are entitled to receive a one-off payment at birth of approximately €250. A lack of financial assistance to families during the stay in hospital, in particular in the case of long-distance transfers, is seen as the main disadvantage of the current system. Issues relating to access to

special products aimed at preterm babies (smaller clothes, nappies etc.) have also been raised by parental organisations.

There are currently no specific maternal or parental leave provisions, or other support measures in the workplace, for workers with preterm infants.

Improvements in this area, particularly the allocation of adequate resources to ensure equal access to supporting measures, are frequently called for by many parents.

OUTLOOK

There is a general consensus that the standards for Polish neonatology are set at a very high level. Unfortunately, the failures of the current healthcare system due particularly to the lack of sufficient financial resources devoted to neonatal care, do not allow the system to function properly. The main areas for improvements include enhancement and modernisation of the three-tiered perinatal system as well as the availability of family-centred care through additional financial and educational support to parents, during and after the hospital stay.

Following public consultations, the Ministry of Health is expected to publish soon the updated standards on obstetric care, parturition care, postnatal care and neonatal care.³⁸

As is the case for the majority of specialised care provisions in Poland, it seems that only serious systematic changes in the Polish healthcare system (e.g. through the introduction of a symbolic patient contribution to the costs of healthcare) are likely to lead to improved financing for healthcare, including perinatal and neonatal care.

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TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

PORTUGAL

Country Snapshot

Key Data

Total live births/year	102,567 in 2007
Preterm births/year	9,296 of live births in 2007 (9.06%)
Estimated cost of preterm births	Not available

Key Policies

National plan	Yes - National Programme for Maternal and Infant Health
Guidelines	Ministry of Health, Portuguese Society of Neonatology
Planned actions	None

In Portugal, universal health coverage is provided by the National Health System; citizens may access additional insurance coverage through public health subsystems, private health subsystems and private voluntary health insurances (VHI). The Portuguese health-care system is financed through both public and private funds.¹ The Serviço Nacional de Saúde (SNS – National Health Service) is predominantly funded through general taxation. The health subsystems², which overlap with the SNS, are funded mainly through employee and employer contributions (including the employer's state contributions).

PREVALENCE & COST DATA

Live births:

In 2007 the *Instituto Nacional de Estatística* (INE - National Institute of Statistics) reported the total number of live births in Portugal as an estimated 102,567. This represents a steady decrease from the estimated 120,071 in 2000.³

Preterm births:

In 2007 there were an estimated 9,296 preterm births in Portugal. This represents an increase in the preterm birth rate from 5.9% in 2000 to 9.06% in 2007.⁴ The severity of preterm births is broken down as follows:

Weeks of gestation	Prevalence
32-36 weeks	8,160
28-31 weeks	866
27 week or less	270

Experts consider that the most common risk factors for preterm births in Portugal are multiple births which are often linked to assisted reproduction and fertilisation treatments, stress and modern life style which often translate into late pregnancies, previous preterm

deliveries, gynaecological infections, hypertension, diabetes, existence of certain chronic diseases and foetal anomalies. Ethnicity or race is also considered as a potential risk factor, as experts note higher prematurity incidence amongst pregnant mothers with African origin.⁵

Neonatal mortality:

Data gathered by the Ministry of Health show that the mortality rates amongst newborns have slightly decreased over the last few years, from 0.28% in 2001 to 0.21% in 2008, both for full term and preterm infants⁶. According to professionals from the national registry of the severe preterm⁷, the survival rate of preterm infants born before 32 weeks is approximately 90 percent.

In its report, the "Current Situation of the National Health Plan - Birth in Health"⁸, the General Directorate of Health (GDH) also notes a sustained improvement in reproductive health indicators.

Cost burden:

There is currently no available data on the cost burden of preterm births in Portugal.

“ Although Portugal is very well positioned in terms of maternal and infant health indicators, there is a clear need not only to analyse the reasons for an increased preterm birth rate, but also to understand whether neonatal policies are being equally implemented throughout the country. ”

Prof. Dr. Maria do Céu Machado, Alta Comissária a Saúde (High Commissioner for Health)

GOVERNMENT HEALTH POLICY AGENDA

The Portuguese *Plano Nacional de Saúde* for 2004-2010 (PNS - National Health Plan)⁹ provides a road map for public health policy measures, which are usually further developed into targeted programmes.

The main health priorities for the government currently include cardiovascular diseases, cancer, mental health, healthy ageing, HIV/AIDS and health promotion. The High Commissariat for Health is responsible for the implementation of the dedicated programmes and meeting the established objectives and targets for each of these health areas.

Maternal and infant health has ranked high on the Portuguese health policy agenda over the last few decades, following the adoption of the National Programme for Maternal and Infant Health in 1991.

The total health expenditure in Portugal has risen from 3% to 10% of the country's GDP between 1970 and 2004, which places the current expenditure above the EU's average (9%).

NEONATAL HEALTH POLICY

Over the last 15 years, Portuguese maternal and infant health indicators have improved considerably. In addition to overall socio-economic progress, this change is also considered to be a direct result of the implementation and delivery of the *Programa Nacional de Saúde Materno Infantil* (PNSMI - National Programme for Maternal and Infant Health).

The first *Comissão Nacional de Saúde Materno Infantil* (CNSMI - National Commission for Maternal and Infant

Health), established in 1989, aimed at ensuring equal access to surveillance programmes for pregnant women, newborn infants, children and adolescents across the country¹⁰. It was responsible for developing the dedicated National Programme, which stressed the need to centralise neonatal care, to improve skilled training for healthcare staff, and to rationally distribute specialised equipment as a means to ensure high quality and safe care during and after birth. As a result, the number of neonatal units has been progressively reduced and hospitals were categorised according to the level of specialised neonatal care that they could provide. The *Hospitais de Apoio Perinatal* (HAP - Perinatal Support Hospitals), provide specialised neonatal care, while the *Hospitais de Apoio Perinatal Diferenciados* (HAPD - Differentiated Perinatal Support Hospitals), provide intensive neonatal care.

In 2006, the renominated *Commission for Maternal and Neonatal Health* (CMNH)¹¹ outlined a number of outstanding challenges and improvements required in Portugal, namely improved coordination of the network, including greater centralisation of care and increased qualified staff in neonatal services. At the time of writing this report, there were no specific plans to address these problems or to follow up on the recommendations of the Commission. The *Alto Comissariado da Saúde* (ACS - High Commissariat for Health)¹² has, however, set a 4.9% target rate of preterm births by 2010.¹³

“ Neonatal policy in Portugal has been a permanent priority. The National Programme for Maternal and Infant Health, created in 1991, allowed Portugal to improve its neonatal indicators. It has been an efficient policy with proven successes. ”

Dr José Carlos Peixoto, National Coordinator of the Registo Nacional do Grande Prematuro

In October 2009 the Ministry of Health published a binding administrative decision (Despacho) which unifies the interventions in the area of maternal and neonatal, child and adolescent health, creating the *Comissão Nacional da Saúde Materna, da Criança, e do Adolescente*

PORTUGAL

(CNSMCA - National Commission for Maternal, Child and Adolescent Health).¹⁴ The newly created Commission is responsible for, inter alia, developing and following technical and organisational aspects, proposing and developing quality control programmes, and updating statistical data on maternal and perinatal mortality.¹⁵

PREVENTION & SCREENING

In the framework of the review of the National Health Plan, the Direcção Geral da Saúde (General Directorate of Health)¹⁶ the Portuguese Health Ministry published a report on the “Current situation of the National Health Plan 2004-2010, Birth in Health”.¹⁷ The study showed that almost all women receive peri/antenatal care in Portugal. While more than 98% of women receive at least a check up during the pregnancy, more than 80% of women initiate medical follow-up before the 16th week of pregnancy. The report estimated that more than 80% of pregnant mothers follow adequate monitoring and screenings schemes during pregnancy. Experts and government officials believe that socio-economic factors play an important role in women's access to prevention and screening programmes.

The Ministry of Health has published recommendations to patients and pregnant mothers on how to prevent health risks and follow adequate care during the pregnancy.¹⁸ The *Sociedade Portuguesa de Neonatologia* (SPN- Portuguese Society of Neonatology)¹⁹ has also published guidance for parents on the process of premature delivery, risk factors and measures to prevent preterm birth.²⁰

There are no standards or guidelines targeted at neonatal professionals with regard to the prevention of preterm birth and screening. Ministry officials believe that there is no consensus with regards to the diseases or risks that should be subject to screening programmes during the prenatal period. The Society of Neonatologists has noted the need for earlier detection of risks of preterm delivery, and for greater focus on the detection of cervical competence, infections and hormonal status of the mother. It also stresses the need for preterm infants and families to receive treatment and care in specialised neonatal services with the required skilled staff and equipment.

There are no existing or planned education and support measures for families at risk of preterm birth. Parents, however, highlight that there is a need for better information about implications of preterm birth and

potential health complications or special needs of the child.

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

In Portugal there are 40 neonatology units, 19 of which provide differentiated perinatal support. According to professionals from the national registry of the severe preterm,²¹ there are 22 *Neonatal Intensive Care Units* (NICUs) in Portugal. Three are controlled by private hospitals, while the others are located in Differentiated Perinatal Support Hospitals (HAPDs). These hospitals have a greater autonomous capacity for surveillance of at-risk newborns, greater multidisciplinary capacity and teams of neonatologists (independent of the paediatrics service) which are available 24 hours a day. They are able to coordinate the medical Neonatal Transport Teams and have the means to provide prolonged ventilation for newborns.

“ We should keep the current policy framework and continue to invest in physical and human resources that are necessary to take care of both the infant and the mother, to ultimately increase quality of healthcare services in line with increasing demand of parents.”

Dr Hercília Guimarães, PhD, MD, Professor of Paediatrics

Similar to HAPDs, the *Perinatal Support Hospitals* (HAP) must guarantee, inter alia, two obstetricians and an intern, a paediatrician, an anaesthetist and a team of specialist nurses in adequate number. HAPs should also have direct access to operating rooms, have a foetal monitor for each bed, two tables of resuscitation equipment for newborns and the capacity to resuscitate all newborns. Additionally, they must be able to ensure stability of the preterm infant's vital functions until the transport to an HAPD which should be done in less than four hours and have a unit for the intermediate care and treatment of newborns in recuperation after staying in an HAPD.

The *Rede de Referência Materno-Infantil* (RRMI - Maternal-Infant Reference Network)²² is responsible for supporting Hospitals and for promoting cooperation

and exchange of information in order to optimise care through, for example, compulsory reporting to the Boletim de Saúde Infantil (Infant Health Bulletin). In 2006, about 80% of Portuguese infants were born in RRMI facilities.²³ In addition to the network, the *Unidades Coordenadoras Funcionais* (UCF - Functional Coordinating Units) are responsible for the overall coordination of neonatal units and the different levels of care, monitoring and evaluating neonatal services and providing skilled training to healthcare professionals through the network.

A recent legislative proposal on private maternity services has suggested, *inter alia*, that private units should refuse to accept preterm births of less than 32 weeks, since these infants have a higher probability of needing neonatal intensive care²⁴ which is mainly available in the public hospitals.

Standards and Guidelines:

In 1986, with the creation of the *Instituto Nacional de Emergência Médica* (INEM - National Institute of Medical Emergency)²⁵, came the introduction of a specialised transport system for newborn babies at high risk of being delivered outside a HAPD. This leading service worldwide enabled ambulances with specialised staff and medical technology to transport preterm babies to hospitals with neonatology services. It has national coverage and is available 24 hours/day, every day of the year.

'Kangaroo care' is a standard technique used in neonatal units in Portugal. Breastfeeding is also promoted due to its perceived benefits for the baby, such as supplying important nutrients, protection against infections and the stimulation of affective links with the mother (some hospitals in Portugal even provide special breastfeeding advisors). The *Newborn Individualized Developmental Care and Assessment Program* (NIDCAP) is also a recent development in neonatology services in Portugal, although only two hospitals are known to have implemented it.

The Neonatology Section of the Portuguese Society of Paediatrics published a manual for parents of preterm babies²⁶ (*Nascer Prematuro - Um manual para os pais dos bebés prematuros* publicado pela Secção de Neonatologia da Sociedade Portuguesa de Pediatria) which include guidelines for feeding premature newborns. This Society also published the "National Consensus in Neonatology".²⁷

Parent Involvement and Education

The Portuguese Society of Neonatology acknowledges that parent participation including staying in the hospital with the newborn is extremely beneficial not only for the baby, but also for the family as a whole.²⁸ In general, parents are allowed to visit their preterm infant 24h/day and other members of the family are allowed to visit the infant within the premises of the NICUs.

The information provided by NICU professionals is intended to help parents understand the decisions of the neonatal staff and the technical aspects involved in the care of their infants. Parents not only have to be informed about the medical treatments of their babies, but they also have to sign a written consent for surgical procedures. According to the parent association, however, parents are generally 'updated' on the status of the infant on a daily basis but do not tend to receive information on possible long-term complications.

Parents are routinely informed about the risks of developing respiratory syncytial virus (RSV) before discharging the baby. In 2007, the Portuguese Society of Paediatrics published *Recomendações para a prevenção da infecção por vírus sincicial respiratório, VRS* (Recommendations for the prevention of infection by respiratory syncytial virus, RSV).²⁹

Parents receive psychological support at the hospital where a dedicated team is available to help families with preterm babies.

Vaccination:

Preterm babies are vaccinated according to the *Programa Nacional de Vacinação* (PNV - National Vaccination Programme)³⁰ when they reach the appropriate chronological age. The Portuguese vaccination plan includes vaccines against tuberculosis and hepatitis B, tetanus, poliomyelitis, meningitis and sepsis, measles, mumps and rubella.³¹ Vaccines included in the vaccination plan are provided free of charge to all babies at the health centres upon presentation of the infant's Health Infant and Juvenile Bulletin (BSIJ).

AFTERCARE & LONG-TERM CARE

Following the discharge from hospital, preterm infants in Portugal benefit from follow-up by doctors from multiple disciplines. Before leaving the neonatal unit, preterms undergo a series of screening exams that will

determine the automatic scheduling (by the principle hospital) of several visits to different specialisations (development, physiotherapy, neurology, ophthalmology, psychology). At discharge, parents receive the Health Infant and Juvenile Bulletin (BSIJ) together with a copy of the clinical information, with an indication of unresolved medical problems and follow-up appointments. A letter is also sent to the nursing team of the Health Centre nearest to the infant's residence.

If necessary, preterm infants are monitored throughout their lives. The Portuguese Society for Neonatology emphasises that although a premature child can lead a normal life, it requires a multidisciplinary programme of support until adult life including screening and early intervention, as well as guidance for families in order to maximise a preterm infant's growth and development. The Portuguese Society of Neonatology also encourages interaction between parents who have had preterms, in order to exchange experiences as a contribution to improving the well-being of the child and the capacity of the family to provide the most appropriate care.³³ These interactions are promoted within the not-for-profit *Instituições Particulares de Solidariedade Social* (IPPS – Private Institutions of Social Solidarity) which are progressively being established in Portugal.

Preterm infants with a chronic illness or disability are also covered by a special provision under *Portuguese legislation Intervenção Precoce* (Early Intervention), a service provided to children and their families by interdisciplinary teams.³⁴ The service is state-funded and is aimed at pre-school infants presenting problems in their psychomotor development (or those children at high risk).

Parent representatives have noted that in view of the high quality of care provided by the healthcare system in this area, if preterms are not receiving proper aftercare, this is often due to parents' failure to accept responsibility and non-compliance with medical appointments. Some parents would, however, like to see schools and crèches equipped with professionals who are trained to deal with preterm infants.

SOCIAL & FINANCIAL SUPPORT

In Portugal, social support to families of preterm infants is only provided if the child is diagnosed with a chronic condition or disability, even if the infant requires constant medical follow up.

Pregnant women are entitled to free medical assistance in prenatal and complementary diagnostic exams in

public services, such as health centres, hospitals and maternities and free hospitalisation in hospitals of the National Health Service. They also benefit from special leave from work due to medical complications of the pregnancy if these imply risks to either the mother or the baby for the time period that the doctor determines is necessary to deal with the risk.

“ In general, neonatal policy in Portugal is positive, the national neonatal health services are professional and competent. Nevertheless, there is a need to improve the quality of support for parents and family, including social and financial benefits depending on the level of prematurity. ”

Paula Guerra, Treasury, XXS – Associação Portuguesa de Apoio ao Bebê Prematuro

With regard to maternity and parental leave, there are no specific provisions for preterm infants. Parents and mothers specifically, have the same rights as those of full-term infants, i.e., 5 months of maternity leave from the moment that the baby leaves the maternity facilities. Only if parents experience a multiple birth are they entitled to an extra 30 days for each child. According to the Law Approving the Regime of Work Contracts of Public Functionaries,³⁵ if a baby is hospitalised during the maternity leave following birth, the leave is temporarily suspended for the time and duration of the hospitalisation. However, if the mother's leave extends beyond the fifth month, her salary is reduced by 20%.

Although preterm care is considered to be of high-quality in Portugal, parents do note that they do not benefit from any social or financial support for the period when preterm babies are hospitalised. They would like to see support from the state and employers which reflects the needs of families that have had preterm babies, including those who are not diagnosed as being disabled or chronically ill.

OUTLOOK

In general, the situation for preterm infants in Portugal is considered to be very positive. Both professionals and services in the area of neonatology are reported to deliver very positive results and are generally regarded as highly efficient and effective. According to experts at

the national registry of the severe preterm, this success can be attributed to universal surveillance during pregnancy, good coordination between hospitals and health centres in obstetric visits, specialised neonatal transportation organised at the national level (before and after birth) and the guarantee of excellent perinatal professional teams.

There are, however, still problems to be addressed. There are currently concerns that health professionals are likely to move from the public to the private health infrastructures due to better salaries and conditions; this lack of human resources is already being felt in the area of obstetric emergencies. Healthcare professionals also fear that new management models for hospitals

could put at risk the regional coordination between hospitals and health centres, one of the key success factors.

According to the parent representatives, the World Health Organization's increasing focus on neonatal health is drawing the attention of national health ministries. Although, no major changes are currently expected in Portugal, both parents and healthcare professionals agree on the need for additional human resources in order to better respond to increasing needs and demands of parents.

¹ Portugal – Health System Review, *Health Systems in Transition*, Vol. 9, No 5, 2007, European Observatory on Health Systems and Policies

² Health subsystems are public and private insurance schemes for certain professional occupations. They provide full or partial healthcare coverage to 5-25% of the Portuguese population., <http://www.euro.who.int/document/E90670.pdf>

³ National Institute of Statistics, http://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_main

⁴ National Institute of Statistics, http://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_main

⁵ Epidemiology of the preterm birth, <http://www.lusoneonatologia.net/usr/files/downloads/838f6d5e9d836b3e68426364ad7ff7a6.pdf>

⁶ Ministry of Health, <http://www.acs.min-saude.pt/pns/pt/nascer-com-saude/mortalidade-neonatal>

⁷ Registo Nacional do Grande Prematuro, Coimbra, Portugal, <http://www.acs.min-saude.pt/pns/pt/nascer-com-saude/mortalidade-neonatal/>

⁸ Directorate General for Health, http://www.dgsaude.min-saude.pt/pns/vol2_211.html

⁹ National Health Plan, <http://www.dgsaude.min-saude.pt/pns/capa.html>

¹⁰ National Perinatal Organisation, National Programme of Maternal Health and Neonatal, Commission of Maternal and Neonatal Health, March 2006, <http://www.min-saude.pt/NR/rdonlyres/3B954880-DAE9-4D5B-BD5E-E80350EC8239/0/orgperinatal.pdf>

¹¹ National Perinatal Organisation, National Programme of Maternal Health and Neonatal, Commission of Maternal and Neonatal Health, March 2006, <http://www.min-saude.pt/NR/rdonlyres/3B954880-DAE9-4D5B-BD5E-E80350EC8239/0/orgperinatal.pdf>

¹² High Commissariat for Health, <http://www.acs.min-saude.pt>

¹³ High Commissariat for Health, Indicators and Targets, "Birth in health", preterm Births, <http://www.acs.min-saude.pt/pns/pt/nascer-com-saude/nascimentos-pretermo/>

¹⁴ Decision to create the National Commission for Maternal, Child and Adolescent Health, 1 October 2009, http://www.min-saude.pt/NR/rdonlyres/B52525A5-CA7D-4D01-808B-A92FA84DF61A/0/21929_2003materna_crianca_adolescencia.pdf

¹⁵ Despacho n° 21929/2009, Gabinete da Ministra, Ministério da Saúde, *Diário da República*, 1 October 2009,

<http://www.min-saude.pt/portal/conteudos/a+saude+em+portugal/noticias/arquivo/2009/10/saude+materna+da+crianca+e+adolescente.htm>

¹⁶ Directorate General for Health, <http://www.dgs.pt>

¹⁷ National Health Plan 2004-2010, Current Situation of the National Health Plan - "Birth in Health", http://www.dgsaude.min-saude.pt/pns/vol2_211.html

¹⁸ Patients' guide of the National Health Service, Ministry of Health, <http://www.dgs.pt/default.aspx?cn=55065715AAAAA>

¹⁹ Portuguese Society of Neonatology, <http://www.lusoneonatologia.net>

²⁰ Epidemiology of the preterm birth, Portuguese Society of Neonatology, <http://www.lusoneonatologia.net/usr/files/downloads/838f6d5e9d836b3e68426364ad7ff7a6.pdf>

²¹ Registo Nacional do Grande Prematuro, Coimbra, Portugal

²² Maternal Infant Reference Network, <http://www.acs.min-saude.pt/wp-content/uploads/2007/12/redreferenciacaomaterno infantil.pdf>

²³ Requalification of Emergency Perinatal Services, National Commission of Maternal and Neonatal Health, March 2006, <http://www.min-saude.pt/NR/rdonlyres/9F554A81-0FA0-443C-B739-60453754171F/0/requrperinatal.pdf>

²⁴ Media article – "Health Minister wants to limit preterm births to public hospitals", *Público*, 29 January 2009, http://www.publico.clix.pt/Sociedade/ministra-da-saude-quer-limitar-nascimentos-de-bebes-prematuros-aos-hospitais-publicos_1357969

²⁵ National Institute of Medical Emergency, <http://www.inem.pt>

²⁶ *Nascer Prematuro – Um manual para os pais dos bebés prematuros publicado pela Secção de Neonatologia da Sociedade Portuguesa de Pediatria (Born premature – a manual for the parents of preterm babies published by the Neonatology Section of the Portuguese Association of Paediatrics)*

²⁷ "National Consensus in Neonatology", http://www.spp.pt/UserFiles/File/Consensos_Nacionais_Neonatologia_2004/Consensos_Nacionais_Neonatologia_2004.pdf

²⁸ Portuguese Society of Neonatology – "Presence of parents in neonatal intensive care units", <http://www.lusoneonatologia.net/usr/files/downloads/52327061374e70c8a5447e496a2d1d06.pdf>

²⁹ Recommendations for the prevention of infection by respiratory syncytial virus (RSV), http://www.spp.pt/Userfiles/File/App/Artigos/3/20080220121750_app_38-4_consenso.pdf

³⁰ National Vaccination Programme, <http://www.portaldasauade.pt/portal/conteudos/informacoes+uteis/vacinacao/vacinas.htm>

³¹ See footnote 30

³² Portuguese Society of Neonatology – "Growth and Development of the preterm", <http://www.lusoneonatologia.net/usr/files/downloads/5213f15b6ac8cd5ed60ed1684a05e7fc.pdf>

³³ Portuguese Society of Neonatology – "Community support", <http://www.lusoneonatologia.net/usr/files/downloads/2da092ccaa04014cb719bc0dcca975e3.pdf>

³⁴ Portuguese Society of Neonatology – "Early Intervention", <http://www.lusoneonatologia.net/usr/files/downloads/3f52708d972e2de3f3fc706f48c0fceb.pdf>

³⁵ Law 59/2008 Approving the Regime of Work Contracts of Public Functionaries, http://www.base.gov.pt/codigo/Documents/L59_2008.pdf

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

SPAIN

Country Snapshot

Key Data

Total live births/year	492,527 in 2007
Preterm births/year	32,921 in 2007 (6.7%)
Estimated cost of preterm births	Not available

Key Policies

National plan	No. Maternal Health Programme(no specific provisions on preterm infants)
Guidelines	Spanish Society of Neonatology; Catalonian Department of Health
Planned actions	Full implementation of support scheme for dependent people Catalonia- Adoption and implementation of regional protocol on neonatal care for preterm infants, 2010

Since 2002, the public healthcare system and health policies in Spain have become completely decentralised. The Ministerio de Sanidad y Política Social (Ministry of Health and Social Policy)¹ is responsible for shaping national health and social affairs policy. Together with the regional governments, the Ministry sets minimum standards and objectives for the entire country, while each of the 17 regions develops and implements policies according to their local needs and priorities.

PREVALENCE & COST DATA

National data on prematurity is only partially available in Spain. SEN1500, a neonatal unit network formed under the auspices of the *Sociedad Española de Neonatología* (SEN-Spanish Society of Neonatology)² gathers together 49 neonatal units and services across the country. Since 2002, it collects data on mortality, diseases and health conditions of newborns, related socio-economic factors and health outcomes after the first two years of life. Its scope remains limited, however, as it focuses on data from newborns with a birth weight lower than 1500g. At the regional level, the Catalonian region for example, manages its own data collection system with the aim of analysing trends in prematurity and ultimately taking measures to reduce the mortality rate of newborns and improve neonatal care.

Live births:

In 2007, the National Statistics Institute reported 492,527 live births in Spain.³ Birth rates remain very low in Spain: in 2007, the birth rate only reached 1.38 children per woman and the average age for the first child was almost 30.⁴ In order to address this challenge, the national and some regional governments now provide economic incentives and support to families with a newborn child.⁵

Preterm births:

In 2007 an estimated 40,281 cases of preterm birth were reported in Spain, out of which 32,921 were considered live births. This represents a significant increase compared to the 17,000 preterm births registered 10 years ago in 1997.⁶ The severity of preterm births is broken down as follows:

Weeks of gestation	Prevalence
32-36 weeks	29,015
28-31 weeks	2,775
Less than 28 weeks	1,131

This increasing trend is considered to be the result of a number of factors, such as the health condition of the pregnant mother (e.g. increased prevalence of diabetes), the increase in the mother's age at pregnancy and higher access to assisted reproduction methods.

Data gathered in Catalonia also shows an increasing trend in the number of premature children. In this region, while the overall average rate of preterm births in the last 20 years has remained quite stable, the number of extremely preterm infants (i.e. newborns at 26 weeks or less) is still increasing, in particular

amongst the migrant population and other groups with special socio-economic conditions.

Neonatal mortality:

The number of babies dying in Spain has progressively declined over the last 40 years. A study carried out between 2002 and 2005 on the basis of data gathered by SEN1500 revealed a decreasing mortality trend amongst preterm infants with a birth weight lower than 1,500g in the participating neonatology units: from 19.4% in 2002 to 15.2% in 2005. The same study found that improvements in transfers and in the management and care of these infants within the first 28 days of life were critical in order to reduce the mortality rate.⁷

Cost burden:

There is currently no comprehensive, official national data on the cost of prematurity in Spain. Some professionals and government officials believe that it is not appropriate or relevant to make an accurate estimation of the total cost burden of prematurity for families and for the society. They point out that public health goals and policy measures responding to citizens' rights, are not always necessarily defined on the basis of the related costs for society or the healthcare system. Parents estimate that 24.8% of newborns whose birth weight is lower than 1,500g need hospitalisation and that 50% of all preterm babies suffering from respiratory problems need to visit hospital at least once during the first year of life.⁸

GOVERNMENT HEALTH POLICY AGENDA

The main national health priorities in Spain currently include the promotion of healthy lifestyles and improving the coherence and quality of the public healthcare system. Diabetes, cancer and cardiovascular diseases have also become relevant health priorities for which the national government has recently adopted specific plans.

Women and children's health have traditionally been public health priorities in Spain. In 1990 the *Consejo Interterritorial del Sistema Nacional de Salud* (Inter-territorial Council of the National Health System), with the involvement of the national and the regional governments, agreed upon the priorities and basic criteria for healthcare programmes for pregnant women and newborn infants.⁹ These do not however include any particular provision on neonatal care for preterm infants. The agreed priorities for women's health cover a range of areas such as family planning, care during

and after pregnancy, education to pregnant women about healthy habits and newborn care, and prenatal diagnosis of defects which could lead to serious intellectual or physical disabilities of the foetus. Accordingly, each region has developed concrete objectives and strategies for their territory. In Catalonia, for example, neonatal care has recently become a high priority for the regional Department of Health.¹⁰ This is however not the case for most of the regions.

NEONATAL HEALTH POLICY

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. At the national level, some attention is given to related aspects such as the prevention of birth defects and vaccination.

The *Programa de Salud Materno-Infantil* (Maternal Health Programme)¹¹ does not include particular measures or policy objectives on preterm infant health. Within this framework, parents are calling for specific measures on the prevention and care of preterm infants in the strategy for the care of normal deliveries. Beside this, there is no national plan or strategy dedicated to neonatal healthcare and preterm infant health.

Looking more specifically at one of the Spanish regions, the Health Department of the Catalanian government is currently developing, with the involvement of neonatal professionals and experts, a special protocol dedicated to the neonatal care of preterm infants. The protocol, which is expected to be ready in 2010, will be targeted at neonatal professionals and will address different aspects of perinatal care, including specific recommendations on prevention (e.g. smoking prevention), care (e.g. transfers) with a focus on parental involvement and family-centred care, treatment and follow up of health outcomes of 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 staffing resources in neonatal services. Professionals believe that in practice very little attention is paid to neonatal care and that decision-makers should be more aware of the importance and specific needs in this area in order to deliver high-quality neonatal care.

PREVENTION & SCREENING

The general Maternal Health Programme in Spain focuses on prevention measures to improve pregnant mothers' and infants' health. Updated recommendations on the early prevention of birth defects and complications and healthy lifestyles of pregnant women (e.g. no smoking and/or alcohol consumption during the pregnancy) have been recently included in the programme. The Ministry of Health currently runs public health campaigns that touch upon related issues, such as promoting good nutrition and healthy lifestyles for pregnant mothers.¹²

Targeted prevention measures have been identified by experts as one of the key aspects which should be improved in order to reduce mortality and health problems related to preterm birth. Some provisions in the framework on health and safety in the workplace are aimed at protecting pregnant mothers' and the foetus' health, including the possibility of changing responsibilities and/or workplace when this is feasible and recommended by the doctor.

Antenatal care begins immediately after the pregnancy is confirmed. Generally, it consists of 10 visits and screening tests during the pregnancy. Mothers that are identified as being at risk of premature delivery are put into special screening and prevention programmes.

There are currently no structured education and support programmes for families at risk of having preterm infants. Education and support may be provided by the responsible general practitioner, obstetrician or nurse, and/or a neonatologist, although the practice varies significantly.

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

In general, the level of specialised care provided in neonatal units in Spain is attributed more often to historical factors rather than to any targeted strategic planning of these services. Neonatal units with different levels of intensive care are spread out across the country. Generally, access to the most appropriate level of care is ensured to patients within 100 km of their home. The level of care provided is organised according to the following categories:

- Resuscitation-stabilisation;
- Intermediate basic care (infants born under 35 gestational weeks with basic special health needs);

- Intermediate special care (infants born under 32 weeks and with a birth weight higher than 1,500g; babies which have improved their health condition following intensive care);
- High dependency intermediate care (babies in need of respiratory and/or nutritional support);
- Intensive care (newborns of less than 28 weeks and a birth weight lower than 1,000g; and/or who might need special intensive care such as mechanic respiratory support, dialysis or surgery);
- Hospital assistance at home (voluntary schemes for parents, where assistance and care is provided at home until full hospital discharge).

Professionals involved in neonatal care, such as the Sociedad Española de Enfermería Neonatal (SEEN-Spanish Society of Neonatal Nursing), have expressed deep concerns about the failure of the national and regional governments to meet the standards recommended by the Sociedad Española de Neonatología (SEN - Spanish Society of Neonatology) in all neonatal units across the country. They believe this failure is putting at risk the safety and quality of the services for both infants and families.

SEEN and parents strongly call for adequate space and neonatal staffing resources, as crucial improvements needed in order to deliver high-quality neonatal care, including family-centred care. Nurse shortages are recognised as an important challenge in Spain, where the average number of nurses per 100,000 inhabitants is 34.22% lower than in the rest of Europe.¹³ In neonatal services, the recommendation is currently one nurse for every 4-5 newborns and one nurse for every 2-3 newborns who need specialised intensive care. Parents have denounced that in some units the ratio of skilled nurses is one per 8 infants. Parents and professionals also identify the need for more specialised healthcare staff and multidisciplinary teams in the neonatal units as another key objective.

Standards and Guidelines:

The Sociedad Española de Neonatología (SEN-Spanish Society of Neonatology) issues recommendations on neonatal care, including on specific aspects such as respiratory assistance, resuscitation, neonatal transfers and the prevention of RSV infection in infants born before the 35th gestational week. It has also published basic guidance on planning and minimum quality standards for neonatal units, although they are not particularly focused on intensive care for preterm infants.¹⁴

Guidance and minimum standards can also be issued at the hospital level. In addition to this, the neonatal network SEN1500 also publishes scientific protocols and studies on care of newborns with a birth weight lower than 1500g, based on the data gathered by the network.

Parent Involvement and Education:

Family-centred care is recognised by leading experts and parent groups in Spain as a key element of quality neonatal care, through parent involvement in the daily care of the baby during the hospital stay and preparing them for going home after hospital discharge. Experts however note that there is a strong need for greater awareness and education amongst professionals about the benefits and practical implementation measures for family-centred care and, in general, humanisation of neonatal care. There are also wide variations across the different regions and hospitals in the level of implementation and resources available for real parent involvement. This has been a long-standing demand from parents and nurses involved in neonatal care.

Neonatal professionals decide on a case-by-case basis on the additional education and information that should be provided to parents about the potential long-term complications that may appear during the first years of the infant's life as a consequence of the preterm birth. The practice is, however, inconsistent across the country, in particular with regard to neurodevelopment and cognitive related issues. Some professionals are concerned that providing wider information to parents on these matters, in such a distressing period, may lead to increased emotional pressure on families and possibly social stigmatisation of the infant during the first years of life. Often, information about potential long-term complications is only provided when concrete risks have been identified as likely, but not for infants for which secondary complications, such as cognitive or behavioural disorders, may only appear during the first years of infancy or adolescence. Parents however feel that they need greater information about the potential complications and how to identify or minimise them. At the regional level, the Catalan government is currently planning to develop a toolkit for parents with information and recommendations for the care and follow up of preterm infants.

Emotional support to parents during and after the hospital stay is lacking in Spain. Professionals and parents believe this to be a forgotten element in neonatal care in Spain and claim that dedicated staff

(e.g. psychologists) should be present in neonatal units. Third party organisations provide support but this remains non professional and limited due to insufficient resources.

Vaccination:

Vaccination of children is not compulsory in Spain, although it is free of charge and practised widely among the population. For preterm infants, there are no specific provisions or recommendations on vaccination of particular diseases or infections, such as respiratory syncytial virus (RSV). The due date of birth is, however, taken into account when administering the vaccination of these babies.

“ The recommended staffing and equipment standards are not met in a significant number of neonatal units in Spain. The training and recruitment of specialised staff are fundamental and urgent in order to ensure safe and quality neonatal care in Spain. ”

María Victoria Martínez Hidalgo, Vice-President of the Spanish Society of Neonatal Nurses (SEEN)

AFTERCARE & LONG-TERM CARE

The follow up of preterm infants is the responsibility of neonatology units or paediatricians, depending on the practical organisation and workload of the particular hospital. There is a tendency to devolve follow up visits to the primary care level and, even then, monitoring of the outcome and follow up is only performed in the case of extremely preterm or low weight infants.

Professionals recognise the need for better access to structured follow up care for both extremely preterm and moderately preterm infants, as well as improved coordination between neonatology units and paediatricians. These are also the traditional claims of parents. Data on the health outcomes of preterm infants is only partly collected by the neonatal network SEN1500, which gathers information on neurodevelopment and physical outcome after the first two years of life. By providing this data, SEN1500 aims at analysing the socio-economic factors and aspects of care that later impact the development and health conditions of

children born with a weight less than 1,500g, as well as assessing the improvements needed in neonatal care and priority areas for research. SEN1500 analyses in particular such concrete aspects as motor, sensorial, cognitive and respiratory conditions and diseases.¹⁵

SOCIAL & FINANCIAL SUPPORT

Since 2006, under the general framework of support for dependent people and people with disabilities, financial support and assistance may be provided to families with a newborn weighing less than 2,200g at birth. If the birth weight is lower than 1,500g, families receive the support during the first six months of an infant's life. The type and level of support ranges from assistance at home to financial support, depending on the family's specific needs. These needs are assessed on the basis of the birth weight as well as the specific health conditions of the baby, such as neurological or physical problems.

These support measures are the joint responsibility of the government, regions and municipalities and implementation is carried out progressively, starting with those with a greater level of dependency.¹⁶ There are nevertheless significant differences in the level of effective implementation across the Spanish regions.¹⁷

Greater social support to families in the workplace, such as extended maternity and parental leaves, is recognised by professionals and parents as a major

outstanding need in Spain. Maternity and parental leave in Spain is amongst the shortest in Europe. Similar regimes to those implemented in France or the Scandinavian countries are among the basic demands from parents. In the public sector, employees with preterm babies are entitled to a 2-hour reduction of their daily working time.

OUTLOOK

There are currently no specific actions planned in Spain to improve neonatal care in the near future. Awareness remains very low among decision-makers about the importance and need for improved quality neonatal services for preterm infants.

The main areas for improvement include prevention, ensuring an appropriately skilled workforce (in particular specialised nursing care), family-centred care and follow up care, all of which require additional financial and educational support to neonatal services.

The Catalan government is expected to adopt its dedicated protocol to health professionals and a toolkit for parents on care and long-term follow up in 2010.

¹ Ministry of Health and Social Affairs, <http://www.msc.es/home.htm>

² Spanish Society of Neonatology, SEN1500, http://www.se-neonatal.es/default_principal.asp?idx=&idioma=2

³ National Statistics Institute, social indicators - 2008, <http://www.ine.es/daco/daco42/sociales08/sociales.htm>

⁴ National Statistics Institute, social indicators - 2008, <http://www.ine.es/daco/daco42/sociales08/sociales.htm>

⁵ Andalusian government, Plan for support to Andalusian families, http://www.juntadeandalucia.es/servicioandaluzdesalud/principal/documentosAcc.asp?pagina=ges_cal_palnapoyofam_4

⁶ National Statistics Institute, Births, 2007, <http://www.ine.es/jaxi/tabla.do?path=/t20/e301/nacim/a2007/10/&file=01011.px&type=pcaxis&L=0>

⁷ Mortality for newborns of birth weight less than 1500g in Spanish neonatal Units (2002-2006), *Amer J Perinatol* 2007;24, <http://www.thieme-connect.de/ejournals/abstract/ajp/doi/10.1055/s-2007-992175>

⁸ APREM, September 2009, <http://www.aprem-e.org/images/stories/documentos/APREM-DatosNiosPrematuros.pdf>

⁹ Consejo Interterritorial del Sistema Nacional de Salud. Criterios básicos de programas de salud materno-infantil, <http://www.msc.es/ciudadanos/proteccionSalud/mujeres/docs/prosaludmaternoCompleto.pdf>

¹⁰ Catalanian Department of Health, <http://www.gencat.cat/salut/depsalut/index.html>

¹¹ Maternal Health Programme, Ministry of Health, 1990, <http://www.msp.es/ciudadanos/proteccionSalud/mujeres/embarazo/embarazo.htm>

¹² NHS Priorities for 2009/10 – the Operating Framework, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445?dcService=GET_FILE&dID=179327&Rendition=Web

¹³ General Council of Nursing, press release, October 2007, http://www.cge.enfermundi.com/servlet/Satellite?cid=1097662346229&id=1190968350377&pagename=SiteCGE%2FNoticia%2FTplNoticia_cge&categ=CaActualidad&idPG=1141051411357&p=1097662346229&dscateg=Actualidad&c=page

¹⁴ Spanish Society of Neonatology, recommendations., http://www.se-neonatal.es/default_principal.asp?idx=&idioma=2

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SWEDEN

Country Snapshot

Key Data

Total live births/year	107,648 in 2008
Preterm births/year	6,388 in 2008 (5.9 %)
Estimated cost of preterm births	€ 38.6 million per year

Key Policies

National plan	No
Guidelines	Regional hospitals, National Neonatal Society
Planned actions	Establishment of registries on retinopathy, lung chronic disease and full term infants with birth asphyxia. Follow-up study on long-term cognitive and intellectual outcomes in preterm infants at the age of 30 months and 6 years

The Ministry of Health and Social Affairs has the main responsibility for shaping the broader health agenda in Sweden. The Ministry's National Board of Health and Welfare¹ is in charge of the organisation of the Swedish healthcare system, social services, and the management of a wide range of related issues, such as environmental health, communicable disease prevention and control, and epidemiology.

PREVALENCE & COST DATA

The National Board of Health and Welfare is responsible for compiling statistical data in the area of health and medical care. In the area of neonatology, this information is gathered on a voluntary basis by neonatal units and compiled in the National Perinatal Quality Register.² The Register includes data on the incidence of prematurity, neonatal mortality according to the week of gestation and region, as well as morbidity (e.g. brain damage, retinopathy and healthcare-associated infections). Neonatal experts have however stressed the need to collect systematic data from all births, including full-term births, in order to facilitate full data comparison and analysis, including at the international level.

Live births:

In 2008 the National Board of Health and Welfare registered 107,648 live births.

Preterm births:

The rate of preterm births in Sweden is considerably lower than in other European and third countries.³ Neonatal professionals believe that this 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 which is restricted to one egg to prevent multiple pregnancies. Another factor lies in improved specialised intensive neonatal services resulting from the centralisation in a limited number of hospitals across the different regions, which has led to a high level of expertise in this area of care.⁴

In 2008, 6388 babies were born prematurely (representing 5.9% of total live births). This figure however does not include babies born before their 28th gestational week and who died after birth because, up to July 2008, these infants are considered as non-born for statistical purposes.

Weeks of gestation	Prevalence
Weeks 33-36	5,060 premature newborns (79.21%)
Before 32 weeks	1,328 premature newborns (20.79%)

Neonatal mortality:

In 2004, the Swedish National Board of Health and Welfare estimated that babies only occasionally survive when birth takes place at the 22nd gestational week or before. Few children survive after birth at the 23rd

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

SWEDEN

gestational week, while the survival rates increase up to 50% in births at the 24th gestational week and to 90% in births at the 26th week.^{6,7} Between 1997 and 2007, the estimated average mortality rate was 39% amongst children born between the 22nd and the 24th gestational weeks, decreasing to 8% in children born between the 25th and 26th gestational weeks.

A recent expert study has analysed short and long-term neonatal mortality of the 1011 extremely preterm infants (before 27 weeks of gestation) born in Sweden between 2004 and 2007. The study estimated that overall perinatal mortality was 45% and concluded that 70% of live-born extremely preterm infants survived during their first year of life.⁸

Information on health complications is limited and has not been gathered in a systematic way over the last few years. Recent data gathered by neonatal practitioners observed retinopathy in 34% of the extremely preterm infants and severe bronchopulmonary dysplasia in 25%. The data also revealed that only 45% of the infants who survive their first year do not suffer from any major neonatal morbidity.⁹ Further studies on longer term health outcomes and complications following preterm birth are expected to be published in 2010; these studies will look at a range of issues such as neurodevelopmental and cognitive outcomes at 30 months and at the age of 6.

A number of neonatal units located across the country are currently setting up registries to collect specific data on retinopathy and chronic lung disease.

Neonatal experts stress the need for continued data collection and analysis of the health outcomes of preterm infants through to their teenage years, but this will require sufficient financial support.

Cost burden:

In 2008 the National Board of Health estimated the cost burden of 'preterm' and 'neonatal intensive care' at €38.6 million (SEK 392 million).¹⁰

Some data recently gathered in the Stockholm region highlight the benefits of implementing family centred care in reducing the average length of a hospital stay by more than 5 days, in particular in patients with chronic lung disease. Such care would therefore reduce the costs related to healthcare of preterm infants.¹¹

“ With adequate funding the Swedish national quality register (PNQ) offers a unique resource for future quality improvement and research projects. ”

*Björn Westrup, MD, PhD
Medical Director of Neonatology
Director of the Karolinska NICCAP Training Center
Astrid Lindgren Children's Hospital-Danderyd
Karolinska University Hospital*

GOVERNMENT HEALTH POLICY AGENDA

Government priorities in the field of health are promoting healthy lifestyles¹² (e.g. nutrition, reducing tobacco use and alcohol consumption), strengthening psychiatric care facilitating access to healthcare by guaranteeing a maximum waiting time for consultations and treatment,¹³ the review and liberalisation of the pharmacy legislation and finally an expansion of the national vaccination programme.¹⁴

In 2007 healthcare expenditure in Sweden amounted to € 27.4 billion (SEK 278 billion) This represented an increase of 6 % over 2006 and almost 9% of Sweden's gross domestic product.¹⁵

NEONATAL HEALTH POLICY

Neonatal and infant healthcare is not the focus of any policy measures in Sweden. In 2004 the National Board of Health and Welfare together with independent experts analysed the state of prenatal care and treatment and the latest developments in the areas of obstetrics and neonatology.¹⁶ The report concluded that there was no need for guidelines or legislation on neonatal care in addition to the existing ethical recommendations to medical staff.¹⁷ Furthermore, healthcare professionals are considered as fulfilling their responsibility for the provision of quality neonatal healthcare on the basis of the latest scientific evidence and developments.¹⁸

PREVENTION & SCREENING

The prevention of preterm births and the promotion of foetal health are dealt with in the framework of prenatal and maternity care, which is widely available to all

women in Sweden. 99% of the population is considered to follow prenatal care. Professional working groups within the Swedish Organisation for Paediatrics, Obstetrics and Gynaecology¹⁹ provide medical statements. Regional hospitals and health authorities issue guidelines on the surveillance and follow up care of pregnancies. The guidelines are aimed at detecting and treating pregnancies at risk of preterm birth. Particular attention is paid to the medical conditions of the pregnant mother (e.g. hypertension, diabetes, weight, multiple pregnancy, malformations, foetal growth and psychiatric problems), social factors (e.g. life-style problems, smoking, drug or alcohol abuse), the prevention and treatment of infections during the pregnancy and the development of better methods to control early contractions.²⁰

Foetal ultrasounds are generally done once between the 18th and 20th weeks of gestation. Routine visits to a midwife are encouraged from the 10th to 12th gestational weeks. Education is provided on a range of different issues, such as foetal screening, iodine, vitamin B and folic acid intakes, delivery and breast-feeding, etc. In case of health complications and/or risk of preterm birth, intensified screening and monitoring are carried out in special out-patient clinics.

Experts and neonatal professionals consider maternity leave, prior to the due date, a key measure in the prevention of preterm births, as it contributes to relieving the mother from additional stress during the pregnancy.

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

The development of specialised neonatal care started in the 1960's-70's when Sweden introduced specialised respiratory care for premature and sick newborns and a series of specialised neonatal intensive care units (NICUs) across the country.

Neonatal care is highly regionalised in Sweden, with 6 main university hospitals responsible for intensive neonatal services and equipped with neonatal professionals, in particular skilled nurses, adequate equipment and infrastructure. In total, there are 37 neonatal units across the country in Sweden, with different levels of care. Of those, 19 treat more than 300 patients per year²¹, and are therefore considered and designed to deliver high quality specialised neonatal care.²² Extreme preterm babies (i.e. born before 28

gestational weeks) are transferred to one of the 6 larger university hospitals for specialised intensive care. The available data has shown that preterm infants who are treated in these specialised units benefit from better health outcomes and survival rates.^{23,24}

Standards and Guidelines:

In 2004 the National Board of Health and Welfare concluded that there is no need for country-wide clinical guidelines on neonatal healthcare in addition to the existing recommendations on ethical issues.²⁵ Medical guidelines are currently defined by hospitals at the regional level and cover a number of issues related to care, treatment and parent involvement. The National Neonatal Society²⁶, which is part of the Swedish Medical Association²⁷, has also issued guidelines on a number of topics covering for example the prevention of healthcare-acquired infections, which are considered to be widely implemented.

Experts however stress the need to develop further guidelines and follow up studies in order to provide guidance to all neonatal professionals, in particular those in local clinics. They see these guidelines as a key step towards narrowing diverse practices across the different regions and to improve the quality of neonatal services across the country. Generally, practitioners think that the National Board of Health and Welfare should develop basic guidelines on a range of issues notably on the following:

- care and related ethical issues for preterm infants born at 22-23 gestational weeks;
- clear criteria to assess and carry out pre and post-birth transfers for preterm infants in need of specialised intensive care;
- humanisation of neonatal care;
- parent involvement and family-centred care;
- follow-up care.

Practitioners consider that the recommendations issued by the National Board of Health have greater weight and are usually implemented effectively across the country. Medical associations are considered to be responsible for issuing guidance on technical and scientific issues, such as neonatal nutrition.

The monitoring and evaluation of the quality of neonatal care are done through the National Perinatal Quality Register.²⁸ This registry contains individualised data on patient health conditions, medical interventions,

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

SWEDEN

treatment and health outcomes. It provides the basis for the assessment of the quality of healthcare in Sweden, including parental assessment of neonatal care, and it identifies areas for improvement.²⁹

Parent Involvement and Education:

Parent involvement is widely practiced in Sweden. In the last two decades neonatal experts have strongly advocated the implementation of family-centred care as a means to both humanise healthcare and improve medical and health outcomes. Family-centred supportive care, newborn individualised development care and the assessment programme (NIDCAP) have had very positive results in Sweden over the last 15 years. This method has been very well received by nursing staff, neonatologists and parents, and has brought benefits to preterm infants in terms of improved care, better health outcomes and also in terms of humanising care.^{30, 31, 32} Neonatal experts estimate that approximately 25 of the 37 neonatal units in Sweden implement NIDCAP at least partly, and that it is being increasingly implemented from the moment of birth. Experts and medical professionals agree that the main outstanding challenge is to ensure sufficient numbers of trained healthcare staff, in particular nurses, which is considered key in order to implement NIDCAP and family-centred care consistently and effectively.

In view of a preterm infant's interaction with his environment, experts believe it is essential to facilitate parental involvement in the care of preterm infants to promote their neurodevelopment. In this context, the Karolinska Hospital in Stockholm is currently leading implementation of the so called 'couplet' care. This refers to the provision of obstetric and other care needed by the mother in the neonatal unit in order to facilitate parent involvement and permanent contact with the baby. It requires coordinated team work, adequate infrastructure and facilities for the parents and family of all preterm babies as well as specialised neonatal professionals. It involves moving an infant to a family room once his health has stabilised. The family room allows for wireless monitoring by healthcare professionals, but also allows the infant to be cared for by the parents and family with the training and guidance provided by the medical staff, in particular specialised nurses.

Skin-to-skin care is also practised widely since the first week of age. Although there is broad consensus amongst medical practitioners in Sweden about the benefits of skin-to-skin care for the infants and the

parents, they recognise the need for further scientific research in this field, notably in order to support its extension and implementation in other countries, including the developing world.

Parents are educated on the potential long-term problems that may appear during the first years of the infant's life. A particular focus is placed on educating parents about possible behavioural problems and some specific needs at school that might be difficult to identify. Parent associations also play an important role in providing education and emotional support to parents during and after the hospital stay.

Vaccination:

Vaccination of preterm infants in Sweden is not compulsory but it is highly recommended by practitioners and is provided free of charge. 99% of all preterm infants are vaccinated, and they follow the same vaccination schemes as full-term babies.

“Sweden has a long experience in the implementation and scientific evaluation of family-centred developmental care including skin-to-skin care. A further development involving the provision of training and research facilities in this field could be a potential resource for other countries for the improvement of neonatal care.”

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AFTERCARE & LONG-TERM CARE

After care and long-term care in Sweden is organised in the neonatal units by multidisciplinary teams including psychotherapists, paediatricians and neurologists. The follow-up team for every patient is composed of the most appropriate specialists, based on a case by case assessment. The level of access to follow-up measures may however vary across the different regions in the country.

Experts have highlighted the need for further research on the medium and long-term health outcomes of less

extreme preterm infants, because they believe that these infants may present specific needs which are often neglected during infancy and teenage years.

Follow-up programmes recently implemented in other countries, such as the Infant Behavioral Assessment and Intervention Program (IBAIP) in the Netherlands, are considered to have shown improvements in the health conditions of preterm infants at the age of 2. Implementation of similar structured programmes would lead to positive improvements in Sweden.

SOCIAL & FINANCIAL SUPPORT

Regular parental leave is 480 days, starting at the due date or the date of hospital discharge in the case of preterm infants. In the case of sick preterm infants, each parent may benefit from an extended leave of up to 120 days per year. In the first year of a preterm's life, the maternal and parental leaves are extended to cover the period between the due date and the actual birth date. Both parents are reimbursed 80% of the salary during their hospital stay.

In the case of a life-threatening condition in a preterm infant such as being born before the 32nd week of gestation, there is a further extension of the parental leave. In these cases, parents are also reimbursed the costs incurred during the entire hospitalisation of the infant.

OUTLOOK

Neonatal healthcare is not high on the policy agenda in Sweden, and no policy changes are foreseen. Nevertheless, the situation for preterm infants in Sweden is considered to be very positive.

Neonatal experts are setting up registries on retinopathy, chronic lung disease and full-term infants with birth asphyxia, as well as continuing a follow-up study on the long-term cognitive and intellectual outcomes of preterm infants at the age of 30 months and 6 years.

They also highlight that the implementation of developmental and family-centred care should be improved by installing adequate infrastructure and equipment across the country and supporting specialised education and training for neonatal professionals, in particular nurses.

Structured follow-up programmes following preterm infants until their teenage years are also viewed as a potential improvement.

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

SWEDEN

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UNITED KINGDOM

Country Snapshot

Key Data

Total live births/year	690,013 in 2006-7 (England and Wales)
Preterm births/year	54,000 in England in 2006-7 (8.3%)
Estimated cost of preterm births	€ 3.209 billion per annum in England and Wales

Key Policies

National plan	NHS Toolkit for High-Quality Neonatal Services (2009)
Guidelines	NICE; neonatal networks; UK Medical Professional Colleges guidelines (British Association of Perinatal Medicine, Royal College of Obstetricians and Gynecologists); Joint Committee on Vaccination and Immunisation (JCVI)
Planned actions	Implementation of NHS Toolkit for High-Quality Neonatal Services Development of NICE quality standards (April 2010)

The UK Department of Health (DoH)¹ is responsible for shaping national health policy in England and health service delivery is managed by the National Health Service (NHS)² through Regional Strategic Health Authorities and Primary Care Trusts at the local level. In the rest of the UK, health issues are dealt with by the Health and Community Care Department (Scotland)³; the Health and Social Care Department (Wales)⁴; and the Department of Health, Social Services and Public Safety (Northern Ireland).⁵ For the purposes of this report, the analysis will focus on the current policy environment in England.

PREVALENCE & COST DATA

Live births:

In 2007, the UK Statistics Office⁶ estimated the total number of live births in England and Wales at 690,013, representing an increase of 0.3% over the last 10 years.⁷

Preterm births:

In England, there are approximately 54,000 preterm births every year – approximately 8.3% of the total number of live births.⁸ The severity of preterm births is broken down as follows:

Weeks of gestation	Prevalence
32-36 weeks	5.67 %
28-31 weeks	1.58 %
27 week or less	1.05 %

NHS data from 2007-2008⁹ also revealed that 12.12% of preterm births occurred during or before 31 weeks of gestation, while 28.4% occurred between the weeks 32 and 36. The same data also revealed that the most common complications recorded at birth were due to premature and low-weight births. According to the Directory of Critical Care, in 2007, approximately 82,000 babies were hospitalised for neonatal care in

the UK. Of those, 68,341 hospital admissions were in England.¹⁰

Neonatal mortality:

The number of babies dying in the UK has declined steadily over time. In 2005, the neonatal mortality rate in England was estimated at 0.35%, similar to other developed countries. In 2007, there were 1,460 neonatal deaths in England.¹¹ A report by the National Audit Office, however, showed wide variations across the country. This report also revealed a general lack of data and understanding of the relevance of the different socio-economic, ethnic, demographic, cultural as well as other factors related to neonatal healthcare services in England.¹²

Cost burden:

While there is currently no comprehensive official national cost data available, a 2009 academic report¹³ estimated the annual total cost of preterm birth to the public sector in England and Wales at £2,946 billion (€3,209 billion). The incremental cost per preterm infant surviving to 18 years (compared with a child born at full term) was also estimated at £22,885 (€24,921). Finally, it was estimated that hospital inpatient costs at the time of birth are responsible for 92% of the incremental cost per preterm survivor.

Research by Bliss in 2007¹⁴ estimated the financial cost to families of having a premature baby at an average of £189 (€206) per week during the period the baby is in hospital. According to a report by the National Audit Office however, there remains a lack of comprehensive data and general understanding about the costs involved in neonatal healthcare in England and how the available resources are actually spent.¹⁵ In 2009, the NHS impact assessment for the Toolkit for High-Quality Neonatal Services estimated the national average daily unit costs for intensive care at £1,027 (€1,172), high dependency care at £788 (€899); and special care at £442 (€504). This estimation does not include other costs related to staffing needs, transfers, follow up and long-term care and treatment.¹⁶

GOVERNMENT HEALTH POLICY AGENDA

The NHS Operating Framework for 2009/10¹⁷ outlined the five national health priorities as:

- improving cleanliness and reducing healthcare associated infections;
- improving access through achievement of the 18-week referral to treatment pledge, and improving access to GP services (including at evenings and weekends);
- keeping adults and children well, improving their health and reducing health inequalities, including maternity and neonatal services;
- improving patient experience, staff satisfaction and engagement;
- preparing to respond in a state of emergency, such as an outbreak of pandemic influenza.

According to the NHS Operational Framework, there are plans to increase the resources allocated to the perinatal care workforce with an additional 1,000 midwives by 2009, increasing to around 4,000 extra midwives by 2012 (contingent on the rising birth rate). In January 2008, the Secretary of State announced that Primary Care Trusts' baselines for 2008/09–2010/11 included £330 million extra funding to support improvements in maternity services.

Reducing the rate of infant mortality is also a target of the NHS campaign to address health inequalities between different socio-economic groups in the UK with a 10% reduction target by 2010.¹⁸

NEONATAL HEALTH POLICY

Until 2003, neonatal health had not featured high on the UK policy agenda. In 2003, the Department of Health

undertook a national review of neonatal services which resulted in the "National Strategy for Improvement", accompanied by £72 million to fund its recommendations. However, a comprehensive report by the National Audit Office (NAO) in December 2007,¹⁹ found that this new investment could not be fully accounted for and identified major challenges and necessary improvements in neonatal care in England.

The publication of the NHS Toolkit for High-Quality Neonatal Services in November 2009, provides for the first time a comprehensive policy framework to ensure high quality and safety in neonatal healthcare as well as improved long-term service management.²⁰ The Toolkit recommendations were developed by the Department of Health's Neonatal Taskforce, established in 2008 as a joint initiative with the NHS and with the involvement of parents, medical professionals and other relevant stakeholders in the neonatal community.²¹

The Toolkit is intended to provide Primary Care Trusts with the necessary guidance to deliver equitable, transparent and auditable neonatal healthcare. On the basis of priority areas for improvement, identified by the Neonatal Taskforce and the NAO report, the Toolkit sets out markers of good practice and audit indicators for benchmarking in the following areas:

- organisation of neonatal services - aimed to ensure appropriate expert treatment and access to high-quality care;
- staffing - with a focus on long-term recruitment and skilled training strategies;
- care of the baby and the family experience - through family-centred care focused on the physical, psychological and social needs of both;
- safe and effective transfers - recognising the importance of family circumstances;
- professional competence, education and training - to enable all the members of the multidisciplinary neonatal team to deliver high-quality care;
- surgical services - where the appropriate level of care, support, resource and specialist input is provided;
- clinical governance - aimed at ensuring effective monitoring and continuous assessment and improvement of high-quality and safe neonatal care, while encouraging excellence and innovation;
- data requirements - including a better understanding of the costs involved and the actual allocation and use of the incurred investments.

The Toolkit also outlines a commissioning framework with the aim of ensuring that infants and their families

remain the focus of neonatal care. It defines the core and developmental elements of specialist perinatal-neonatal care and includes a set of quality indicators for evaluation and long-term service management and planning.

The framework does not address particular health risks or diseases which should be considered in the provision of neonatal care. Stakeholders, nevertheless, emphasise an increasing interest and need for improvement in the area of neurodevelopment, with specific reference to the practice and developments in the Scandinavian region.

“The review of neonatal care by the NHS Neonatal Taskforce, if implemented, would make a dramatic and lasting improvement to the way neonatal care is delivered. One-to-one nursing in intensive care remains one of the most crucial improvements needed.”

Andy Cole, Chief Executive of BLISS

Neonatal stakeholders have strongly welcomed the creation and recommendations of the Neonatal Taskforce while, at the same time, stressing the need for clear monitoring; evaluation; regular review and financial mechanisms in order to ensure the effective implementation of the new framework. These comments are made with reference to the different reviews and reports aimed at improving neonatal policies over the last 30 years, which have failed to be fully implemented.

At the time of writing this report, no additional funding had been made available by the UK government for implementation of the Toolkit recommendations, the total cost of which was calculated by the Department of Health as £89 million a year with one-off costs of £102 million.²² Professional associations, such as the Royal College of Nursing, and the UK baby charity Bliss have expressed their deep concerns about the lack of sufficient funding to back the new guidance.²³

PREVENTION & SCREENING

The commissioning framework outlined by the NHS Toolkit recognises that pre-conception care and early referral for specialist fetal maternal medicine or obstetric

care plays an important role in preventing or reducing the risks of preterm birth. Obstetric and fetomaternal medicine should, therefore, be interdependent and well coordinated with neonatal care. The criteria and procedures to identify pregnant women at risk are established at the Neonatal Network level. The Department of Health issues broad guidelines in this respect, which are further developed by the Primary Care Trusts (PCTs).

In general, antenatal care begins immediately after the pregnancy is confirmed. NHS data gathered through the Hospital Episode Statistics (HES) showed that most women consulted a midwife or a maternity healthcare professional for health and social care assessment between the 9th and 13th gestational weeks, with the majority at the 12th gestational week.²⁴

Mothers that are identified at risk of preterm birth are put into special screening and prevention programmes. Stakeholders note, however, the need to improve access to preventive and specialist screening, in particular among ethnic minorities.

There are currently no structured education and support programmes for families at risk of preterm birth. Education and support may be provided by the responsible general practitioner, obstetrician or nurse, and is also made available to patients by the Royal College of Obstetricians and Gynaecologists.²⁵ The Department of Health currently runs public health campaigns that touch upon related issues, such as promoting good nutrition and healthy lifestyles for pregnant mothers.²⁶

MEDICAL TREATMENT & CARE

Organisation of Neonatal Care:

Following the Department of Health's "National Strategy for Improvement" in 2003, 24 Neonatal Clinical Networks were set up across the country on the basis of available resources, capacity, geography and the availability of skilled and trained staff. The aim was to ensure robust clinical governance and auditing of neonatal services by guaranteeing equal access to appropriate neonatal care and by gathering quantitative and quality information on the services provided and particular local needs.

Each Network groups a number of hospitals and neonatal units with different levels of care (i.e. intensive care; high dependency care; special care and normal care) in order to ensure access to appropriate care as close to home as possible. There are currently 162

UNITED KINGDOM

neonatal units and 46 neonatal intensive care units in England. Within each Network, at least one hospital must have intensive care facilities and is expected to work very closely with other units in the same Network providing short-term intensive care, high dependency care and special care. There is a general consensus that the creation of the Neonatal Networks marked a crucial step forward in improving preterm infant healthcare in England. The 2007 National Audit Office report nevertheless identified further areas for improvement by the Networks, primarily to address:

- shortages in nursing staff
- lack of regular specialised training for nurses
- lack of equipment (namely cots) in the right place and with the right level of care
- lack of widespread specialist transport

Standards and Guidelines:

The 2007 NAO report concluded that care and treatment practices are inconsistent across the country. Specific protocols and guidelines may be developed by local hospitals and are sometimes shared by a group of hospitals, resulting in varying practices. Neonatal stakeholders have traditionally called for the development and implementation of stricter, comprehensive national guidelines.

The NHS toolkit aims to address some of the issues outlined above by setting out eight Principles for Quality Neonatal Services, each underpinned by a number of markers of good practice for neonatal care and with a commissioning framework, which will be further developed as NICE quality standards in 2010. The Principles aim to define the standard of neonatal care that hospitals and professionals should provide. They address a range of areas including staffing (e.g. nursing and midwifery; neonatologists and paediatricians; specialist paediatric surgeons; respiratory physiotherapists; paediatric pharmacists and specialists in neurodevelopment), professional education and training, parent involvement and family-centred care; transfers including equipment; surgical services; quality and clinical governance of the neonatal care; and data collection. Specific standards tackle other issues such as screening and treatment for specific diseases, such as group B streptococcal infection and jaundice, hypoglycaemia or sepsis. The commissioning framework aims to provide guidance to managerial staff and sets up a number of indicators and measures to assess the neonatal care provided by each Network and to allow for improved long-term planning.

In addition to the Neonatal Taskforce standards, the UK Medical Professional Colleges develop guidelines to inform the practice. The British Association of Perinatal Medicine²⁷ (BAPM) guidance on the provision of neonatal care, revised in 2001 and currently under review, specifies that infants requiring intensive care should receive one to one nursing as a minimum, based on scientific evidence that this will result in a significant decrease in the infant mortality rate. Babies needing high dependency care should benefit from a minimum nurse-to-baby ratio of one to two, and for those in special care, a ratio of one to four. This guidance still applied in 2009, although nursing shortages have led to an increased number of hospitals which are unable to meet these standards.²⁸ Together with the Standards for Maternity Care published by Royal College of Obstetricians and Gynaecologists (RCOG), these complement the Toolkit guidance.²⁹

BAPM and RCOG have also issued guidelines in a number of additional areas, including the management of complications during pregnancy, extremely preterm babies (born at less than 26 weeks of gestation), retinopathy and respiratory distress syndrome. The British Maternal and Fetal Medicine Society³⁰, the Neonatal Society³¹ and the Neonatal Nurses Association³² also publish recommendations and organise education activities aimed at neonatal healthcare professionals.

Other local guidelines may be produced on particular issues by ad hoc working groups, as is the case for neonatal jaundice, hypoglycaemia and sepsis. NICE also produces guidance on particular issues, such as jaundice, and it is now expected to develop neonatal quality standards on the basis of the NHS Toolkit for High-Quality Neonatal Service in 2010. Many neonatal networks also publish their own guidance for collaborative issues (e.g. transfer, early care, etc.).

Parent Involvement and Education

Parent involvement and family-centred care is one of the central elements of neonatal care as established by the NHS Toolkit. The level of parent involvement has traditionally varied across the country as it was defined by the individual hospital unit or practitioner. Improving the degree and quality of family involvement in care, and ensuring that adequate resources are made available, have been long-standing demands made by neonatal stakeholders.³⁴

The new framework provided by the NHS Toolkit includes a number of standards aimed at promoting family-centred

care during the hospital stay through a number of measures, such as:

- encouraging parent participation in the baby's care;
- ensuring that information about the diagnosis, care and treatment is available and discussed with the responsible staff;
- providing unrestricted access to the baby;
- providing staff trained in providing emotional support and preparing parents for going home after hospital care.

Neonatal professionals decide on a case-by-case basis on additional education and information that should be provided to parents about the potential long-term complications that may appear during the first years of the infant's life as a consequence of preterm birth. The practice is, however, inconsistent across the country, in particular with regard to neurodevelopment and cognitive issues. Some hospitals establish follow up teams, which pay regular visits to the families during the months following the hospital discharge, while in other cases this is performed by local assistance centres, which may not always have expertise in preterm infant related care.

Emotional support provided to parents also varies widely. While some hospitals have dedicated staff (e.g. psychologists), others refer parents to support schemes, such as the general social support scheme aimed at vulnerable families in general. Third party organisations, such as BLISS, also organise specialised emotional support.

Vaccination:

Vaccination is provided free of charge through the NHS. While vaccination is not compulsory in England, it is strongly recommended by doctors and generally followed by parents. The vaccination programme for preterm infants is the same as for full term babies. Specific vaccines are recommended in the case of certain conditions. For example, vaccines against RSV are available for babies with chronic lung disease and heart diseases amongst other indications. The Joint Committee on Vaccination and Immunisation (JCVI) issues guidance on vaccination for full and preerm newborns. Third party organisations, such as BLISS, also organise awareness raising campaigns on specific diseases and health risks, such as RSV infection.

AFTERCARE & LONG-TERM CARE

In England, the Neonatal Networks and hospital units are responsible for short and long-term follow up care

and ongoing assessment of preterm infants when a particular risk or complication has been detected, starting with two-year outcomes.

Local (neuro) disability teams are responsible for follow up interventions with children and their families. Hospital neonatal teams are assigned to screening and referral, assessment of outcomes in two year-old infants, and eventual reporting. The British Association of Perinatal Medicine (BAPM) has developed guidance on follow up during the two years after birth.³⁵ Ongoing studies by the University College London (EPICure group) aim to provide a better picture of the longer term needs of extremely preterm infants (i.e. born before the 26th gestation week).³⁶

Neonatal stakeholders claim that better access to structured and adequately resourced follow up care is still required for secondary and less serious disorders.

SOCIAL & FINANCIAL SUPPORT

There are currently no specific maternal or parental leave provisions, or other financial support measures in the workplace, for the families of preterm infants.

Some hospitals in England provide financial assistance to families during the hospital stay, in particular in the case of long-distance transfers. Following discharge, families may eventually access a disability living allowance, however this is limited to the case of preterm infants with serious complications categorised as a 'disability'. There is currently no structured assistance that applies consistently across the country.

The Neonatal Taskforce recommendations provide for dedicated facilities for parents in the hospital premises during their stay. Further improvements in this area, particularly the allocation of adequate resources to ensure equal access to supporting measures, are called for by many parents.

OUTLOOK

On the basis of the recommendations put forward in the NHS Toolkit for a High-Quality Neonatal Service, the Clinical Neonatal Networks and Strategic Health Authorities are now expected to jointly review the Toolkit and its implications for their respective local areas in order to formulate strategic action plans for implementation. The Neonatal Taskforce will also be providing advice and guidance in this process.

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

UNITED KINGDOM

Specialised Commissioning Groups will also undertake specific actions to meet the Toolkit principles. The NHS has also committed to publish revised reference cost guidance in February 2010.³⁷ The NHS Toolkit will also be the basis for formal quality standards, which NICE is expected to publish by April 2010.

However, it is unclear whether the recent government decision not to allocate resources and additional funding to the implementation of the Neonatal Taskforce's recommendations will prevent the improvements from being delivered.

The main areas where improvements are still considered to be needed include ensuring an appropriately skilled workforce (in particular specialised nursing care) and improving family-centred care by providing additional financial and educational support to parents, during and after the hospital stay.

¹ Department of Health, <http://www.dh.gov.uk/en/index.htm>

² National Health Service (NHS), <http://www.nhs.uk/Pages/HomePage.aspx>

³ Health and Community Health Department of Scotland, <http://www.scotland.gov.uk/Topics/Health>

⁴ Health & Social Care Department of Wales, <http://wales.gov.uk/topics/health/?lang=en>

⁵ Department of Health, Social Services and Public Safety of Northern Ireland, <http://www.dhsspsni.gov.uk/>

⁶ UK Statistics Office, <http://www.statistics.gov.uk/hub/index.html>

⁷ UK Statistics Office, Birth Statistics, http://www.statistics.gov.uk/downloads/theme_population/FM1_36/FM1-No36.pdf

⁸ Bliss, preterm babies – definitions and statistics, <http://www.bliss.org.uk/page.asp?section=760§ionTitle=Premature+babies+%96+definitions+and+statistics>

⁹ NHS Information Centre for Health and Social Care, <http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=1009>

¹⁰ Directory of Critical Care, CMA Medical Data, 2008

¹¹ Impact assessment of Principles for Quality Neonatal Care, DoH, September 2009,

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/@sta/@perf/documents/digitalasset/dh_107853.pdf

¹² Caring for Vulnerable babies: The Reorganisation of Neonatal Health Services in England", NAO, December 2007, http://www.nao.org.uk/publications/0708/caring_for_vulnerable_babies.aspx

¹³ The Cost of Preterm Birth Throughout Childhood in England and Wales", Pediatrics Vol. 123 No.2, February 2009, <http://pediatrics.aappublications.org/cgi/content/abstract/123/2/e312?etoc>

¹⁴ Baby Steps To Better Care: Bliss Baby Report 2008", Bliss, October 2008, <http://www.bliss.org.uk/page.asp?section=67§ionTitle=Document+library>

¹⁵ Caring for Vulnerable babies: The Reorganisation of Neonatal Health Services in England", NAO, December 2007, http://www.nao.org.uk/publications/0708/caring_for_vulnerable_babies.aspx

¹⁶ Impact assessment of Principles for Quality Neonatal Care, DoH, September 2009,

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/@sta/@perf/documents/digitalasset/dh_107853.pdf

¹⁷ NHS Priorities for 2009/10 – the Operating Framework,

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445?dcService=GET_FILE&dID=179327&Rendition=Web

¹⁸ Department of Health, health inequalities guidance on infant mortality, http://www.dh.gov.uk/en/PublicHealth/Healthinequalities/Healthinequalitiesguidancepublications/DH_064261

¹⁹ "Caring for Vulnerable babies: The Reorganisation of Neonatal Health Services in England", NAO, December 2007, http://www.nao.org.uk/publications/0708/caring_for_vulnerable_babies.aspx

²⁰ Toolkit for High-Quality Neonatal Services, NHS, November 2009, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107845

²¹ Department of Health, Neonatal Taskforce, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101241

²² Department of Health, Impact Assessment for Principles for Quality Neonatal Services,

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/@sta/@perf/documents/digitalasset/dh_107853.pdf

²³ Extra millions for baby units denied, The Independent, 4 November 2009, <http://www.independent.co.uk/life-style/health-and-families/health-news/extra-millions-for-baby-units-denied-1814192.html>

²⁴ NHS maternity data in HES, <http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=925>

²⁵ Royal College of Obstetricians and Gynaecologists, patient information, <http://www.rcog.org.uk/womens-health/patient-information>

²⁶ NHS Priorities for 2009/10 – the Operating Framework,

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445?dcService=GET_FILE&dID=179327&Rendition=Web

²⁷ British Association of Perinatal Medicine guidelines, <http://www.bapm.org/publications/index.php> \ "guidelines

²⁸ BAMP Standards for hospitals providing neonatal intensive and high dependency care, http://www.bapm.org/media/documents/publications/hosp_standards.pdf

²⁹ Royal College of Obstetricians and Gynaecologists guidelines, <http://www.rcog.org.uk/womens-health/guidelines?filter0%5B%5D=11>

³⁰ British Maternal and Fetal Medicine Society, <http://www.bmfms.org.uk/default.htm>

³¹ Neonatal Society, <http://www.neonatalociety.ac.uk/>

³² Neonatal Nurses Association, <http://www.nna.org.uk/index.asp?page=education>

³³ Perinatal Medicine 2008, <http://www.perinatalmedicine2008.ukevents.org/programme.htm>

³⁴ Bliss 30th Birthday Baby Report; Three decades and counting, November 2009,

http://www.bliss.org.uk/news_item.asp?itemid=1483&itemTitle=Bliss+30th+Birthday+Baby+Report%3A+Three+Decades+and+Counting§ion=22§ionTitle=News+and+media

³⁵ BAMP guidance on classification of health status at 2 years as a perinatal outcome, <http://www.bapm.org/meetings/Outcome%20at%202%20yrs%20Jan%2008.pdf>

³⁶ Epicure study, <http://www.epicure.ac.uk/>

³⁷ Impact assessment of Principles for Quality Neonatal Care, DoH, September 2009,

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/@sta/@perf/documents/digitalasset/dh_107853.pdf

KEY FINDINGS & CONCLUSIONS

The research carried out in the 13 EU countries revealed a number of important findings, which should be carefully considered by both national and European decision makers in shaping future maternal, infant and neonatal health and social policies. This section of the report contains a concise analysis of the main research findings.

PREVALENCE & COST

The statistical data collected from the 13 European countries demonstrate the significant and growing prevalence and cost of prematurity in Europe. While much of the data is not easily comparable, due to the different reporting mechanisms and methodologies, there is still a clear indication of the size and growth of this extremely vulnerable patient group as well as the short and long-term financial burden they represent to European economies.

According to the 2008 European Perinatal Health Report, which is based on data from 2004, as well as statistics collected from national sources, the following observations can be made:

- According to data from 2004, preterm birth rates in the 13 European countries vary from 6.3% (Sweden, France) to 11.4% (Austria). At least 8 of the 13 European countries have preterm birth rates of 7% and above.¹
- The lowest preterm birth rates can be observed in countries such as Sweden, France and Portugal, although these still account for over 6% of live births.²
- In the last five years, there has been a considerable increase in preterm births – for example, in Portugal, the rate has risen from 6.8% in 2004 to 9.0% in 2008 – an increase of 32%.³
- Very preterm births (births before 32 weeks of gestational age) are estimated to account for approximately 1% of all live births.
- A decreasing mortality rate among preterm infants is observed in most European countries.
- Some countries have begun to improve data collection to assess the health risks and implications of prematurity in the short and long-term (e.g. Czech Republic, Netherlands, Sweden, UK).
- A few countries have also put in place structured programmes to evaluate the quality of neonatal healthcare services (e.g. Sweden, UK).

Percentage of live births with a gestational age under 32 weeks and between 32-36 weeks



TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

There are a number of important conclusions which can also be drawn from the report's findings:

- There is currently no single source of up-to-date, comparable European data on the prevalence, mortality and morbidity associated with preterm births.
- Official national sources of prematurity data do not appear to be available to decision-makers in a number of countries to support the development of neonatal policies.
- Data on prematurity including risk factors, management and outcomes of neonatal healthcare is not collected and analysed consistently across EU member states - reliable statistics are scarce and, where they do exist, are often inconsistent.
- Even in the absence of rigorous data collection, available data suggest a clear trend of increasing prevalence of preterm births in all of the EU countries (with the exception of Sweden).
- Existing data also highlight considerable inequalities in the preterm birth rates in European countries, with wide variations both between and within countries.
- Data collection systems are often voluntary resulting in significant variation in the level of detail, the indicators used (e.g. different weekly categories v. weight), the definition of the indicators themselves and the definition of prematurity.
- With regard to costs, there is an absence of reliable and comprehensive cost data in countries demonstrating the health-economic impact of prematurity (with the exception of Denmark).
- Where data exists, it tends to be limited to direct costs in the immediate period after birth – there is no comprehensive assessment of the long-term costs associated with preterm births.

POLICIES ON PREMATURETY

While the available data suggests a considerable and growing number of preterm births across the European region, there is, nevertheless, a notable absence of targeted national policies aimed at reducing the prevalence and improving the health outcomes associated with prematurity.

- There are currently only two countries in Europe with a targeted national policy for neonatal health and preterm infants (Portugal, UK).
- Several countries have general national plans for maternal and infant health, although they contain no specific provisions for preterm infants (e.g. Spain).
- A number of countries have no dedicated maternal, infant or neonatal health programme in place (e.g. Austria, Germany).
- In those countries without a national policy, preterm infant care appears to be provided for in the framework of other health and social policies.

Country	National Plan or Policy Framework
Austria	No dedicated maternal, infant or neonatal health programme
Belgium	No dedicated maternal, infant or neonatal health programme
Czech Republic	No dedicated maternal, infant or neonatal health programme
Denmark	No dedicated maternal, infant or neonatal health programme
France	No dedicated maternal, infant or neonatal health programme
Germany	No dedicated maternal, infant or neonatal health programme
Italy	No dedicated maternal, infant or neonatal health programme
Netherlands	No dedicated maternal, infant or neonatal health programme
Poland	No dedicated maternal, infant or neonatal health programme
Portugal	National Programme for Maternal and Infant Health (<i>Programa Nacional de Saúde Materno Infantil</i>) with specific provisions for preterm infants
Spain	Programme of Maternal and Infant Health (<i>Programa de Salud Materno-Infantil</i>) – no explicit provisions for preterm infants
Sweden	No dedicated maternal, infant or neonatal health programme
United Kingdom	<i>NHS Toolkit for High-Quality Neonatal Services</i>

There are a number of important conclusions which can also be drawn from the report's findings:

- Neonatal and preterm infant health currently ranks low on the political agendas of EU member states – very few countries have targeted policies focused on preterm infants.
- Instead, there is a relatively fragmented approach to policies on preterm birth and in most countries the issue is addressed in the framework of other, more general, health and social policies. In this respect, it remains a secondary priority for action.
- Where governments have chosen to prioritise neonatal health policies, often with multi-stakeholder support, the rate of preterm births has remained below the European average.
- In some countries, current economic pressures are considered to be a key factor influencing the future development and effective implementation of neonatal health policies (e.g. UK, Spain, Czech Republic).
- In some cases, the reluctance of policy makers to make preterm infant health a priority can be partly attributed to a fear of costly interventions and the diversion of funds from other maternal and perinatal health problems.

PREVENTION & SCREENING

With regard to the prevention of prematurity, the research also revealed an absence of national policies and programmes targeted at pregnant mothers at risk of preterm birth.

Those countries with national prevention or screening measures in place include the following:

Country	Prevention Measures
Austria	No special prevention or screening measures
Belgium	No special prevention or screening measures
Czech Republic	Additional screening provided at discretion of individual doctor. At risk mothers transferred to Perinatology Centres
Denmark	At risk mothers receive intensified screening at specialised neonatal units
France	At risk mothers put into special prevention and screening programmes
Germany	Additional screening tests reimbursed by some health insurance providers (e.g. vaginal pH tests)
Italy	Regional guidelines on prevention and screening
Netherlands	At risk mothers put into special prevention and screening programmes, but no wide access
Poland	At risk mothers receive intensified screening at specialised perinatal centres
Portugal	No special prevention measures. At risk mothers receive screening at specialised perinatal centres
Spain	At risk mothers put into special prevention and screening programmes
Sweden	Complicated pregnancies referred to specialised outpatient clinics, facilitated leave and working arrangements during last 1-2 months of pregnancy
United Kingdom	At risk mothers put into special prevention and screening programmes. Department of Health guidelines on identification of at risk women

- Prevention programmes targeted specifically at preterm birth are generally voluntary and are not consistently organised in each country.
- Programmes are often dependent on hospital guidelines or on the individual practice of healthcare professionals.
- Education and awareness campaigns are implemented in some countries by parent associations and public authorities. However their scope and impact remain rather limited.
- There is a general lack of information to parents about the risk factors, warning symptoms and/or recommended lifestyles to prevent preterm births.

MEDICAL TREATMENT & CARE

With regard to the medical treatment and care of preterm infants the following trends could be observed across the European countries:

Organisation of care

- Care for preterm infants is generally organised at different 'levels' according to the intensity of care assumed to be required. However, a clear definition of the necessary infrastructure and specialisation of neonatal care at each of these levels is lacking in many countries.
- A number of initiatives have been implemented in several countries to promote the centralisation and specialisation of the care provided by neonatal units, while this is also considered to pose a challenge in ensuring equal access to specialised care and safe transfers when needed.
- Quality control and management programmes to ensure high standards of quality in neonatal services remain very limited. Where data exist, comparability remains very difficult.
- Follow up care is not organised in a structured manner for all preterm children. Some countries have organised follow up checks for very preterm infants, while structured follow up for other preterm infants appears to be infrequent and, in most cases, inexistent.

Country	Follow up & Long-term care
Austria	High risk infants receive regular checks during first two years after birth (specialised aftercare up to 6 years in some clinics in Vienna)
Belgium	No national follow-up care program.
Czech Republic	Follow up and aftercare provided by general practitioners in line with general schedules of preventive examinations
Denmark	Preterm infants born after 30 weeks monitored during first 2-3 years after birth. Infants between 25-30 weeks monitored until school
France	No structured programme. Centres for Medical and Social Attention provide a number of services up to 6 years of age
Germany	No structured programme. Follow up organised by neonatal units as considered appropriate; one obligatory check-up at 2 years of age
Italy	Follow up and aftercare for extremely preterm infants (below 25 weeks) provided until 13 years of age
Netherlands	Hospitals responsible for follow up and aftercare during the first 2 years of life. Later follow up checks by paediatricians at the age of 5 and 8
Poland	Preterm infants monitored in specialised perinatal centres during first two years after birth. Follow up also devolved to local neonatologists/paediatricians/general practitioners.
Portugal	Highly developed system of aftercare and long-term care by multi-disciplinary teams
Spain	No structured programme. Follow up devolved to primary care level and generally limited to extremely premature/low weight infants
Sweden	Highly developed system of aftercare and long-term care. Follow up measures organised by neonatal units in cooperation with multi-disciplinary teams
United Kingdom	High risk infants receive short and long-term follow up provided by neonatal networks during at least the first two years after birth

Healthcare resources

- The need for specialised training of doctors and nurses and for increased multidisciplinary staffing for neonatal units, including psychologists and social workers, is highlighted as an urgent need by parents and professionals in a number of countries including Germany, Spain, France and the UK.
- More consistent guidelines, specialised training for professionals and financial resources to ensure effective and wide follow up are demanded by both parents and professionals in all EU member states.

FINANCIAL & SOCIAL SUPPORT

Overall, social policies aimed at protecting preterm infants and their families are also lacking in the majority of EU member states:

- In general, there is no specific social and/or financial support provided to families with a preterm infant, unless the child has been recognised as having a specific disability.
- Awareness of the existing support schemes is shown to be very poor amongst the general population. Very few countries have put in place services aimed at providing guidance and orientation to parents. The level of access to support services is often associated to the education level and the socio-economic status of the family.
- Selected countries offer an extended period of maternity and/or parental leave to the families of preterm infants; however the majority offer no additional benefits on top of the standard period of leave.

Country	Maternity/Parental Leave
Austria	Extended maternity leave by 8 weeks. Extended parental leave up to 36 months after the birth
Belgium	No special provisions for preterm infants in addition to standard 15 week entitlement
Czech Republic	No special provisions for preterm infants
Denmark	Extended maternity and parental leave in addition to the standard 4 weeks prior to and 14 weeks following birth
France	Extended maternity leave to cover the period between the due and actual birth date, in addition to general 16 week entitlement
Germany	Extended maternity leave by 4 weeks in addition to 14 weeks entitlement (up to 3 years under special circumstances)
Italy	Extended maternity leave possible in addition to standard 20 week / 5 month entitlement
Netherlands	No special provisions for preterm infants in addition to standard 16 week entitlement
Poland	No special provisions for preterm infants
Portugal	No special provisions for preterm infants in addition to standard 5 month entitlement. Maternity leave is temporarily suspended in the case of a hospitalisation
Spain	No special provisions for preterm infants. A 2-hour reduction of working day for public sector workers
Sweden	Standard 18 months entitlement, commencing the date of birth or of hospital discharge in case of hospitalisation
United Kingdom	No special provisions for preterm infants

OUTLOOK

Based on the results of the country desk research and feedback received in the course of the stakeholder interviews, the outlook with regard to improvements in the field of preterm infant care appears to be quite poor:

- Very few countries are reported to be planning new policy initiatives in the area of preterm infant and neonatal health in the coming months.
- Neonatal stakeholders view the situation quite negatively and are not optimistic about the prospect of significant changes in the near future.

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

Country	Planned Actions
Austria	No planned actions
Belgium	Development of federal prevention and screening guidelines, adoption of follow-up/long-term care scheme, review of neonatal financial support schemes
Czech Republic	Launch of centre for complex care for preterm infants in 2011
Denmark	Increasing centralisation of neonatal services. Development of national guidelines for care of preterm infants
France	No policy measures planned. Ministry study on perinatal health. Outcome of working group on information to parents
Germany	No planned actions
Italy	No planned actions
Netherlands	Pregnancy and Delivery Project Board recommendations to the government on neonatal health
Poland	Updated common standards for perinatal care
Portugal	No planned actions
Spain	No planned national policy measures. Full implementation of support schemes under new law to protect dependent people. At regional level, adoption and implementation of regional protocol on neonatal care for preterm infants (Catalonia)
Sweden	Professional registries and follow-up studies on health outcomes
United Kingdom	Implementation of NHS Toolkit through strategic action plans. Development of NICE quality standards in 2010

When consulted on the areas most in need of improvement, the key demands made by stakeholders included the following aspects:

- Ensuring equal access to qualitative prevention programmes, specialised (long-term) treatment and care;
- Increased financial and human resources – in specialised medical staff, equipment and knowledge;
- Adopting a more family-centred approach to care.

Country	Stakeholder Demands
Austria	Increased financial support and improved screening programmes. Wider access to specialised treatments
Belgium	Long-term follow-up care, improved psychological support for families and infants, national data collection system
Czech Republic	Improved access to prenatal, neonatal and follow-up care
Denmark	Improved coordination and access to follow-up and long-term care. Increased specialised medical staff in neonatal units
France	Establishment of data collection system across the country, improved skill training for healthcare staff, improved follow-up care, education to parents
Germany	Improved access to screening and prevention programmes. More guidance on the treatment and care of preterm infants. Improved education and support to parents (before and after discharge) and reassessment of service provision by neonatal units
Italy	Improved organisation of maternity wards, emergency transfers and wider prenatal and neonatal screening
Netherlands	Better structured follow-up care, including education to parents and financial support
Poland	Improved financing of perinatal health system, improved family-centred care through additional financial and educational support to parents
Portugal	Preventing the move of specialist staff to the private sector minimising impact of new hospital management model on regional coordination
Spain	Improved prevention, increased specialised medical staff (particularly nurses), improved family-centred care and follow up care through additional financial and education support to neonatal units
Sweden	Wider access across the country to parent facilities at hospital to facilitate family-centred care
United Kingdom	Increased specialised medical staff (particularly nurses) and improved family-centred care through additional financial and education support to parents

¹ *European Perinatal Health Report (2008) www.europeristat.com*

² *Idem*

³ *Alto Comissario da Saude, Ministerio da Saude (2009)*

HIGHLIGHTING BEST PRACTICE

Although it is clear from the report findings that very few countries in Europe are taking serious steps to address prematurity, the research does highlight some good examples of best practice - particularly in the development of national policies and the creation of national stakeholder groups.

Three of these examples are set out below and should be shared with other countries as they begin to develop their own national neonatal policies and programmes.

PORTUGAL

Portugal has succeeded in reducing its previously high neonatal and infant mortality rate to one of the lowest in Europe (and the world). Following reforms in the early nineties, maternal and infant health has been put high on the health policy agenda with the adoption of a national Programme for Maternal and Infant Health. This comprehensive and multidisciplinary approach to neonatal care unified interventions in the area of maternal, neonatal, child and adolescent health as well as providing support to families. Portugal increased access to **prevention and screening** programmes, introduced a system of centralised care with improved **specialist neonatal services and multidisciplinary teams**, including psychologists. A nationwide **transport system** for pregnant women and newborn babies was also established, and training of professionals was increased through **post graduate education in neonatology**. The government also introduced a **regular review** of achievements and upcoming challenges with the involvement of experts and parents. The effective implementation of this policy, by government and healthcare professionals, has succeeded in reducing the morbidity and mortality rate associated with preterm birth.

SWEDEN

In Sweden, the rate of preterm births is considerably lower than in other EU countries. This is attributed to a number of factors, including broad access to prenatal care and high quality services which have resulted from the centralisation and specialisation of intensive neonatal care units. Sweden has invested significantly in **research, specialised training for healthcare staff, equipment and adequate facilities**, which has led to worldwide recognition of its expertise in high quality specialised neonatal care, including **family-centred and developmental care**. Additional social support measures and **long-term aftercare and follow up programmes**, such as extended maternal and parental leave, have also proven to be crucial in improving the well-being of newborns and their families. Another reason why the prevalence of preterm births is not increasing in Sweden, unlike most other EU member states, is thought to be the tighter controls on IVF treatment in order to prevent multiple births, which are frequently associated with premature delivery.

UNITED KINGDOM

Most recently, the UK has taken concrete steps to address prematurity by introducing a comprehensive policy framework to ensure high quality neonatal care. The **Toolkit for High-Quality Neonatal Services** (adopted in November 2009) was developed by the National Health Service in close cooperation with key stakeholders, including healthcare professionals from different disciplines. The toolkit defines **clear policy priorities and objectives** and sets out **indicators for benchmarking** neonatal service organisation and management, education and training of specialised staff and structured follow-up programmes by multidisciplinary teams. Furthermore, **parent involvement and family-centred care** are acknowledged as a key component and overarching objective of the neonatal services and policies. The success of the Toolkit and its policies, however, will be highly dependent on the allocation of additional government funding resources, which have so far not materialised.

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

Based on these three examples, as well as the broader feedback received in conducting this research, it is also possible to identify key factors which determine an effective and successful approach to tackling prematurity. These include:

- A national neonatal health policy/programme
- Formal dialogue between government, healthcare professionals and parents
- Comprehensive data collection on prevalence/morbidity/mortality/cost burden based on standardised definitions and common measurement criteria (e.g. through registries)
- Comprehensive data collection on neonatal intervention outcomes/neonatal service management based on common measurement criteria
- Access to antenatal care and prevention/screening programmes
- Specialisation of intensive care units (e.g. through centralisation/regionalisation)
- A national transportation system for preterm babies and mothers at risk
- National treatment and care guidelines
- Structured after-care and long-term care/follow up programmes
- Specialised education and training of healthcare staff in NICUs
- Financial and social support for families of preterm infants (e.g. extended maternity/parental leave)
- Investment in neonatal research

These criteria may serve as the basis for the ongoing assessment and benchmarking of national neonatal policies.

POLICY RECOMMENDATIONS

Based on the key findings and conclusions of this report, there are a number of clear priorities for policy action - at both the European Union and national level. These policy recommendations are summarised below, together with a brief rationale.

EU POLICY RECOMMENDATIONS

The European Union should:

1 Recognise the growing challenge of prematurity in Europe and its significant impact on infant morbidity and mortality. Acknowledge the health and social inequalities linked to prematurity which exist across the EU's member states.

Preterm infant health is currently absent in the development of EU health and social policies - a surprising observation given the significant and rising prevalence of preterm births and related health complications in Europe. In order to rectify this situation, a first step for the EU will be to acknowledge the extent of this growing challenge for national healthcare and social systems, as well as to recognise the impact that different policies and practices across the EU member states have on growing social and health inequalities. Reducing health inequalities in Europe is a clear mandate of the EU following the adoption of the Treaty of Lisbon and, based on the findings of this report, prematurity is one area where the EU could make a significant impact.

2 Demonstrate the EU's commitment to improving neonatal health through the development and implementation of coordinated EU health and social policies.

The EU has an essential role to play in raising neonatal health standards across Europe. While respecting member state responsibility for healthcare delivery, the EU should contribute through the development of targeted health and social policies, by providing a forum for the sharing of best practice among countries and supporting the development and implementation of national neonatal policies. A first step for the EU would be to nominate a policy officer in the European Commission (DG Sanco) to be responsible for neonatal health and prematurity. This would ensure continued and consistent analysis of the necessary improvements and coordinated

policy initiatives, including by systematically integrating these issues into all EU policies impacting maternal and child health.

3 Address the lack of comparable European data on prematurity, including prevalence, mortality, acute morbidity, long-term impairment, health-care service management and health outcomes. Support the creation and strengthening of data collection systems with common measurement criteria.

Reliable epidemiology and quality outcomes data, are necessary to develop meaningful, evidence-based health policies at EU level and to support complementary efforts at the national level. While there have been attempts to create independent European networks with the aim of improving data collection (e.g. EuroNeoNet), such initiatives remain limited and require improved coordination as well as more sustainable, long-term funding and a broader scope in order to make a real impact. A first step for the EU would be to establish a single, centralised European registry for epidemiological and quality outcomes data. Such a registry should be founded on the basis of common definitions and measurement criteria in order to allow for comparative analysis.

4 Increase the standard of neonatal care across Europe by supporting the development and implementation of a European medical guideline and quality standard for the prevention, treatment and long-term care of preterm infants.

As evidenced by the results of our research documented in this report, the policies and practices in place for the prevention, treatment and long-term care of preterm infants vary considerably across Europe, with a considerable impact on the quality of care, health and social

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

outcomes. In order to address these disparities, the EU would benefit from a set of basic independent, evidence-based professional guidelines for the prevention, treatment and long-term care of preterm infants. These guidelines should focus primarily on the provision of trained medical personnel and medical equipment, recommended treatment and care methods, and the recommended infrastructure, logistical cooperation, neonatal service evaluation and scale up schemes which are fundamental to delivering high quality neonatal care. Family-centred and developmental care, including parent involvement at all stages – from the preventive interventions during pregnancy to the provision of care – should be essential overarching elements of the guidance.

⑤ *Prioritise and allocate EU funding to promote coordinated European neonatal and perinatal research to improve the prevention, treatment, care and outcomes of preterm births. Support the establishment of European research centres and networks.*

The field of neonatology has so far been neglected in the definition of priorities for EU funded research. In order to address this omission, the EU should first identify opportunities under the current 7th Research Framework Programme (FP7) for funded projects in the areas of a broad range of chronic diseases and disorders linked to prematurity as well as effective prevention and care strategies. In the longer-term, the 8th Framework Programme should include perinatology and neonatology as a key priority area for future EU-funded health research. The EU would also benefit from the establishment of neonatal research centres, which are characterised by top and basic research activities, as well as the creation of a centrally managed European research network.

⑥ *Support the development of a European postgraduate training programme in Peri- and Neonatology in order to increase the quality and availability of trained healthcare professionals.*

In the majority of EU member states, there is a shortage of trained neonatal healthcare and research professionals

(specialised nurses and doctors, as well as scientists) to meet the specific needs of a growing number of preterm births. One way in which the EU could address these shortages, is by supporting the establishment of European postgraduate training programmes which include local, onsite training programmes for neonatal units and hospitals, European postgraduate courses and seminars, and the exchange of neonatal trainees between certified European educational centres of excellence.

NATIONAL POLICY RECOMMENDATIONS

National governments should:

① *Recognise the challenge of prematurity and its significant impact on infant mortality and morbidity. Acknowledge the health and social inequalities linked to prematurity which exist within countries.*

Preterm infant health is frequently absent in the development of national health and social policies – a surprising observation given the significant and rising prevalence of preterm births in most countries. In order to rectify this situation, a first step for national governments will be to acknowledge the extent of this growing challenge for the health and social system. In many countries, it is also important for governments to recognise the inequalities which exist in the access to high quality prevention, treatment and long-term care of preterm infants and that poor health outcomes resulting from prematurity – which can be largely prevented or improved – may lead to greater social and health inequalities in the longer-term.

② *Prioritise the development and implementation of a targeted national neonatal health policy, which is integrated into mainstream maternal health and social services with the involvement of stakeholders and, in particular, parents and medical professionals.*

In Europe, there appears to be an absence of targeted national policies aimed at reducing the prevalence of and improving the health outcomes associated with prematurity. In most countries, there is a fragmented,

uncoordinated approach to neonatal health policy which impacts the quality of care. National governments, together with the key stakeholders, should therefore develop and implement a national neonatal health policy which is fully integrated into mainstream maternal health and social services. Political commitment to invest in the appropriate infrastructure, medical and scientific knowledge and systems of care (from prevention and treatment to long-term care) is essential for the successful implementation of such policies.

avoidable risk factors associated with prematurity, namely smoking, alcohol, drugs, teenage and delayed pregnancies. The programmes should take account of ethnic minorities and lower socio-economic groups and include workplace recommendations to minimise stress in pregnant women. Special attention should also be given to increasing awareness of the risks of delayed childbearing and the need for more controlled use of IVF treatment to minimise multiple embryo implantations.

③ Address the lack of comprehensive epidemiological and economic data on prematurity - prevalence, mortality, acute morbidity and long-term impairment, outcomes and costs. Support the creation and strengthening of data collection systems with common measurement criteria.

In the absence of reliable epidemiology, cost, and quality outcomes data, national policy makers are unable to develop meaningful, evidence-based health policies. While there is a basic level of reporting in most EU countries, the data is rarely comprehensive and fails to measure key indicators (e.g. costs). National governments should establish a single, centralised registry for epidemiology, cost and quality outcomes data associated with prematurity. Such a registry should be founded on the basis of common definitions and measurement criteria in order to allow for comparative analysis and exchange of best practices.

④ Reduce the preterm birth rate through the development and implementation of targeted, evidence-based prematurity prevention programmes.

The prevalence of preterm birth continues to increase despite the continuous improvements in neonatal care. In order to reduce the prevalence of preterm birth, there is a need for targeted national prevention programmes which promote awareness raising of prematurity and its risk factors, screening measures, and education and support measures for families at risk of preterm birth. Health promotion campaigns, starting at an early age, should be targeted at the main,

⑤ Improve neonatal health outcomes by increasing access to high quality maternal and neonatal health services, including specialised healthcare professionals and dedicated neonatal transport services.

The EU member states which have demonstrated the most successful neonatal health policies are those which have improved access to high quality health services, including prevention programmes. Nevertheless, the information and medical advice does not always reach parents at risk of having a premature baby, specialised healthcare staff are frequently lacking in NICUs (nurses and neonatologists) and neonatal assistance is often being provided without the necessary specialisation. In order to improve neonatal health outcomes, national governments should implement policies aimed at improving the recruitment, education and training of specialised healthcare staff in NICUs, implementing effective neonatal service management policies as well as providing an effective national transportation system for preterm babies and mothers at risk and/or in need of specialised intensive care. Positive experiences exist in a number of countries where intensive neonatal care units have been progressively centralised or regionalised.

⑥ Increase access to specialised and appropriate aftercare for developing preterm infants. Develop and implement structured programmes and systems to document medical checks and aftercare.

Although many preterm infants are at risk of developing long-term related disorders or chronic diseases (e.g.

TOO LITTLE, TOO LATE?

Why Europe
should do more
for preterm infants

behavioural, developmental and neurological disorders, chronic lung disease, visual and hearing impairments, motor problems, etc.), there is a lack of appropriate aftercare in a number of member states. National governments should therefore implement policies which provide for organised and specialised follow up care for preterm infants in order to prevent, screen and provide the adequate level of care for potential long-term related disorders or chronic diseases. These policies should be supported by structured programmes involving professional multidisciplinary teams and systems to document the medical checks received by the preterm infant.

7 Increase access to professional psychological, social care and support for families with preterm infants, in hospitals and following discharge.

The preterm birth of an infant and the following period of neonatal intensive care can cause considerable psychological distress to parents. As parental involvement plays a key role in the provision of optimal care to preterm infants, national governments should develop and implement policies which facilitate access to psychological and social support by professionals -

throughout the infant's hospitalisation and also following discharge. These measures should aim at reducing post-traumatic stress disorder and facilitating access to the existing social support schemes.

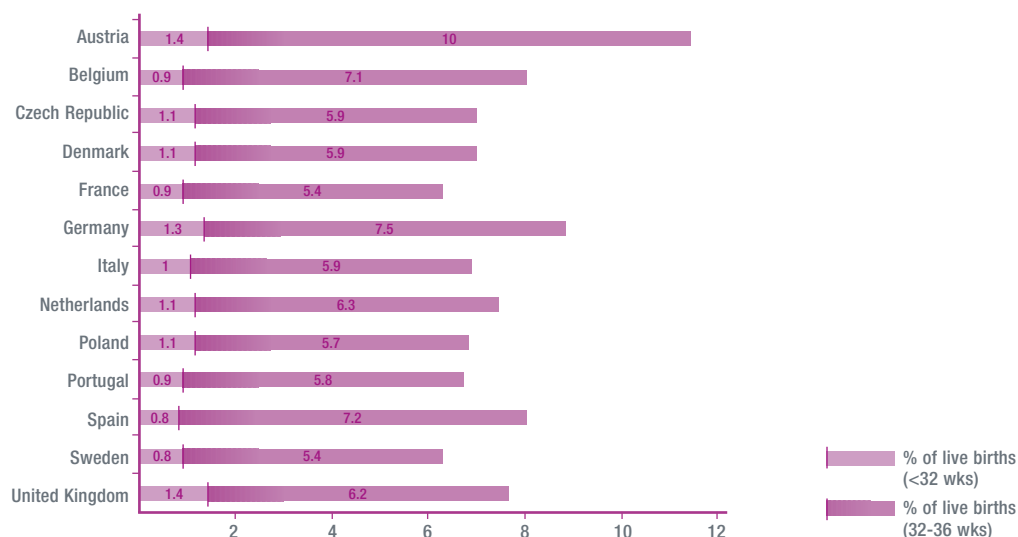
8 Provide increased social support to families through extended maternity (and parental) leave and financial support for the parents of preterm infants.

Few member states make special social and financial provisions to help the families of preterm infants with the additional financial burdens they face after hospital discharge and in the longer-term. National governments should consider extending the period of maternity (and paternity) leave for the parents of preterm infants as a means of ensuring the optimal development and care of preterm infants by allowing for greater contact with their parents. This would also allow for a quicker recovery from the post-traumatic stress which may be experienced following the preterm birth. In order to support families and infants with longer-term complications, complementary financial support schemes should also be considered.

ANNEXES

ANNEX 1 - DATA SOURCES

Percentage of live births with a gestational age under 32 weeks and between 32-36 weeks



Country	Prevalence rate of preterm births*	Mortality rates*
Austria	11.1% (2008)	0.4% of total births (2008)
Belgium	7.4% (2007)	0.19% (Flanders) (2008)
Czech Republic	7.6% (2007)	66 deaths (during first year of life) (2008)
Denmark	6.8% (2008)	0.38% (2008)
France	8.0% (2008)	1.31% of total births (during first year of life) (2007)
Germany	6.8% (2007)	0.35% (2007) - 2.371 deaths (2007)
Italy	6.5% (2005)	0.37% (2005)
Netherlands	7.6% (2007)	0.37% of preterm births (2007) - 634 deaths (2007)
Poland	6.8% (2008)	0.49% (2008)
Portugal	9.1% (2007)	0.21% (2008)
Spain	6.7% (2007)	Not available
Sweden	5.9% (2007)	Not available
United Kingdom	8.3% (2007)	0.35% (England) (2005) - 1.460 deaths (England) (2007)

* Data from national sources collected during the research for this report

TOO LITTLE, TOO LATE?

Why Europe
should do more
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ANNEX 2 – CONSULTED ORGANISATIONS

Country	Consulted organisations
Austria	Bundesministerium für Gesundheit Verein "Initiative für Früh- und Neugeborene"(IFN) Universitätsklinik für Kinder- und Jugendheilkunde, Klinische Abteilung für Neonatologie, Graz Medizinische Universität Wien, Abteilung für Kinder- und Jugendheilkunde
Belgium	Federale Overheidsdienst Volksgezondheid Vlaamse minister van Welzijn, Volksgezondheid en Gezin Vlaamse Vereniging voor Ouders van Couveusekinderen (VOC) Leuven Universitair Ziekenhuis (UZ Leuven) Société Belge de Neonatologie et de Pédiatrie Intensive (BVNPI) Ministre des Affaires sociales et de la Santé publique Kind en Gezin Office de la Naissance et de l'Enfance (ONE) CAP48
Czech Republic	Ministry of Health, Department of Healthcare Nedoklubko University Hospital Pilsen Institute for the Care of Mother and Child
Denmark	Sundhedsministeriet Sundhedsstyrelsen Præmatur Jordemoderforeningen Hvidovre Hospital
France	SOS Prema Groupe d'Etudes de Neonatalité (GEN) Hopital Robert Debré, Paris
Germany	Bundesministerium für Gesundheit Bundesverband "Das frühgeborene Kind" e.V. Universitäts-Kinderklinik Tübingen
Italy	Ministero del Lavoro, della Salute e delle Politiche Sociali Direzione Generale Prevenzione Sanitaria Vivere onlus Università di Torino
Netherlands	Inspectie voor de Gezondheidszorg Ministerie van Volksgezondheid, Welzijn en Sport Neonatology Section Dutch Pediatric Association TNO research institute Vereniging van Ouders van Couveusekinderen (VOC)
Poland	Ministerstwo Zdrowia, Departament Matki i Dziecka Fundacja Wcześniak Rodzice-Rodzicom Konsultant wojewódzki w dziedzinie Neonatologii i członek Polskiego Towarzystwa Neonatologicznego Konsultant Krajowy w dziedzinie Neonatologii
Portugal	Alta Comissária da Saúde XXS-Associação Portuguesa de Apoio Bebê Prematuro Registo Nacional do Grande Prematuro Sociedade Portuguesa de Neonatologia Grupo de Registo de Recém-nascidos de Muito Baixo Peso
Spain	Ministerio de Sanidad y Política Social Generalitat de Catalunya – Departament de Salut Prematura Sociedad Española de Neonatología Sociedad Española de Enfermería Neonatal
Sweden	Socialstyrelsen Karolinska Institutet Föräldrarföreningen för prematurfödda barn
United Kingdom	BLISS, UK special baby care charity British Association of Perinatal Medicine NHS Neonatal Taskforce

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