



SURVEILLANCE OF PERINATAL HEALTH IN EUROPE

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2.1 WHY MONITOR PERINATAL HEALTH IN EUROPE?

Perinatal health, defined as maternal and child health during pregnancy, delivery, and the postpartum, has improved dramatically in Europe in recent decades. In 1975, neonatal mortality ranged from 7 to 27 per 1000 live births in the countries that now make up the European Union (EU); today, it ranges between 2 and 5 per 1000 live births. Likewise, maternal deaths from childbirth have become increasingly rare. These across-the-board improvements in perinatal health reflect technological advances in obstetrical and neonatal care, the development of maternity and child health services, and improved standards of living across Europe.

CONTINUING RISKS TO MOTHERS AND BABIES

Despite this good news, pregnancy and childbirth still involve risk for pregnant women and their babies and health in the perinatal period remains an important public health priority. Although poor outcomes are increasingly rare, the population at risk is numerous. This report includes more than 5.25 million pregnant women and newborns in 29 European countries. Around 40 000 babies are stillborn or die before their first birthday every year. A still larger number of the survivors have severe sensory or motor impairments¹ and a further 90 000 have major congenital anomalies.² Impairments that stem from the perinatal period, because they affect the youngest members of society, carry a disproportionate and long-term burden for children, their families, and social services. Mothers in Europe still die in childbirth – approximately 5 to 15 women per 100 000 live births. Alarming, around half of these cases are associated with substandard care and are potentially avoidable.³

INEQUALITY IN PERINATAL HEALTH

These health risks and burdens are not distributed equally either across or within the countries of Europe. In our previous EURO-PERISTAT report, we found that rates of fetal and neonatal mortality were twice as high in high versus low mortality countries.⁴ Within countries, social factors are major determinants of perinatal health; individual family characteristics (maternal education and occupation, household income, and marital status) as well as community-level characteristics (deprivation, poverty, unemployment, and segregation) are associated with risks of fetal, neonatal, and infant death, preterm birth, low birth weight, growth restriction, and the prevalence of some congenital anomalies.^{5,6} These inequalities in the burden of ill health during pregnancy and childbirth have far-reaching consequences for poor families and children because of the psychological costs of ill health and loss during this formative period, the financial costs of raising a child with special needs, and the long-term health consequences related to perinatal complications. Moreover, a growing body of research is revealing myriad links between events during pregnancy and infancy and the risks of adult illnesses, such as hypertension and diabetes.⁶⁻⁸ Perinatal outcomes are thus an important component in understanding and addressing health inequalities among children and adults.

EFFECTIVE AND SAFE USE OF NEW TECHNOLOGIES

Another reason to monitor perinatal health is that medical innovations for the care of mothers and babies create new risks and raise ethical issues. For instance, babies born alive at 25 and 26 weeks of gestation now have a more than 50% chance of survival, but survivors have high



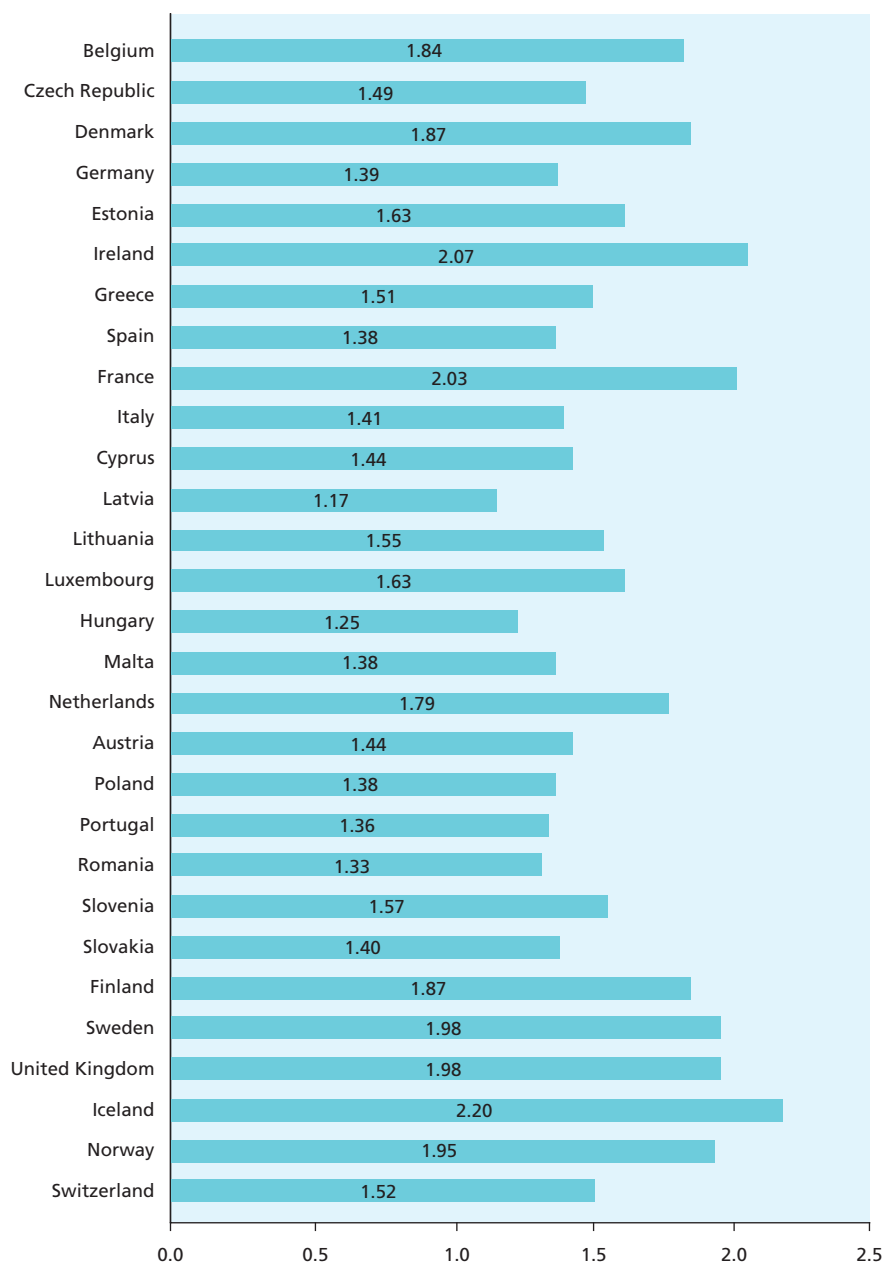
impairment rates.^{9,10} Medical procedures have made it possible for more and more couples with fertility problems to conceive, but those same procedures increase multiple births (twinning), which are associated with preterm delivery, higher perinatal mortality, and other adverse pregnancy outcomes.¹¹ European policy makers and health professionals are struggling with the challenges of how to optimise the use of new technologies while minimising their negative effects, and how to do this without over-medicalising pregnancy and childbirth for the large majority of women who have uncomplicated pregnancies.

WHY EUROPE?

There are many reasons to monitor perinatal health on the European level. First, this fits with the larger goals of the EU to establish European health information systems. Starting with the Health Monitoring Programme (1997-2002), which was succeeded by 2 Health Programmes (Public Health Programme, 2003-2008, and Health Programme, 2008-2013), the Commission has invested in the conceptual and methodological work required for developing high quality indicators, establishing networks of excellence, and producing reports on the health of Europeans. EURO-PERISTAT was initiated as part of these programmes and aims to provide the conceptual and methodological underpinnings for a high quality European perinatal health surveillance system.

Another reason is that European countries face common challenges related to the health of mothers and babies. Some risk factors associated with perinatal health, such as older age at childbirth or maternal obesity, are increasing in all countries. Questions about the optimal use of new health technologies are of concern everywhere. An understanding of how neighbouring countries structure their healthcare systems and policies to manage these risks adds to the assessment of national policies. Furthermore, great diversity in cultural, social, and organisational approaches to childbirth and infant care exists within Europe, diversity that raises important questions about the best use of healthcare interventions and the quality of care provided to pregnant women and babies.¹² While the ultimate aim is not to promote one model of care, routine data on health care and outcomes make it possible to identify the achievements as well as failings of existing models and this information can be used by governments and health professionals to improve the health of pregnant women and babies.

A final reason is that European countries face similar economic and demographic pressures and share an interest in monitoring their impact on health outcomes nationally and across Europe. Many European countries are experiencing low fertility, as measured by their total fertility rates, illustrated in Figure 2.1, although recent trends for some countries are positive.¹³ These rates vary from lows of under 1.5 births per woman or less in eastern and southern Europe to 1.9 to 2.1 in the Nordic countries, the UK, Ireland, and France. A total fertility rate of 2.1 is considered the level required to keep population size constant.¹³ In light of these demographic trends, investing in young families and children is a priority in many countries. Our report illustrates the challenges of providing good quality health care for mothers and newborns.

Figure 2.1 Total fertility rates in European countries in 2010

Data source: Eurostat (2010)



2.2 PERINATAL HEALTH INDICATORS FOR EUROPE: THE EURO-PERISTAT PROJECT

The EURO-PERISTAT project's goal has been to develop valid and reliable indicators that can be used for monitoring and evaluating perinatal health in the EU. The project began in 1999 as part of the Health Monitoring Programme and has enlisted the assistance of perinatal health professionals (clinicians, epidemiologists, and statisticians) from EU member states and Iceland, Norway, and Switzerland as well as other networks, notably SCPE (a network of European cerebral palsy registries), ROAM (Reproductive Outcomes and Migration Collaboration), and EUROCAT (a network of European congenital anomaly registries), to develop its recommended indicator list.

In the first phase of the project, we developed a set of indicators with members from the then 15 member states.¹⁴ This indicator set was developed by a procedure that began with an extensive review of existing perinatal health indicators. The resulting list was used as the basis of a DELPHI consensus process, a formalised method in which selected experts respond to a successive series of questionnaires with the aim of achieving a consensus on key principles or proposals. Our first panel in 2002 was composed of clinicians, epidemiologists, and statisticians from the then 15 member states. We also invited the Surveillance of Cerebral Palsy in Europe (SCPE) Network to assist with the indicator on cerebral palsy. A second DELPHI process was also conducted in 2002, with a panel of midwives to ensure that their perspectives on perinatal health were represented. A third DELPHI process was conducted in 2006 with a panel of 2 participants (clinicians, epidemiologists, and statisticians) from each of the 10 new EU member states. The result of this multi-stage formal method is that we were able to achieve consensus on a list of 10 core and 24 recommended indicators of perinatal health.¹⁴ A first study using data for the year 2000 was conducted to assess the feasibility of the indicator list, and these results were published in a special issue of the *European Journal of Obstetrics, Gynecology and Reproductive Biology*.¹⁵ In 2008, we published the first *European Perinatal Health Report*, based on data about our indicators from births in 2004.¹⁶

In our most recent project, we enlisted our expanding Scientific Committee, data providers, and advisors in another consensus process to update the list. This process resulted in the addition of several new indicators and the elimination of others. The changes to the indicator list reflect the emergence of new priorities as well as our experiences testing the feasibility and utility of collecting and presenting the indicators and our work developing new indicators.

The current EURO-PERISTAT indicator list includes 10 core indicators and 20 recommended indicators and are grouped into 4 themes: (i) fetal, neonatal, and child health, (ii) maternal health, (iii) population characteristics and risk factors, and (iv) health services. We defined core indicators as those that are essential to monitoring perinatal health and recommended indicators as those considered desirable for a more complete picture of perinatal health across the member states. We also identified several indicators for further development, defined as those that represent important aspects of perinatal health but require further work before they can be implemented.

Table 2.1 presents the list of EURO-PERISTAT'S 10 core and 20 recommended indicators. Changes in this list since our last report include the addition of an indicator on mothers' prepregnancy body mass index (BMI) as well as a second socioeconomic indicator, mothers' and fathers' occupation. We also added some subgroups to existing indicators: we decided to collect data separately for terminations of pregnancy and fetal deaths where this is possible and added gestational

age subgroups to our indicator on mode of delivery (C10) and mode of onset of labour (R15). We decided not to collect data on maternal mortality by mode of delivery. We separated out our indicator on trauma to the perineum into incidence of perineal tears, which is an indicator of maternal morbidity, and episiotomy, which is an indicator under healthcare services. Two indicators for further development were removed from the list — prevalence of faecal incontinence and postpartum depression — because the data to construct them are not available in routine systems. Because of these changes, the numbering of the recommended indicators has also changed since our last report.

Table 2.1 EURO-PERISTAT indicators (C=core, R=recommended)

FETAL, NEONATAL, AND CHILD HEALTH

- C1:** Fetal mortality rate by gestational age, birth weight, and plurality
- C2:** Neonatal mortality rate by gestational age, birth weight, and plurality
- C3:** Infant mortality rate by gestational age, birth weight, and plurality
- C4:** Distribution of birth weight by vital status, gestational age, and plurality
- C5:** Distribution of gestational age by vital status and plurality
- R1:** Prevalence of selected congenital anomalies
- R2:** Distribution of Apgar scores at 5 minutes
- R3:** Fetal and neonatal deaths due to congenital anomalies
- R4:** Prevalence of cerebral palsy

MATERNAL HEALTH

- C6:** Maternal mortality ratio
- R5:** Maternal mortality by cause of death
- R6:** Incidence of severe maternal morbidity
- R7:** Incidence of tears to the perineum

POPULATION CHARACTERISTICS/RISK FACTORS

- C7:** Multiple birth rate by number of fetuses
- C8:** Distribution of maternal age
- C9:** Distribution of parity
- R8:** Percentage of women who smoked during pregnancy
- R9:** Distribution of mothers' educational level
- R10:** Distribution of parents' occupational classification
- R11:** Distribution of mothers' country of birth
- R12:** Distribution of mothers' prepregnancy body mass index (BMI)

HEALTHCARE SERVICES

- C10:** Mode of delivery by parity, plurality, presentation, previous caesarean section, and gestational age
- R13:** Percentage of all pregnancies following treatment for subfertility
- R14:** Distribution of timing of first antenatal visit
- R15:** Distribution of births by mode of onset of labour
- R16:** Distribution of place of birth by volume of deliveries
- R17:** Percentage of very preterm babies delivered in units without a neonatal intensive care unit (NICU)
- R18:** Episiotomy rate
- R19:** Births without obstetric intervention
- R20:** Percentage of infants breast fed at birth



Areas targeted for further development include indicators of severe neonatal morbidity among high risk infants (F1), the prevalence of neonatal encephalopathy (F2), causes of fetal and neonatal death other than congenital anomalies (F3), neonatal screening policies (F4), and the content of antenatal care (F5).

2.3 EUROPEAN PERINATAL HEALTH REPORT

AIM

This report is the second of what we hope will be a series of regular reports on perinatal health in the EU and follows the first *European Perinatal Health Report*, which was issued in 2008 and reported data from 2004.

The aim of this report is to provide data that can be used as points of comparison for individual countries. Because this report reveals the strengths and weaknesses of perinatal health information systems in each participating country, countries can use their neighbours' experiences to expand their information systems to cover the entire spectrum of EURO-PERISTAT indicators. For those indicators for which there are reliable data, this report makes it possible to benchmark performance in providing effective health services and promoting the health of mothers and their newborns.

Beyond outcomes, these data also underline the varied approaches to the provision of care in the countries of Europe and raise important questions about ways to optimise the care and health of women and babies. By pooling European experiences, data, and expertise, we aim in the future to develop research capacity and to produce evidence to support policy decisions about these questions. Regular reporting on the EURO-PERISTAT indicators is a first step in this direction.

COLLABORATIONS

Two European networks contributed to the report — SCPE (Surveillance of Cerebral Palsy in Europe) and EUROCAT (European Surveillance of Congenital Anomalies). The objectives, scope, and methods of both of these networks are described in Chapter 8. SCPE provided information about the indicator on cerebral palsy. This essential indicator of the longer term consequences of perinatal events relies on networks that register all cases of cerebral palsy within a geographic area. As CP is not reliably diagnosed in the first years of life, it cannot be derived from the data sources used to produce the other perinatal health indicators published in this report, which relate to pregnancy, delivery, and the first year after birth. EUROCAT, a collaborative network of population-based registries for the epidemiologic surveillance of congenital anomalies in Europe, provided data on congenital anomaly prevalence. Collecting reliable data on congenital anomalies requires registries dedicated to this task; the EUROCAT network has carried out the work of harmonising definitions across Europe and compiling data from registries in European countries. Data and reports on these data are made available annually on their websites.

SCOPE AND FORMAT

In order to provide timely data, the EURO-PERISTAT group made a decision to publish its results from 2010 in 2 steps. This report constitutes the first step and provides key data on our indicators in 2010 and trends since 2004. We use the same format as in our first report; each indicator is presented separately and includes the justification for the indicator's selection, the methods for collecting and interpreting it, availability of data, results, and a summary of key points. We have

favoured graphic presentation of indicators within the text of the report to make our messages clearer. At the end of the report, there is a summary table for each indicator; this summary table provides information on the data source, the number of women or babies for whom there are data about the indicator, and the number for whom the information was not available. More detailed breakdowns of the indicator categories are given in these tables.

The second step, the release of the full set of EURO-PERISTAT tables, will take place after the summer of 2013 to give us more time to verify the complete set of data for each indicator. We collect our indicators by subgroup in order to be able to make more meaningful comparisons by specifying comparable populations (for instance, using the same gestational age cutoffs for mortality rates). These data also make it possible to carry out more in-depth analysis of many indicators.

Three indicators will also be issued in this second step. The first is EURO-PERISTAT's indicator on congenital anomalies. Before publishing this indicator, we are comparing prevalence rates with data from the EUROCAT registry. The second indicator is on parental occupation. This is the first time that this indicator has been collected, and further work is needed to harmonise definitions across countries. Finally, the third indicator measures the frequency of birth without obstetric intervention (or straightforward delivery) and brings together data on several indicators (mode of onset of labour, mode of delivery, and episiotomy); it thus requires more in-depth analysis.

GUIDELINES FOR ORDERING COUNTRIES

We have adopted the following guidelines for ordering countries and graphically presenting indicators in this report:

- For the presentation of data on our 2010 indicators, countries are presented in alphabetical order by their official EU titles. Country names are based on EU conventions.¹⁷
- Countries are not ranked for the presentation of data about indicators in 2010. The EURO-PERISTAT project tries to avoid a league-table approach to international comparisons that simply identifies the best and worst performers. There are many reasons that indicators vary across countries, and we aim to stress this point in the way the data are presented.
- Countries without data are included in all figures and tables presenting 2010 data. One of the goals of this report is not only to describe and analyse existing data, but also to point out the gaps in health information systems. This is another reason that we have not ranked countries.
- For comparisons with 2004, we have sometimes ordered countries by their 2004 indicator values. This makes it easier to visualise whether changes were related to initial values of the indicator (for instance, to show that countries with higher mortality in 2004 experienced greater declines).
- For indicators where definitions are less comparable, we have opted to show data in tables in order to emphasise that comparisons should be made with caution.

2.4 THE FUTURE

The EURO-PERISTAT network has developed an action plan for sustainable perinatal health reporting in 2010 (available on our website) which endorsed the idea of producing a comprehensive European perinatal health report every 4 or 5 years. If this path is followed, the next report would cover data from 2014 or 2015 and be issued in 2017 or 2018. The group also suggested that data



on the core indicators be collected annually or every 2 years. Whether these aims are achievable depends in large part on the availability of support, both financial and political, at European and national levels.

Given the current financial and political situation in Europe, there are reasons to be concerned about the future. While the European Commission invested heavily in health monitoring projects and provided the impetus and financial backing for the development of the EURO-PERISTAT network, the future of health monitoring in Europe remains uncertain. Unlike the European Centre for Disease Prevention and Control (ECDC), which monitors infectious diseases, there is no institution devoted to the surveillance of maternal or child health or of chronic diseases. Thus, health information networks rely primarily on projects financed by the Commission. The new EU programme for public health does not prioritise programmes to reinforce information systems, but stipulates that health monitoring and reporting activities should be implemented as a part of the routine work of DG Sanco (Directorate General for Health and Consumers). Most health information projects, including the European Community Health Indicators Monitoring project, have been discontinued because of absence of funding. More generally, the current health agenda in the EU appears to be moving away from public health research to a focus on investments in biomedicine that can lead to patents and new technologies, and there is widespread concern that Horizon 2020, the next EU research programme, does not encourage research on public health, health systems, or health policy.¹⁸

In collaboration with Eurostat, we have also explored the option of integrating our indicators into existing routine European statistical processes. However, this is unlikely to be a solution for our network because of the regulatory context governing Eurostat. Indicators in Eurostat become obligatory for all countries after they have been approved by EU member states, which restricts the possibilities of implementing the best recommendations (as illustrated by recent guidelines removing the mandatory reporting of stillbirths by birth weight).¹⁹ A final option, finding national sources of funding, is challenging, especially in a context of reduced national spending on information systems; the cost and administrative complexity of lobbying and collecting funds from multiple countries would also be a disadvantage.

Despite this discouraging context, there are 2 sets of reasons to be positive about the future of perinatal health reporting on the European level. First, the skills and motivation that underpin high quality health information are strong in Europe. That we are able, in this report, to provide comprehensive data from 29 countries in Europe on a large spectrum of indicators describing perinatal health testifies to the commitment of our network members to having comparable European data on mothers and children during pregnancy, childbirth, and the postpartum period. The efforts of our Scientific Committee members and data providers have been impressive; many of our indicators require additional data analysis beyond what is routinely produced nationally; our members have participated in multiple rounds of data checking and provided their opinions and insights into these data in several meetings. Since our last report, we have expanded our network, adding Romania, Switzerland, and Iceland. Furthermore, our Scientific Committee members have guided us through complex situations as national health information systems reorganise and institutions change.

Second, and most importantly, data underpin sound decisions. These data serve a purpose for the key stakeholders in perinatal health. The data from the first *European Perinatal Health Report* were widely used by health providers, planners, policy makers, researchers, and users across

Europe and beyond. It was downloaded more than 8000 times from our website and resulted in over 100 media articles in the press when it was issued. Individual European countries increasingly rely on this reference list of indicators to evaluate their policy initiatives and benchmark their performance; in France, the EURO-PERISTAT indicators are the reference for evaluating perinatal networks.²⁰ In the Netherlands, where the country's poor ranking relative to other European countries attracted wide media attention to the first EURO-PERISTAT report, this report shows major improvements in fetal and neonatal mortality over the past 5 years. For example, a perinatal audit was set up to review perinatal deaths at term (ie, 37+ weeks), and mortality at term declined by 39% from 2004 to 2010. Another example comes from Germany where, since publication of international comparisons of caesarean section rates, there has been a growing concern over their continued increase. The Federal Office for Quality Assurance in Health Care (AQUA-Institut) is currently proposing to extend their performance indicators (for benchmarking obstetric departments) to include caesarean rates. Similarly, debates about obstetric unit size and quality of care resulted in legislation mandating a minimum number of 14 annual admissions of neonates under 1250 g in order to operate as a level III perinatal centre. In the light of higher minima outside Germany, there have been further calls for raising this threshold. Still another example comes from Slovenia, which had issued a 10-year report entitled *Perinatologia Slovenica 1987-1996* before the PERISTAT project started. Now, after 2 EURO-PERISTAT reports, it has decided to issue a second report, *Perinatologia Slovenica 2, 2002-2011*. In addition, Slovenia uses suggestions from this European data collection in updating its own national perinatal Information system; the last update went into effect on January 1, 2013.

Our indicators have been analysed by our team and others to gain insight into what factors affect the health of women and children in Europe. The EURO-PERISTAT network has published 20 articles in peer-reviewed journals based on these data (please see our website for a full list of articles). Articles published over the past year have addressed the issues of preterm birth trends,²¹ maternal mortality and morbidity,²² and how to present European data to make comparisons more meaningful;²³ another analysed recommendations to improve the reporting of fetal mortality rates.²⁴ Others have also used the EURO-PERISTAT data — which are made available freely on our website — for research perinatal health in their own countries.^{25,26} We expect that research on these new data from 2010 — which will allow exploration of the reasons for time trends in maternal and health system risk factors as well as health outcomes — will further underscore the value of having comparable data from the countries in Europe.



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