EUROPEAN PERINATAL HEALTH REPORT

Health and Care of Pregnant Women and Babies in Europe in 2010

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ABBREVIATIONS AND ACRONYMS

AED	Antiepileptic drug
ART	Assisted reproductive techniques
BMI	Body mass index
CHD	Congenital heart disease
CP	Cerebral palsies
ESPR	European Society for Paediatric Research
EU	European Union
FGR	Fetal growth restriction
FMR	Fetal mortality rate
ICD-10	International Classification of Diseases, 10th revision
ICU	Intensive care unit
IVF	In vitro fertilisation
IVH	Intraventicular haemorrhage
MMR	Maternity mortality ratio
NICU	Neonatal intensive care unit
NTD	Neural tube defect
PDA	Symptomatic patent ductus arteriosus
PPH	Postpartum haemorrhage
SCPE	Surveillance of Cerebral Palsy in Europe
SES	Socioeconomic status
TOP	Termination of pregnancy
TOPFA	Termination of pregnancy for fetal anomaly
VLBW	Very low birth weight
WHO	World Health Organisation

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EXECUTIVE SUMMARY

A HEALTHY START: THE HEALTH AND CARE OF PREGNANT WOMEN AND BABIES IN EUROPE IN 2010

I. MONITORING PERINATAL HEALTH IN EUROPE

Healthy mothers and children are building blocks for a strong future in Europe. While infant and maternal mortality continue to decline, the burden of mortality and morbidity in the perinatal period — pregnancy, childbirth, and the postpartum — remains a major concern. This is because of the high number of births per year (over 5 million in Europe), the youth of the population harmed by adverse perinatal events (babies and women of childbearing age), and the long-term consequences of disabling complications of pregnancy such as very preterm birth or severe hypoxia.

The principal factors behind perinatal mortality and morbidity include very preterm birth, fetal growth restriction, and congenital anomalies. Babies born preterm and with low birth weight are more likely to die and to have long-term neurological and developmental disorders than those born at term. The incidence of these complications has increased in many countries, reflecting limited achievements in preventing high risk situations, compared with the medical advances that have reduced mortality for these infants. Stillbirths have declined less rapidly than neonatal deaths and, in many cases, their causes remain unknown. Women continue to die during childbirth, and substandard care is associated with a significant proportion of these deaths. As they grow up, babies born with major congenital anomalies or very preterm and with low birth weight may have important medical, social, and educational needs. These burdens fall disproportionately on socially disadvantaged women and babies and contribute to lifelong health inequalities.

Research on the early origins of adult diseases underscores the vital importance of the perinatal period for future health. Pregnancy complications which cause short-term morbidity — such as preterm birth and fetal growth restriction — are also associated with the development of chronic illnesses such as hypertension and metabolic disease across the life course. Further, risk factors for poor perinatal outcome — smoking, obesity, and alcohol use during pregnancy — continue to exert an effect through the child's increased susceptibility to asthma, obesity, and developmental delays.

Despite the risks faced by women and children during pregnancy and childbirth, pregnancy is not an illness. Achieving optimal perinatal health thus involves a balance between intervening to manage and prevent complications, while minimising interventions that have negative side effects on health and induce anxiety among pregnant women and their families. Unnecessary medical interventions also contribute to the costs of providing health care without achieving gains in health.

The Euro-Peristat project aims to provide health professionals, health planners, and users of the healthcare systems with comparable data about the health and care of pregnant women and their babies in Europe. It uses routinely collected data, thus adding value to the resources used to generate them and providing opportunities for sharing and use of information. While many countries collect routine data nationally about women and children, these data are not available in currently existing international databases. The first Euro-Peristat report, published with 2004

data in 2008, found wide differences in indicators of perinatal health and care between the countries in Europe. Documenting this variation is important because it shows that gains are possible in most countries, provides information about alternative options for care provision, and raises important questions about the effectiveness of national healthcare policies and the use of evidence-based care.

The data in this report can be used as a point of comparison for individual countries. For those indicators for which reliable data exist, countries can benchmark performance in providing effective health services and promoting the health of mothers and their newborn babies. Another aim is to reveal the strengths and weaknesses of perinatal health information systems and to encourage countries to invest in the resources needed to improve the completeness and quality of the data necessary for evidence-based public policy.

II. THE EURO-PERISTAT PROJECT

The 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 EU's 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. Our indicator list was developed by a series of successive Delphi consensus processes with members of our network as well as external advisors.

Twenty-nine countries currently participate in EURO-PERISTAT, including all current EU member states (except Bulgaria) and Iceland, Norway, and Switzerland. Romania, Switzerland, and Iceland have joined the project since our previous report. One person from each country is a representative on the Scientific Committee, but many countries have constituted teams comprising experts in the field of perinatal health surveillance (please see www.europeristat.com/our-network/country-teams.html, for a full list of participants).

The current EURO-PERISTAT indicator list includes 10 core and 20 recommended indicators, grouped into 4 themes: (i) fetal, neonatal, and child health, (ii) maternal health, (iii) population characteristics and risk factors, and (iv) health services. Core indicators are those that are essential to monitoring perinatal health, while recommended indicators are considered desirable for a more complete picture of perinatal health across European countries.

EURO-PERISTAT aims to compile population-based data at a national level from routine sources (ie, administrative or health registers, hospital discharge reporting systems, or routine surveys). If national level data are not available, population-based data for regions or constituent countries are collected. In defining our indicators, EURO-PERISTAT has sought to reduce the differences in indicators that are attributable to differences in data collection systems and definitions. We have accomplished this by selecting definitions most likely to be feasible and by carefully designing the data collection instrument. Country participants are actively engaged in checking and interpreting the data.

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. EUROCAT, a collaborative network of population-based registries for the epidemiologic surveillance of congenital anomalies in Europe, provided data on their prevalence. The EUROCAT network has carried out the work of harmonising definitions across Europe and compiling data from registries in European countries. Annual reports on these data are made available on their website.

Scope and Format of this report
In order to provide timely data, EURO-PERISTAT made a decision to publish its results from 2010 in 2 stages. This report constitutes the first stage and provides key data on our indicators in 2010 and trends since 2004. The second stage, 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 and to analyse our indicators by subgroups. Some additional indicators will be issued in this second step (prevalence of selected congenital anomalies, parents' occupational classification, and birth without obstetric intervention). Ongoing work about social inequalities in perinatal health outcomes will also be released then.

We use the same format as in our first report; each indicator is presented separately and includes the justification for selecting the indicator, the methods for collecting and interpreting it, availability of data, results, and a summary of key points. Countries are not ranked for the presentation of data about indicators in 2010. The EURO-PERISTAT project avoids a league-table approach to international comparisons intended solely to identify the best and worst performers. There are many reasons that indicators vary between 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 perinatal health information systems. This is another reason that we have not ranked countries.

III. HIGHLIGHTS OF HEALTH AND HEALTH CARE IN EUROPE IN 2010

HEALTH OUTCOMES

Fetal, neonatal, and infant mortality rates vary widely between the countries of Europe.
Fetal mortality rates at or after 28 weeks of gestation ranged from lows under 2.0 per 1000 live births and stillbirths in the Czech Republic and Iceland to 4.0 or more per 1000 in France, Latvia, the region of Brussels in Belgium, and Romania. The countries from the United Kingdom also had higher fetal mortality rates.

Neonatal mortality rates ranged from 1.2 per 1000 live births in Iceland to 4.5 in Malta and 5.5 in Romania. After excluding births and deaths before 24 weeks of gestation, these rates fell, ranging from 0.8 per 1000 live births in Iceland to 4.3 in Romania. Infant mortality rates ranged from 2.3 per 1000 live births in Iceland and Finland to 5.5 in Malta, 5.7 in Latvia, and 9.8 in Romania. Countries where terminations of pregnancy are not legal or access is very restricted may have

higher fetal, neonatal, and infant mortality rates due to deaths attributed to lethal congenital anomalies.

Europe experienced across-the-board declines in fetal, neonatal, and infant mortality, although rates of change differed.
Most countries contributing data to EURO-PERISTAT in 2004 and 2010 experienced declines in their fetal, neonatal, and infant mortality rates. For fetal mortality, the decreases (on average 19%; range: 0-38%) tended to be more pronounced for western European countries with higher mortality rates in 2004 (Denmark, Italy, and the Netherlands). Some countries with low mortality rates in 2004, such as the Czech Republic, achieved significant continued improvements in outcomes. Decreases in neonatal mortality averaged 24% (range: 9% to 50%), and infant mortality fell 19% (range: 6%-40%). The largest declines were in 3 Baltic countries: Estonia, Latvia, and Lithuania. Decreases were again most pronounced for countries with higher mortality rates in 2004, although some countries with lower mortality in 2004 also showed significant continued improvements (Slovenia, Finland, and Austria, for example). Neonatal and infant mortality were low (under 2 and 3 per 1000 live births for neonatal and infant mortality, respectively) in some European countries.

Preterm babies born before 28 weeks of gestational age constitute over one-third of all deaths, but data are not comparable between countries.
About one-third of all fetal deaths and 40% of all neonatal deaths were of babies born before 28 weeks of gestational age. Unfortunately, between-country differences in legislation governing registration of births and deaths and misclassification of stillbirths and neonatal deaths make it difficult to compare mortality at these early gestations. EURO-PERISTAT presents fetal mortality rates at 28 weeks of gestation and over and neonatal mortality at 24 weeks of gestation and over because our analyses have shown that these cutoffs provide more comparable data and thus allow more useful comparisons. However, given the large proportion of deaths before 28 weeks, it is essential to improve information systems in Europe by developing common guidelines for recording these births and deaths.

Another related issue is the variation in notification procedures for terminations of pregnancy at 22 weeks or later. These are included in fetal mortality rates in some but not all countries, and only some countries which include them can distinguish terminations from spontaneous deaths. Six percent of all fetal deaths were terminations in Scotland versus 40-50% in France. Terminations were 13% of fetal deaths in Hungary, 15% in Switzerland, and 19% in Italy.

The percentage of low birthweight babies is geographically patterned, partially reflecting differences in population birth weight, and was stable over time in most countries.
The percentage of live births with a birth weight under 2500 g varied from under 4 to over 9% in Europe. Countries from northern Europe had the lowest percentages of low birth weight (Denmark, Estonia, Ireland, Latvia, Lithuania, Finland, Sweden, Iceland, and Norway). The proportion of VLBW babies ranged from 0.6 (Iceland) to 1.9 (the region of Brussels in Belgium). Proportions of low birth weight remained similar in the 2 study periods. However, the rate of babies with low birth weight declined in some countries (France, Scotland, England and Wales, Malta, and Poland) whereas it increased in others (Luxembourg, Spain, Brussels, the Czech Republic, Slovakia, and Portugal).

Preterm birth rates were similar in 2004 and 2010 in many countries; differences in rates and trends raise questions about possible preventive strategies.
The preterm birth rate for live births varied in 2010 from about 5 to 10% in Europe. We observed relatively lower preterm birth rates (below 6.5%) in Iceland, Lithuania, Finland, Estonia, Ireland, Latvia, Sweden, Norway, and Denmark, and higher rates (above 8.5%) in Cyprus (10.4%) and Hungary (8.9%). Rates were around 8% in Austria, Germany, Romania, the Czech Republic, Luxembourg, Portugal, the Netherlands, and all regions of Belgium. In comparison to 2004, proportions of preterm live births were similar for many countries. However, they increased over this period in Luxembourg, the Brussels region, the Czech Republic, Slovakia, Portugal, Northern Ireland, and Italy, while they declined in Norway, Scotland, Germany, England and Wales, Denmark, and Sweden. The fact that rates are stable or declining in many countries goes against widely held beliefs that preterm birth rates are rising and raises questions about policies and practices associated with divergent trends between countries.

Maternal deaths are rare in Europe, but under-reporting is widespread.
Generally speaking the maternal mortality ratio in Europe is low, due to both the very low level of fertility (fewer than 2 children per woman, as shown in Chapter 2) and the high levels of care. The range in Europe is from lows under 3 per 100 000 (in Estonia, Italy, Austria, and Poland) to highs over 10 per 100 000 live births (Latvia, Hungary, Slovenia, Slovakia, and Romania). There is good evidence that maternal deaths derived from routine statistical systems are under-reported, and this must be suspected particularly where ratios are very low. Confidential enquiries and record linkage are recommended to obtain complete data on pregnancy-related deaths and also to make it possible to understand how these deaths happened and to make recommendations to prevent the recurrence of those that could have been prevented. When confidential enquiries are undertaken, as in France, the Netherlands, and the UK, almost half the maternal deaths are associated with substandard care. This should not occur in high-income countries.

Because mortality is rare, Euro-Peristat also collects data on severe maternal morbidity, which occurs in approximately 1% of all deliveries. However, the comparability of these indicators, when derived from hospital discharge systems and other routine sources, is still limited. Ongoing work is focused on assessing the quality and completeness of the data about diagnoses and procedures in routine hospital discharge systems so that we can propose better definitions.

An estimated 140 000 fetuses and babies had a major congenital anomaly in the EU-27 countries in 2010.
Data from EUROCAT were used to derive the overall prevalence of major congenital anomalies diagnosed during pregnancy, at birth, or in early infancy — 26 per 1000 births in 2010. This prevalence has shown a recent very shallow decrease, and there is a need to improve primary prevention policies to reduce environmental risk factors in the pre- and periconceptional period. Four fifths of cases were live births, the vast majority of whom survived the neonatal period and may have special medical, educational, or social needs. The largest group of congenital anomalies is congenital heart disease. An overall 0.81 perinatal deaths per 1000 births in 2010 were associated with congenital anomalies according to data from 13 EUROCAT registries. The rate of terminations of pregnancy for fetal anomaly (TOPFA) varies widely between countries from none (Ireland and Malta) to 10.5 per 1000 births (Paris, France), reflecting differences in prenatal screening policies and uptake and in abortion laws, practices, and cultural attitudes. The rate of live births with certain anomalies, such as spina bifida and Down syndrome, in a given country is inversely related to its rate of terminations of pregnancy for fetal anomaly.

Cerebral palsy registers in collaboration with their clinical networks make it possible to assess a group of rare conditions that develop in the perinatal period and lead to lifelong activity limitations and participation restrictions.
The increased survival of newborn babies in all birthweight and gestational-age groups correlates with a decrease in the prevalence of certain subtypes of cerebral palsies. For example, the proportion of babies born between 1980 and 1998 with a birth weight over 2500 g who developed bilateral spastic cerebral palsy decreased from 58 to 33 per 100 000 live births. In the same 2 decades, the proportion of cerebral palsy in the babies born at a gestational age between 32-36 weeks decreased by 3% annually. These downward trends coincided with a decrease of one third in the proportion of bilateral spastic cerebral palsy in babies with a birth weight between 1000 and 1499 g.

POPULATION RISK FACTORS

Age at childbirth has increased in Europe.
The age at which women bear children in Europe varies widely, and this has an impact on the health of mothers and babies. Both early and late childbearing are associated with higher than average rates of preterm birth, growth restriction, perinatal mortality, and congenital anomalies. Overall, teenage pregnancies are uncommon in Europe with a median of 2.7% of births to mothers aged younger than 20 years. However, some countries of eastern Europe have higher proportions. The UK also stands out from its neighbours with a high proportion of very young mothers (over 5%). The situation in Europe contrasts with the United States where 9.2% of births are to mothers under 20 (CDC: Births: final data for 2010: www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_01.pdf).

At the other end of the age spectrum, the percentage of older mothers, defined as women giving birth at 35 years or older, ranged from 10.9% in Romania to 34.7% in Italy. The proportion of women bearing children later in life varies substantially, but in 40% of countries or regions, at least 20% of births were to women aged 35 years or more, and the proportion of births in this age group increased substantially in almost every country. Only Finland experienced a decrease between 2004 and 2010 in this proportion. The increase was relatively small in the United Kingdom (under 1 percentage point), and substantially larger (over 5 percentage points) in Italy, Estonia, Hungary, the Czech Republic, and Spain. Encouraging earlier childbearing may require policies to support young parents and working mothers, as well as informing the public about possible consequences of having children at later ages.

More than 1 woman in 10 smoked during pregnancy in many countries despite declines between 2004 and 2010.
Maternal smoking during pregnancy may be considered the most important preventable factor associated with adverse pregnancy outcomes. It is a well-established risk factor for adverse perinatal outcomes. It can impair normal fetal growth and development and thus increase the risk of low birth weight, preterm birth, intrauterine growth restriction, and some congenital anomalies. Smoking cessation is one of the most effective interventions for improving mothers' and children's health and thus serves as an indicator of the quality of antenatal preventive healthcare services. Smoking during pregnancy or in the last trimester varied from under 5% in Lithuania and Sweden to 14% in Catalonia in Spain, 15% in Northern Ireland, 16% in Wales, 17% in France, and 19% in Scotland. Countries that had data points for 2004 and 2010 reported slightly lower proportions of smokers in the last trimester in 2010 — by about 1-3%. In France, the Netherlands, and the UK, the decrease was more pronounced. Some countries were not able

to provide data on smoking Belgium, Ireland, Greece, Italy, Hungary, Austria, Portugal, Romania, Slovakia, Iceland, and Switzerland. In many countries, the quality of data needs to be improved, and this indicator is likely underestimated. Given the adverse effects of smoking on fetal and infant health and since pregnancy care is considered an ideal setting for intervention, having high quality and comparable information on smoking before and during pregnancy should be a priority.

Monitoring social status and pregnancy outcomes is a challenge in Europe.
Social disadvantage remains a major determinant of poor perinatal outcome and requires effective action. Many perinatal health indicators, including maternal mortality, preterm birth, congenital anomalies, and duration of breast feeding, are inversely related to variables that are proxy measures of social disadvantage, such as the mother's level of education and the parents' parents' occupational classification. The distribution of mothers' levels of education varies widely between the European countries that provided data for this indicator; for instance, between 22 and 61% are reported to have some postsecondary education. Many countries cannot provide data on mothers' educational levels, which was one of the reasons that Euro-Peristat added a second indicator of social status, parents' occupational classification, to its list of indicators. Further research will be required into the possibility of effectively comparing measures of education level and occupational class as it seems unlikely that the countries that do not record mothers' educational levels will do so in the near future. However, even if educational and occupational levels are not comparable, collecting these data — either or both, according to availability — will make it possible to compare fetal and neonatal mortality outcomes between these groups within countries and call attention to the differences related to social factors. Euro-Peristat is currently analysing these data for 2010, and results will be issued shortly.

Foreign-born women constitute a large proportion of pregnant women in many countries.
International migration to Europe may be accompanied by health disparities in perinatal outcomes between migrants and women born in receiving countries and also between groups of migrants. The percentage of foreign-born mothers ranged from lows of 3% (the Czech Republic) to over 60% (in Luxembourg and the Brussels region of Belgium), and the proportion of women with a foreign nationality from less than 1% in Iceland and Poland to 30% in Latvia. The proportions of foreign-born or foreign-nationality mothers in most countries in western Europe exceeded 20%. Data are available in many countries to permit an analysis of health outcomes by mothers' countries or regions of birth. This will be one of the themes pursued in the future by the Euro-Peristat network.

More than 1 in 10 pregnant women are obese in countries with data, but many countries do not monitor this indicator.
Maternal weight before and during pregnancy can affect the course of pregnancy, its outcome, and the offspring's lifelong health, yet 18 countries have no available national data on the body mass index of pregnant women. Both underweight and overweight women experience higher rates of adverse outcomes. In countries that could provide data, from 2.5 to 8.7% of delivering mothers were underweight; the highest proportions were in Poland (8.7%), France (8.3%), and Wallonia (7.1%), and the lowest in Sweden (2.5%), Scotland (2.6%), Finland (3.6%), and Germany (3.6%). Obese women accounted for 7.1 (Poland) to 20.7% (Scotland) of all pregnant women. In most countries, more than 10% of childbearing women are obese. This indicator should be monitored in more European countries in view of the possible changes in proportions of underweight, overweight, and obese women in the upcoming generations of women of childbearing age and the impact of these changes on perinatal health outcomes and long-term health.

HEALTH SERVICES AND CARE

Artificial reproductive techniques (ART) are used in up to 5 to 6% of all deliveries; differences in multiple birth rates reflect, in part, the impact of these practices.

Up to 5 to 6% of births in some countries may occur after use of some form of ART, although the use of the less invasive procedures is under-reported in most data systems or not reported at all. Births after in vitro fertilisation (IVF) account for 2 to 4% of all births.

One of the consequences of ART is an increase in multiple pregnancies, unless only one embryo is transferred. Babies from multiple pregnancies have a 10-fold risk of preterm birth and are 4 times more likely to die in the neonatal period. Multiples have higher risks of congenital anomalies and growth restriction, and their mothers higher risks of morbidity and mortality. There are wide differences in multiple birth rates in Europe — from lows of 9 to 13 per 1000 women with live births or stillbirths in Romania, Latvia, Lithuania, and Poland to more than 20 per 1000 in Brussels, the Czech Republic, Denmark, Cyprus, Spain, and Malta. These differences reflect the age distribution of the European population: the incidence of multiple pregnancy is higher for older mothers, separately from their higher prevalence of subfertility and higher utilisation rate of ART. Twin birth rates decreased in Denmark, the Netherlands, and Norway, which had the highest twinning rates in 2004. The twinning rate increased slightly in Finland, Sweden, and Northern Ireland, and increased further in the other countries. Many countries are implementing policies to prevent multiple pregnancies in assisted conception, and the decrease in twin rates observed in some countries may be the result of these policies.

Most women begin antenatal care in the first trimester, but differences in the organisation of health systems make it difficult to compare data about late care between countries.

The vast majority of women begin antenatal care during the first trimester; care begins in the second or third trimester for 2% (Poland) to 33% (Malta) of all women. Half the countries reported between 4 and 7% of women with care starting after the first trimester (10 of 19). The percentage of women with no antenatal care at all ranges from 0 to 2.8%. Some of the variation in late care is related to differences in how timing of antenatal care is recorded. In systems where the majority of antenatal care takes place outside hospital, it may be the first visit to hospital rather than the first contact with a health care provider during pregnancy which is recorded. Nonetheless, given the importance of starting care early in pregnancy, this variation raises questions about whether the most vulnerable women in each country have access to appropriate health care. Using this indicator in conjunction with mothers' educational level and country of birth could provide a useful basis for comparing the ability of healthcare systems to provide access to care for all pregnant women.

Congenital anomaly screening differs across Europe.

In Europe some congenital anomalies are very commonly diagnosed through antenatal screening programmes. For some anomalies, antenatal diagnosis leads to better preparation of families and health services for an affected baby and can improve the care provided. For other anomalies, antenatal diagnosis is commonly followed by the option of termination of pregnancy for fetal anomaly. Data from EUROCAT illustrate wide-ranging differences in antenatal screening policies and how their implementation can affect differences between European countries in their antenatal diagnosis rates.

Variations in caesarean section rates testify to differences in approaches to obstetric care.
The variation in caesarean section rates in Europe reflects the differences in approaches to childbirth in Europe. The risk factors for caesarean section — such as maternal age or parity — are not sufficiently marked to explain the wide disparities. Countries with high proportions of older mothers have both high (Italy and Portugal) and lower (the Netherlands and Finland) rates. Cyprus had the highest overall caesarean rate, at 52.2%, followed by Italy with 38.0%, Romania with 36.9%, and Portugal with 36.3%. Germany, Luxembourg, Malta, Poland, and Switzerland also had rates of 30% or higher. Everywhere else, rates were below 30%. The Netherlands, Slovenia, Finland, Sweden, Iceland, and Norway had rates below 20%.

Caesarean rates have risen almost everywhere, especially in eastern Europe.
Apart from slight reductions in Finland and Sweden, caesarean rates rose everywhere between 2004 and 2010. Increases occurred among countries with both high and low levels of caesarean deliveries in 2004. Increases ranged from under 0.2% in Italy to over 7% in Lithuania, Slovakia, and Poland. In general, increases were most marked in the countries of central and eastern Europe and in Germany and Austria.

Variations in obstetric practices raise questions about how scientific evidence is integrated into clinical decisions.
In addition to the wide variations reported above for caesarean deliveries, other obstetric practices differ in Europe. Rates of instrumental vaginal delivery exceeded 10% in Ireland, the Flanders region of Belgium, the Czech Republic, Spain, France, Luxembourg, the Netherlands, Portugal, the 4 countries of the United Kingdom, and Switzerland and accounted for fewer than 2% of deliveries in the Czech Republic, Latvia, Lithuania, Poland, and Romania, and at least 2% but fewer than 5% in Estonia, Italy, Cyprus, and Slovenia. Episiotomy rates ranged from 5% to 70% of vaginal deliveries. They were around 70% in Cyprus, Poland, Portugal, and Romania, 43-58% in Wallonia and Flanders in Belgium and in Spain, 16-36% in Wales, Scotland, Finland, Norway, Estonia, France, Switzerland, Germany, Malta, Slovenia, Luxembourg, the Brussels region in Belgium, Latvia, and England, and 5-7% in Denmark, Sweden, and Iceland. Episiotomy rates have fallen or stayed the same in many countries with data from 2004, with the exception of England, Scotland, and the Netherlands, where they rose.

Multiple models of obstetric and neonatal care provision exist in Europe; understanding their strengths and weaknesses could help to improve healthcare systems in all countries.
The organisation of delivery and postpartum services is an important domain for public policy. Most pregnant women have normal pregnancies requiring little or no obstetric intervention. However, when risks arise, access to highly specialised care can be essential for both mother and baby. Organising access to risk-appropriate health care for mothers and babies is thus a central pillar of a successful perinatal health system and one in which government policy and regulation play an important role. Data from this report find wide differences in the ways that European countries have addressed this challenge.

Some countries concentrate care in large units, while others provide care in small ones. Overall, few births occurred in maternity units with fewer than 500 births in 2010, but this varied considerably by country, as did the care provided in small units. For example, in the UK and some Nordic countries, care in small units is provided by midwives for women with uncomplicated pregnancies. In contrast, in Cyprus, which has a very high caesarean section rate, 61.9% of births took place in units of this size, while in 8 countries, from 10 to 20% of births did. At the other end

of the size spectrum, more than a quarter of births in Denmark, Sweden, and England took place in units with more than 5000 births, while Slovenia, Latvia, Scotland, and Ireland had even larger proportions of births in units with more than 5000 births; in 14 countries or regions, more than a third of births took place in units with 3000 or more births.

In most European countries, less than 1% of births took place at home. In England, this figure was 2.5%, in Wales 3.7%, in Iceland 1.8%, and in Scotland 1.4%. In the Netherlands, where home births have been a usual option for women with uncomplicated pregnancies, 16.3% of all births occurred at home. This is, however, a substantial change from 2004, when this proportion exceeded 30%. Women in the Netherlands now also have the option of giving birth in a birth centre (a homelike setting) under care of a primary midwife; there are 26 birth centres in the country, and 11.4% of births occurred in them. Almost all birth centres are adjacent to or in hospitals. Similar facilities exist in some hospitals in the UK, but births in them cannot usually be identified separately.

The regionalisation of care for high-risk births is associated with better survival for very preterm infants. Many, but not all, countries in Europe have clearly designated levels of care that make it possible to assess whether high-risk babies are born in specialised maternity units with on-site neonatal intensive care. Most of these countries also have data on their place of birth. The proportion of very preterm babies born in the most specialised units varies widely. It would be useful to develop a common European classification for maternity and neonatal units to facilitate monitoring the care of these high-risk babies. Whether these classifications exist or not, it is important for countries to be able to monitor where these infants are born.

The percentage of babies breast fed at birth ranges from 54% to 99%.
Breast feeding provides benefits for babies including important nutritional advantages and improved resistance to infections. Success of breast feeding during the first 48 hours after birth depends on public health policies and healthcare practices during pregnancy and in the immediate postpartum. Data on breast feeding at birth are available from 19 countries or regions. More than 95% of babies received some breast milk at birth in the Czech Republic, Latvia, Portugal, and Slovenia. Rates were lowest in Ireland, Scotland, Cyprus, France, and Malta (54-69%). Data collection in every country and greater precision and consistency in defining the modes of breast feeding are necessary to assess the efficacy of national policies and to know to what extent the recommendations to promote it are achieved.

IV. NEXT STEPS IN PERINATAL HEALTH REPORTING IN EUROPE

This report demonstrates the feasibility and value of using statistical indicators to monitor perinatal health at a European level. Our results also illustrate, however, that continuing international collaboration is needed to improve the consistency of definitions and to prioritise the development of methods for collecting data for many perinatal health indicators. Many of the questions about mothers' and babies' health raised by this report will remain unanswered unless health information systems are improved and extended to record key data items.

Investments in national surveillance systems are needed; no country was able to provide all the data required to compile the full set of Euro-Peristat indicators, and availability of some key indicators was poor.
Even though the availability of indicators improved between 2004 and 2010, no country could

provide the full set of EURO-PERISTAT indicators. Indicators with limited availability include those needed to monitor prevention policies: smoking during pregnancy, maternal underweight and overweight, timing of antenatal care initiation, breast feeding, and measures of social status. Data on maternal health are also lacking. The quality of data for these indicators and use of different definitions in some countries also impedes comparisons between countries. A European-wide perinatal survey would be one way to get a good baseline for essential indicators on maternal risk factors and care and to develop better common definitions that could be integrated into routine systems.

Routine systems for ascertainment of very preterm births and maternal deaths require improvement.
Standardising the definition of stillbirths and enabling them to be distinguished from terminations of pregnancy is a priority for international comparisons, since the current guidelines are inadequate. Routine systems tend to under-report maternal mortality. Further work to enhance data about maternal deaths is essential, for example, by using data linkage and by creating specific systems to ascertain and analyse the causes of a wider range of pregnancy-related deaths.

Wider use of data linkage, building on methods already in use in Europe, would yield immediate gains for perinatal health monitoring in many countries.
Linking of data from two or more routine systems can extend the scope, coverage, and quality of perinatal data, as can be seen from the experience of the many countries which already link data either routinely or for specific projects. Both national and international efforts are necessary to remove the obstacles to combining data from statistical and healthcare organisations, such as difficulties of coordination between different administrations. Challenges can arise from European Data Protection legislation and differences between member states in how they choose to implement it. Data linkage and the associated need for data protection is an area where countries have a lot to learn from each other and can benefit from sharing experiences.

A sustainable European surveillance system requires an active network of clinicians, researchers, and statisticians from all countries.
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. Furthermore, our Scientific Committee members have guided us through complex situations as national health information systems reorganise and institutions change. Maintaining and reinforcing the EURO-PERISTAT network is thus central to our strategy for achieving sustainable health reporting in Europe.

V. CONCLUSION

The Euro-Peristat network developed an action plan for sustainable perinatal health reporting in 2010 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.

Whether this aim is achievable depends mainly on the availability of political and financial support at both European and national levels. Currently, the future of health surveillance in Europe is uncertain. The new EU health programme Health for Growth 2014-2020 does not prioritise programmes to reinforce information systems and many health information projects, including the European Community Health Indicators Monitoring project (ECHIM), have been discontinued because of absence of funding. More generally, there is concern that the current health agenda — as set out in the new research programme Horizon 2020 — gives no encouragement or support to research on public health, health systems, or health policy.

Nonetheless, these issues are a priority in many countries and on the European level, as shown by our experience with the first *European Perinatal Health Report*. Data from this report were widely used by health providers, planners, policy makers, researchers, and users across Europe and beyond. The report was downloaded more than 8000 times from our website. More than 100 media articles reported its publication. Individual European countries increasing rely on this reference list of indicators to evaluate their policy initiatives and benchmark their performance (see Chapter 2 for some examples).

Our indicators have been analysed by our team and others to gain insight into the factors that 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 (see our website www.euro-peristat.com for a full list of articles). Others have also used the Euro-Peristat data — which are made available freely on our website — for research on perinatal health in their own countries. 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 highlight the value of having comparable data from the countries in Europe.

2

SURVEILLANCE OF PERINATAL HEALTH IN EUROPE

2. SURVEILLANCE OF PERINATAL HEALTH IN EUROPE

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 impairments[1] 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. Alarmingly, 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.

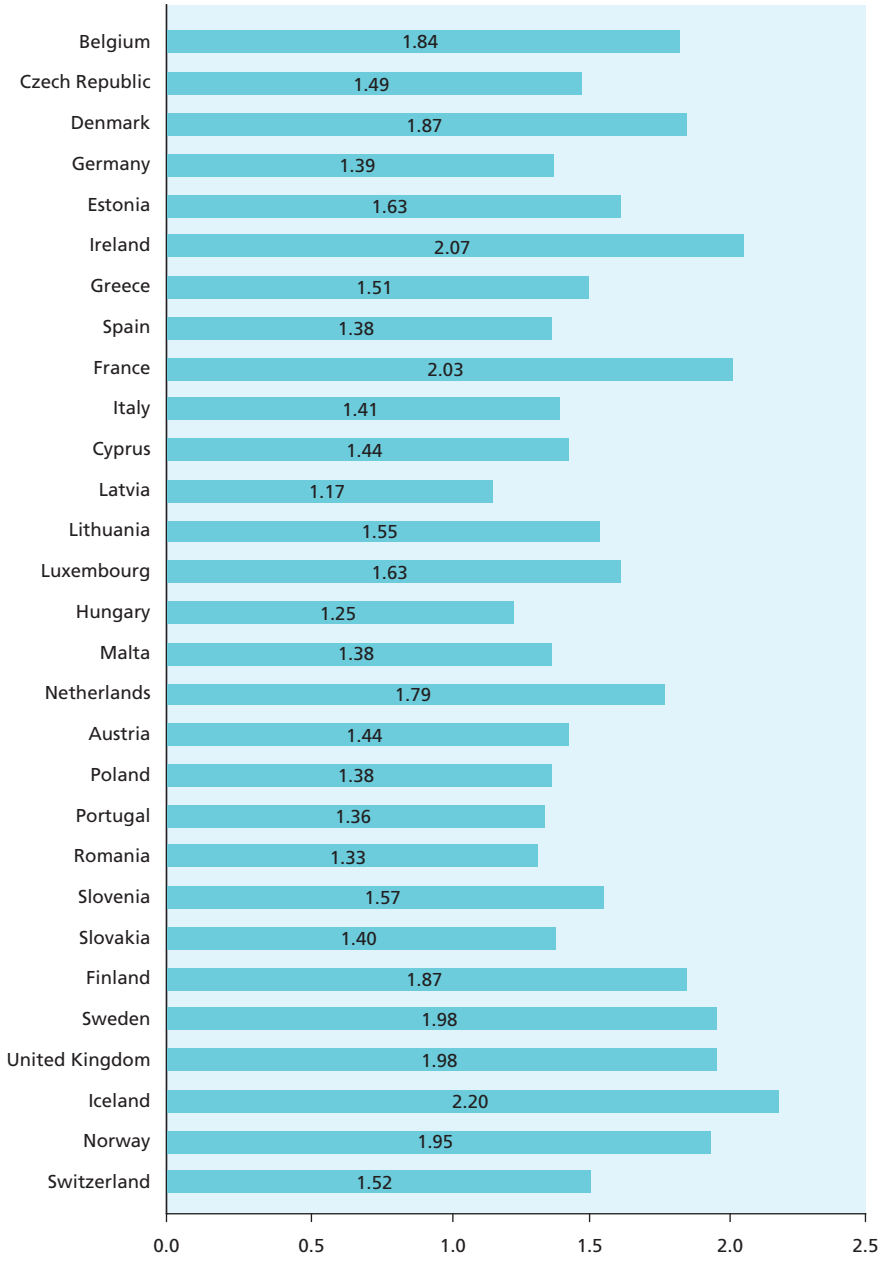
WHY EUROPE?

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
F7: 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 Heath 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 increasing 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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3

DATA FOR PERINATAL HEALTH MONITORING IN EUROPE

3. DATA FOR PERINATAL HEALTH MONITORING IN EUROPE

This report presents perinatal health indicators from national and regional perinatal health information systems in the European member states that participate in the Euro-Peristat Action project (all EU member states with the exception of Bulgaria) and Iceland, Norway, and Switzerland (29 countries). Data collected by EUROCAT (for congenital anomalies) and SCPE (for cerebral palsy) are also included.

3.1 Euro-Peristat DATA COLLECTION PROCESS

Country representatives on the Euro-Peristat Scientific Committee were responsible for overseeing national or regional data collection for their country (see Appendix A1 for the list of contributors).[1,2] Euro-Peristat aims to gather population-based data at the national level from routine sources (ie, administrative or health registers, statistical systems, or routine surveys). If national level data are not available, data for regions or constituent countries are collected, as in Belgium, France, Spain, and the UK.

Euro-Peristat collects aggregated data using an Excel-based instrument that covers all 10 core and 20 recommended indicators. We asked for data about births in 2010 or in the most recent year for which data are available. Information was also collected about data sources and quality. TNO (Netherlands Institute for Applied Scientific Research) oversaw the data collection and verification process, which included data entry and data crosschecks. Queries were then sent to Scientific Committee members and data providers for a first review.

The Euro-Peristat project held a meeting in Malta in November of 2012 to discuss preliminary results. This process also made it possible to identify outlying values and consider questions related to indicator definitions. Scientific Committee members had a final chance to check all the indicators and endorse the Euro-Peristat data before publication of this report.

3.2 DATA SOURCES

Euro-Peristat Scientific Committee members and collaborating data providers from each country decided which data sources to use. The number of sources for each country varied between 1 (Greece and Flanders) and 17 (for the UK and its 4 constituent countries). For each indicator, the data source is provided in the summary tables of Appendix B. More detail on each of these data sources can be found in Appendix C. These sources included civil registers based on birth and death certificates, medical birth registers, hospital discharge systems, and survey data. Table 3.1 summarises countries' main sources of data for perinatal health reporting.

Civil registration systems provide information related to perinatal health. All participating countries have a civil registration system that includes all births and deaths. Registration is required by law and is very complete for citizens and permanent residents. Non-residents, however, are excluded, except in Ireland and the countries of the UK. In Northern Ireland, births to non-residents are registered, but data about them are excluded from tables prepared for

publication. Countries derive numbers of live births, stillbirths, infant deaths, and maternal deaths from civil registration. In all countries, civil registration includes a compulsory medical certification of causes of death, although some countries process this separately. Some civil registration systems also record background characteristics, such as mothers' age, parity, plurality or babies' birth weight, but most countries only record a limited number of variables related to perinatal health.

Most Euro-Peristat core and recommended indicators are derived from medical birth registers and child health systems. These contain more information about maternal characteristics and about diagnosis, care, and interventions during the perinatal period for mothers and children. Data provision is mandatory in most countries; although these registers are voluntary in Malta and the Netherlands, coverage is good. Midwives, nurses, or doctors usually send information to the registers from hospital maternity units, either on a data collection form or directly from electronic patient data systems. Civil registration and medical birth register data are the most comprehensive on the population level; coverage usually exceeds 95%. For further information, please see Appendix C where coverage is estimated for each of the data sources used in this report.

Besides civil registration and medical birth registers, data for perinatal health indicators can come from hospital discharge systems which include information about hospital births. In contrast to civil registration, which usually includes only citizens and permanent residents, healthcare data systems include information about all care provided in the relevant area, including births to women without permanent residence status (immigrants, refugees, and asylum seekers) as well as visitors and women from other countries seeking health care. This can cause discrepancies in the total number of births when compared with civil registration data.

Hospital discharge systems record data about births and interventions during the hospital stay (ie, caesarean or instrumental deliveries, maternal diagnoses during pregnancy, childbirth, hospital care after delivery, and interventions and clinical diagnoses in mothers and babies before discharge). However, these systems usually do not cover use of primary healthcare services or home or other out-of-hospital births. There are other methodological concerns about using these databases. For instance, use of these data to estimate incidence or prevalence data may result in overestimates if the systems do not use a unique identifier to record multiple admissions of the same person.[3] Some countries do not distinguish between confirmed and suspected diagnoses. In other countries, such as Cyprus, data collection is mandatory only for public hospitals, so that information from private hospitals may be less complete or even entirely missing. If the diagnoses or interventions in the hospital discharge systems are used for financial purposes, there may be a bias towards more complicated diagnoses or interventions, or those that provide funding for the hospitals.

Other data collection systems include specific health registers such as: the metabolic diseases register in Spain, the birth defect, very low birth weight, and breastfeeding registers in Portugal, and Iceland's databases of ultrasounds of congenital anomalies and of angiographies. In Germany, Estonia, Spain, Norway, England and Wales, Scotland, Finland, and Sweden, data about induced abortions are derived from notifications of terminations of pregnancy. Termination data are based on reports that doctors performing the induced abortion must complete and send to statutory authorities.

Some of the Euro-Peristat indicators come from survey data rather than systems that aim to capture all events routinely. France,[4] Cyprus, and Spain use surveys to monitor births and perinatal

care on a regular basis. Other surveys used in this EURO-PERISTAT data collection exercise covered specific subjects, such as induced abortions in Italy, infant feeding in the UK, and pregnancy risk assessment in both Poland and the UK. Some surveys combine data abstracted from medical records with information obtained from interviewing mothers. Survey data can better grasp mothers' personal experiences of pregnancy, including factors such as exposure during pregnancy and birth experiences, thereby adding to the quality and breadth of the perinatal health data available. In addition, regular surveys are more flexible in their ability to add new variables, while routine data collection is often rigid and slow. However, surveys are not suitable for the study of rare events, such as mortality, as sample sizes are necessarily limited. Participation and reporting and recall bias can also be issues. In particular, while coverage can be very good, some surveys have low response rates; more data on the surveys used in this report can be found in Appendix C.

To collect fuller information about maternal and infant mortality, some countries organise confidential enquiries or audits which use case ascertainment to assess whether substandard care or other avoidable factors contributed to the death. Countries performing such audits are included in Table 3.1. The system in the UK has been in a state of transition and data for 2010 were not available for EURO-PERISTAT, although data were contributed from perinatal audits in Scotland, Wales, and Northern Ireland and from the Confidential Enquiry into Maternal Deaths for 2006-2008. The UK audit has now been relaunched as the MBRRACE-UK collaboration.

Many countries use some form of linkage procedure to merge data from different sources. Nineteen countries reported linking data. Some countries perform these linkages routinely, combining, for example, medical birth register data with civil registration to increase the completeness of data and obtain information on deaths after the perinatal period. Linkages also provide information on birth outcomes such as birth weight, gestational age, or plurality, and social status for infant and maternal deaths. Data from birth certificates and death certificates are also routinely linked in some countries. In a few countries, these kinds of linkages can only be done for ad hoc statistical or research purposes. The availability of unique identification numbers in different data collection systems makes these linkages technically easy, but deterministic linkages can also be performed successfully by using other information, such as name, date of birth, and address.[3]

Further analysis of the data sources used to report on perinatal health in Europe can be found in publications by the EURO-PERISTAT group.[3,5]

3.2 COLLABORATION WITH EUROPEAN REGISTRIES (EUROCAT AND SCPE)

Two European networks of registries, EUROCAT[6] and SCPE,[7] compile data on 2 of the EURO-PERISTAT recommended indicators, based on information from national registries: prevalence of congenital anomalies (R1) and prevalence of cerebral palsy (R4). Obtaining accurate and comprehensive data on these indicators requires specific systems for ascertainment and harmonisation of definitions.

These networks have contributed the sections of this report on these indicators (Chapter 8). These sections present the data sources and methodological issues related to the collection of comparable and high quality data.

3.3 REGISTRATION CRITERIA FOR BIRTHS AND DEATHS

EURO-PERISTAT requested data for all stillbirths and live births from 22 weeks of completed gestation or, if gestational age was missing, a birthweight cutoff of 500 g. However, countries have different criteria for registration of stillbirths, and some had different limits for live births. This leads to differences in the lower inclusion limits for births and deaths for data provided to EURO-PERISTAT, as shown in Table 3.2. In some countries, legal limits for registration are different from those used for the EURO-PERISTAT data collection because the data do not come from civil registration data. For instance, Hungary, the Netherlands, and the UK were able to provide data for births that occurred below the lower limits for legal registration. These cases are noted in the table. Most countries were able to provide data with a gestational age limit of 22 completed weeks, although some countries use birthweight thresholds and therefore cannot provide data on births below that cutoff. Most countries do not have legal registration limits for live births and therefore were able to provide data based on EURO-PERISTAT's inclusion criteria.

There have been some changes since our data collection in 2004;[5] Cyprus now has data on stillbirths, and Greece, Latvia, and Sweden have lowered their registration criteria. In France before 2008, the registration limits for stillbirths were 22 weeks or 500 g. However, since 2008, parents choose whether or not to record stillbirths in the French Civil Register, regardless of gestational-age or birthweight limits, starting at the end of the first trimester. As a result, stillbirth data from vital statistics in France cannot be compared to other countries' fetal mortality data for which gestational-age and birthweight limits apply — France has put into place a new system for monitoring stillbirths from its hospital discharge data, but data from this system will not be available until 2012.

For this report, we requested data about notifications of terminations of pregnancy. We hypothesised that some of the variation in fetal mortality across European countries could be due to differences in reporting terminations performed at 22 weeks or later. Some countries register these as stillbirths, whereas elsewhere terminations are recorded in a separate system or not reported at all.[8] This information is presented in Table 3.2, which illustrates the diversity of practices in Europe at present. Moreover, it is not easy to correct for the impact of these different reporting practices because many countries do not collect the data on termination in a way that enables stillbirth rates to be computed with and without terminations. This is sometimes because the information is not included in birth registers and sometimes because there is no separate source for recording terminations. Note also that women from countries where terminations are restricted or illegal may seek care elsewhere and this may have an effect on the number of terminations in these countries, although this is less likely to apply to late terminations.

Because of differences in legislation, regulations, and practices for registering births and deaths, we present mortality statistics using gestational-age limits that make these rates more comparable across countries. The first *European Perinatal Health Report*[5] showed wide variation between European countries in fetal (2.6–9.1‰) and neonatal (1.6–5.7‰) mortality rates in 2004. We analysed the part of this variation that might have been due to differences in the recording of births and deaths.[8] Based on our results, the EURO-PERISTAT network decided to exclude from our comparison the deaths most likely to be affected by registration differences: 22–23 weeks for neonatal mortality and 22–27 weeks for fetal mortality.[8] Using a lower limit of 28 weeks for the fetal mortality rate reduces the impact of terminations on reporting differences, since terminations are very rare in most countries after that point.[9] Further analyses of our data

confirmed our choice of a gestational-age versus a birthweight limit. We found that using a birthweight cutoff of 1000 g versus a gestational-age cutoff of 28 weeks underestimated the burden of third-trimester stillbirths.[10] One of the research themes pursued by EURO-PERISTAT is how to improve the comparability of mortality indicators.

While differences in the recording of births and deaths at the limits of viability have a considerable impact on mortality rates, they affect other perinatal health indicators much less because they represent a very small proportion of all births. On average, births before 26 weeks of gestation account for 0.45% of all births.[5]

3.4 COMPARING PERINATAL HEALTH DATA

In defining our indicators, the EURO-PERISTAT network seeks to reduce variation in indicators attributable to the use of different definitions. We have accomplished this by selecting definitions most likely to be feasible and by carefully designing the data collection instrument. However, many countries cannot produce the EURO-PERISTAT indicators according to the recommended definitions because the data are collected according to national definitions that differ from EURO-PERISTAT definitions or because the data we request are not available in their systems.

For example, not all countries could provide the requested denominators, such as childbearing women rather than births, or total births rather than live births. Some countries were able to provide information for all births, but not separately for singletons and multiples. When asked to report data for different time periods, countries were often unable to provide data for the requested time frames. For example, smoking during pregnancy was defined as the proportion of women who smoked during pregnancy among those with live born or stillborn babies. When possible, data were collected for 2 time periods: an earlier (ideally, first-trimester) and a later (ideally, third-trimester) phase but countries could not always report on both periods. Timing of the first antenatal visit provides an indicator of access to antenatal care, but some countries could not provide data according to EURO-PERISTAT definitions. They may, for example, code the first trimester as less than 12 weeks instead of less than 15 weeks or report the timing of the first visit to the maternity unit and not the first visit with a healthcare provider about the pregnancy.

Issues of definition are particularly problematic for indicators of maternal morbidity during pregnancy. We analysed our 2004 data and concluded in an article that we entitled "What about the mothers?" that the data then collected in routine systems were inadequate for comparing maternal morbidity during pregnancy between countries in Europe.[11] EURO-PERISTAT is currently assessing whether data from hospital discharge summaries can be used for meaningful comparisons.

Another issue which can affect the comparability of indicators is the management of missing data. Ideally, the data should be collected with "unknown" as a separate potential answer. This is not always the case, however. If check-box answers are interpreted as a positive answer (yes), missing data tend to be automatically but erroneously interpreted as a negative answer (no). The data tables in Appendix B report the number of missing cases for each indicator, when this information is available, in the column labelled "not stated". In our data exercise, we systematically calculated rates and percentages excluding cases with missing data.

Finally, random variation must be taken into account in comparisons. The largest EU member states — France, Germany, Italy, and the UK — each have more than half a million births per year. The annual number of births is smallest in Malta and Iceland (around 4000), Luxembourg (around 5500), and Cyprus (around 8000). Estonia and Brussels, in Belgium, have only 14 000-18 000 births per year. For these areas, the data for a single year may not contain sufficient numbers of events to construct reliable rates to measure rare events or rare maternal or child outcomes. For maternal mortality, which is extremely rare, rates are measured with data for 5-year periods. The Euro-Peristat group has studied the best ways to present data to call attention to the variation in indicators due to small population size.[12]

For each indicator in the report, we detail the specific methodological questions that should be kept in mind when interpreting variations, in the sections entitled **"Methodological issues in the computation, reporting, and interpretation of the indicator".**

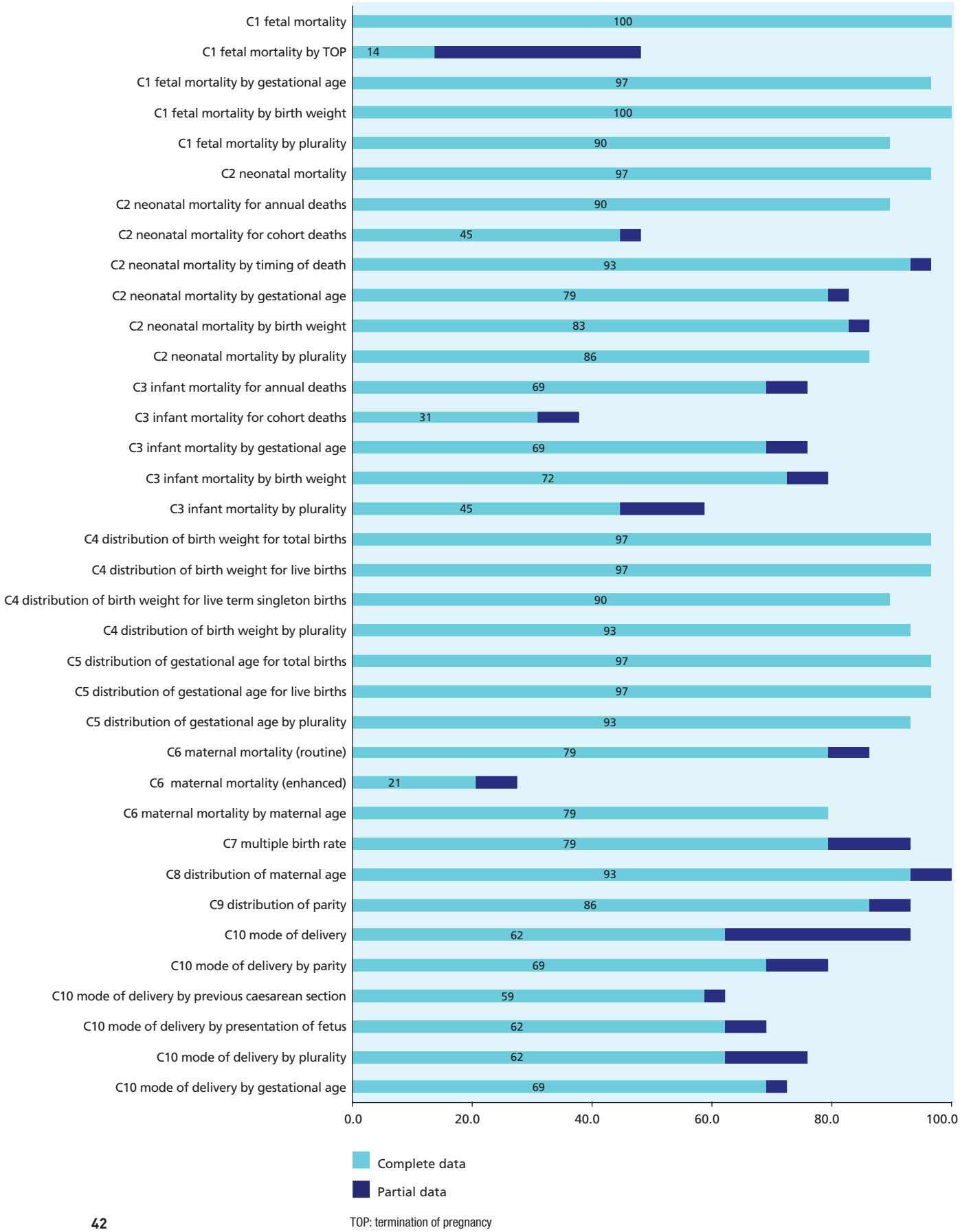
3.5 DATA AVAILABILITY

Figures 3.1 and 3.2 present the percentage of countries that provided the Euro-Peristat core and recommended indicators. Partial availability describes situations where some data are available but where there are significant differences with the Euro-Peristat definition or where coverage is not national. Coverage that is complete but based on several subnational systems that have not been merged to provide a national value (as for some indicators in Belgium and the UK) is considered full availability.

In general, availability for the core indicators was good, with a few exceptions for terminations and cohort deaths, infant deaths by birth characteristics, maternal deaths from enhanced systems, and mode of delivery for specific subgroups. Availability for the recommended indicators was more limited and variable. Data about fetal and neonatal mortality attributed to congenital anomalies, about pregnancy risk factors such as smoking and maternal body mass index, and about maternal morbidity, assisted reproduction procedures, births without obstetric intervention, and breast feeding were limited, and countries could not always provide data based on the Euro-Peristat definitions. On the other hand, data about mode of onset of labour, Apgar score, maternal mortality by cause of death, maternal country of origin, and newborn place of birth were more widely available, with 70% or more of all countries providing complete or partial data

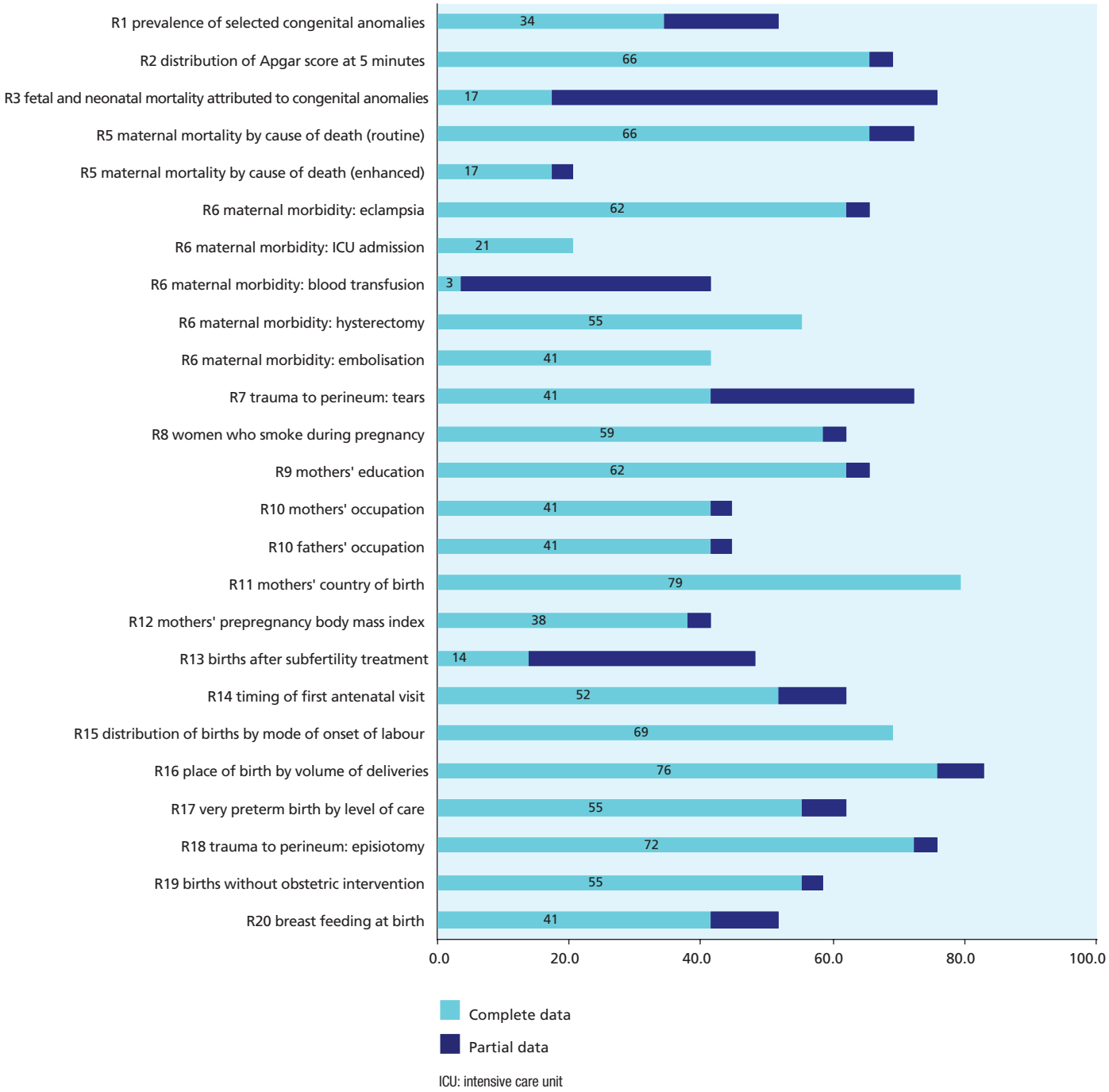
There has not been much change in data availability since our report in 2004 and this is cause for concern, especially since some of the indicators essential for monitoring preventive health policies — such as smoking during pregnancy, obesity, and initiation of antenatal care — and social disparities in health are those that are not recorded in many countries.

Figure 3.1 Percentage of countries that provided the EURO-PERISTAT core indicators in 2010



TOP: termination of pregnancy

Figure 3.2 Percentage of countries that provided the EURO-PERISTAT recommended indicators in 2010



ICU: intensive care unit

3.6 CONCLUSIONS AND RECOMMENDATIONS FOR IMPROVING HEALTH REPORTING

The strengths of our data collection exercise were the standardised definitions and uniform collection of aggregated data. We relied on the expertise of our Scientific Committee members and data providers. Our members are statisticians, health researchers, physicians, midwives, and university professors. All data were checked according to a protocol involving rounds of internal validation with multiple reviewers and the data providers. This and our previous Euro-Peristat report[5] testify to the feasibility and the importance of the collection of indicators of maternal and infant health and of routinely compiling data that are available at the present time. However, this exercise also highlights the shortcomings of current systems and helps us identify the priorities for improving European health reporting. The following are some areas where further work is required and where national and international efforts could yield substantial benefits for perinatal health surveillance.

IMPROVING ASCERTAINMENT OF BIRTHS AND DEATHS

Standardising the definition of stillbirths and differentiating these from terminations of pregnancies is a priority for European comparisons,[5,8,13] yet current guidelines are not sufficient. Mandatory reporting of stillbirths to Eurostat covers only the total number of stillbirths without any detail about gestational age or birth weight. More detailed information about stillbirths with birth weights from 500 g to 999 g (or, when birth weight does not apply, gestational age from 22 to 27 completed weeks, or, when neither applies, crown-heel length from 25 to 34 cm) and with birth weight of 1000 g and more (or, when birth weight does not apply, gestational age after 27 completed weeks, or, when neither applies, crown-heel length of 35 cm or more) is collected on a voluntary basis only.[14] In addition, the guidelines do not include any recommendations about whether late pregnancy terminations after 22+0 weeks are to be reported as stillbirths. It is our understanding that the forthcoming implementation regulation on demographic statistics do not currently include additional guidelines for improving the collection of perinatal data at Eurostat. In this context, Euro-Peristat is essential for providing more detail on stillbirths and demonstrating that — at the very minimum — voluntary reporting of fetal deaths by birth weight should be strongly encouraged in European databases.

Further work is also necessary for improving data on maternal deaths.[15] Several European countries have accomplished this by creating specific systems to identify and analyse maternal deaths. For this report, we collected data from enhanced as well as routine systems. As these data show, enhanced systems make it possible to obtain better data about the number and causes of maternal deaths, and these should be implemented in all countries.

LINKAGE OF ROUTINE DATA SOURCES TO IMPROVE COVERAGE AND QUALITY OF DATA

Perinatal care is in essence a multidisciplinary field. Midwives, gynaecologists, obstetricians, neonatologists, and paediatricians are all involved in the process of providing care to pregnant women and newborn babies. In many countries, data about these aspects of care are recorded in separate systems. Linkage between these and other datasets containing data about deliveries and births, including civil registration data, hospital discharge data, and medical birth registers can improve the scope and range of data available.[3] Many European countries have integrated data linkage into their routine surveillance systems, but this is not systematic practice. Data linkage between civil registration and health information systems, or between data from statistical and health authorities are often limited by the difficulties of coordination between different organisations, the strictness of data-protection legislation, and the way that these statutes are implemented and interpreted. In some countries, a system of unique identification numbers

makes these types of data linkage technically straightforward. In countries without such a system, matching algorithms have been shown to be feasible for linkage. While many countries in Europe already routinely link data from birth and death registration, many do not; the Euro-Peristat group hopes to encourage other linkages that could enhance the data available for monitoring and surveillance of perinatal health. Linking existing data on perinatal health is a readily available option for improving the quality and completeness of some indicators and adds value to existing investments in health information systems.

DEVELOPING HEALTH INFORMATION SYSTEMS AT THE NATIONAL AND EUROPEAN LEVELS

This report aims to show the value of monitoring perinatal health at the European level. Nonetheless, continuing international collaboration is needed to improve definitions and prioritise data collection methods for many perinatal health indicators. Many of the questions about mothers' and infants' health raised by this report will remain unanswered unless health information systems improve.

Recent cuts in healthcare information system spending at the national level, as in the Czech Republic, Hungary, Latvia, and the UK, undermine health monitoring and surveillance as data collection systems suffer staff departures and departments close down. At the European Union level, proposals for the next 7 years also include reductions in EU staff. There is still no health monitoring system for the European Union, and international organisations, such as Eurostat, OECD, and WHO, collect relatively few indicators useful for perinatal health monitoring. The European Community Health Indicators Monitoring project, to develop and implement health indicators and health monitoring in the EU and all EU member states, included some indicators of perinatal health, but its funding was discontinued in 2012, and the system for data collection and public health monitoring has not yet been implemented. In the current environment, it is vital to promote and preserve national and European health information systems.

USING DATA FOR POLICY AND RESEARCH

The most effective way to promote the development of health information systems is to use the data they produce. Improving data systems is costly and time-consuming and requires input from multiple participants, including clinicians, hospital administrators, statisticians, and health planners. Given the many demands on resources and time, the types, definitions, and quality of data that are collected will change at the national level only if the value of comparable data is recognised.

Data from our last report were analysed by the Euro-Peristat group and others for reports and scientific publications about perinatal health in Europe[8,11-13,16] and North America.[17,18] Involving researchers in the analysis and interpretation of data contributes to reinforcing these systems. This is readily apparent in the Nordic countries where birth registers are widely used by researchers to understand the aetiology and risk factors for adverse perinatal outcomes and their consequences.[19,20] While putting national data together for Europe in this way is not an achievable goal for the near future, collaborative projects — for instance, a European-wide perinatal survey — would be a way to validate the data in national systems and answer important questions about the adequacy of care received during pregnancy, the socioeconomic factors that affect health, and women's experiences of pregnancy and childbirth.

Making the most of the Euro-Peristat indicators requires the involvement of all stakeholders in its interpretation and use. Our aim therefore is to continue to build and reinforce a network of clinicians, researchers, policy makers, and users with an interest in obtaining good quality information on the health of pregnant women and babies.

Table 3.1 Main sources of data used by Euro-Peristat in 29 European countries in 2010

Country	Total births in 2010 (N)	Civil registration	Medical birth register or child health system	Hospital discharge system	Perinatal survey	Confidential enquiry	Other routine surveys	Linked data source
Belgium								
BE: Brussels	25 098	x	x					
BE: Flanders	69 976	x	x					
BE: Wallonia	38 430	x	x					
Czech Republic	116 920	x	x	x				
Denmark	63 513	x	x	x				x
Germany	638 126	x						x
Estonia	15 884	x	x					x
Ireland	75 595	x						
Greece	111 741	x						
Spain	400 415	x	x	x				
France	810 430	x		x	x	x		
Italy	547 569	x	x				x	x
Cyprus	8602	x	x		x			x
Latvia	19 248	x	x					
Lithuania	30 977	x	x					x
Luxembourg	6560	x	x					x
Hungary	90 920	x						
Malta	4036	x	x					x
Netherlands	178 838	x	x				x	x
Austria	78 989	x	x	x				x
Poland	415 015	x		x			x	
Portugal	101 790	x	x	x		x		
Romania	213 055	x	x					x
Slovenia	22 416	x	x					
Slovakia	55 825	x	x					
Finland	61 421	x	x	x				x
Sweden	115 135	x	x	x				x
United Kingdom						x	x	
UK: England and Wales	721 925	x		x				x
UK: England				x				
UK: Wales			x	x		x		
UK: Scotland	57 488	x		x		x		x
UK: Northern Ireland	25 692	x	x			x		x
Iceland	4903	x	x	x				
Norway	62 612	x	x					x
Switzerland	80 276	x		x				x

NOTE: Confidential enquiries covers maternal deaths in France, perinatal and maternal deaths in the Netherlands, stillbirths and infant deaths in Scotland, and stillbirths in Northern Ireland. For Slovakia, these data sources do not cover the recommended (R) indicators, which accordingly have not yet been submitted.

Table 3.2 Inclusion criteria for births and deaths provided to the EURO-PERISTAT project in 2010

Country	Stillbirths using EURO-PERISTAT criteria[1]	Comments	TOP included as stillbirths	Provided number of TOP[2]	Live births using EURO-PERISTAT criteria[1]
Belgium					
BE: Brussels	Y		Y		Y
BE: Flanders	Y		Y		Y
BE: Wallonia	Y		Y		Y
Czech Republic	Y		Y	Y	Y
Denmark	Y		N		Y
Germany	500+ g		Y		Y
Estonia	Y		Y		Y
Ireland	500+ g		TOP not legal		500+ g
Greece	24+ weeks		?		24+ weeks
Spain	180 days		N	Y	Y
France	Y	Civil registration based on parental choice	Y	Y	Y
Italy	Y	At <180 days, registered as miscarriages , > 180 days registered as stillbirths	Y	Y	Y
Cyprus	22+ weeks perinatal register; 28+ weeks death register		Y		Y
Latvia	22 weeks and 500 g		N		Y
Lithuania	Y		N		Y
Luxembourg	Y	Civil registration: 6 months GA or 500+ g when GA is missing	Y		Y
Hungary	24+ weeks fetal deaths and TOP at 22-23 weeks included	Civil registration: 24+ weeks or 500+ g or 30+cm	Y	Y	Y
Malta	Y		TOP illegal		Y
Netherlands	Y	Civil registration: 24+ weeks	Y		Y
Austria	500+ g		N		500+ g
Poland	500+ g		No TOP		Y
Portugal	24+ weeks, voluntary data at 22-23 weeks		N		22+ weeks (no standard resuscitation policies at 22-23 weeks)
Romania	Y	GA or BW not specified	N		Y
Slovenia[3]	500+ g		Y		Y
Slovakia					
Finland	Y		N	Y	Y
Sweden	Y		N		Y
United Kingdom					
UK: England and Wales	24+ weeks	No lower limit for registration but used linkage to provide 22 week cutoff for C1 to C5	TOP should also be registered as stillbirths from 24 weeks	Could not obtain data	Y for C1 to C5, not for other indicators
UK: Scotland	22+ weeks; incomplete voluntary notification at 22-23 weeks	No lower limit for registration but used Scottish Morbidity Record (SMR02) to provide 22 week cutoff	Y	Y	Y for data from SMR02 but not for civil registration
UK: Northern Ireland	24+ weeks	No lower limit for registration but used child health system to provide 24 week cutoff for C1 to C5	Terminations not available		Y
Iceland	Y		Y		Y
Norway[4]	Y	Perinatal register includes births starting at 12+ weeks	N	Y	Y
Switzerland	Y		Y	Y	Y

TOP: termination of pregnancy; GA: gestational age; BW: birth weight.
NOTES: (1) Euro-Peristat criteria – 22 completed weeks of gestation; if gestational age missing then include a birth weight of 500 g or more.
(2) Termination of pregnancy can be identified in the data source for stillbirths (when included) or is available in a separate source (when not included with stillbirths)
(3) In Slovenia, in cases of multiples, all babies are included if any fulfills criteria.
(4) Provided TOP for fetal anomalies only.

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4

CHARACTERISTICS OF CHILDBEARING WOMEN

4. CHARACTERISTICS OF CHILDBEARING WOMEN

CORE

Multiple birth rate by number of fetuses (C7)
Distribution of maternal age (C8)
Distribution of parity (C9)

RECOMMENDED

Percentage of women who smoked during pregnancy (R8)
Distribution of mothers' educational level (R9)
Distribution of parents' occupational classification (R10)
Distribution of mothers' country of birth (R11)
Distribution of maternal prepregnancy body mass index (R12)

Pregnancy outcome varies considerably between social and demographic groups within populations. An understanding of the social and demographic characteristics of childbearing women is therefore crucial to interpreting differences between outcomes in EU member states. The EURO-PERISTAT indicator list includes 8 indicators which describe childbearing women — 3 core and 5 recommended. Two of the recommended indicators, maternal BMI and parental occupation, were added in the most recent update. Data on parental occupation, however, are not included in this report because of ongoing work to harmonise the presentation of occupational categories across countries.

All these indicators describe multiple and interrelated characteristics which affect the risk of adverse maternal or infant outcome during pregnancy. For each indicator, we describe the associations with maternal and infant health and the hypothesised pathways for these associations. These indicators are also important because they can reflect the success of preventive policies aiming to improve health — such as those to provide access to contraception, reduce smoking, and promote good eating habits.

C7 MULTIPLE BIRTHS BY NUMBER OF FETUSES

JUSTIFICATION

Compared with singletons, babies from multiple births have much higher rates of stillbirth, neonatal mortality, infant mortality, preterm birth, low birth weight, congenital anomalies, and subsequent developmental problems.[1-6] All of these have consequences for families and for society. Rates of multiple birth vary between countries and over time. They are influenced by differences in the proportions of older women giving birth (see C8), the extent of use of ovarian stimulation and assisted conception (see R13), and the policies for preventing multiple pregnancies in those situations, as well as by other factors.[1,7] They therefore contribute to variations in rates of mortality and morbidity in infancy and childhood, both geographically and over time.

DEFINITION AND PRESENTATION OF INDICATOR

Figure 4.1 shows the rates of twin and triplet and higher order births, expressed as numbers of women with twin and with triplet or higher-order births per 1000 women giving birth to one or more fetuses.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

Almost all countries provided data for this indicator. Data came primarily from medical birth registers as well as from civil registration systems. In the Netherlands, data came from linked professional registers.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

The pregnancies included in civil registration systems depend on the laws governing the births requiring registration. These affect the extent to which multiple births in which one or more babies die before birth or registration are included. In addition, multiple births are rare events. In small populations such as those of Cyprus, Malta, and Luxembourg, year-to-year variation and confidence intervals are relatively wide. In comparing these data with other data sources, it is important to note that the multiple birth rate can be presented with births as the denominator (rather than pregnant women, as in the Euro-Peristat definition).

RESULTS

Multiple birth rates varied from a low of 9 to 13 per 1000 women with live births or stillbirths in Romania, Latvia, Lithuania, and Poland to more than 20 per 1000 in Brussels, the Czech Republic, Denmark, Cyprus, Spain, and Malta (Figure 4.1). There was no apparent association between the rates for triplet and higher-order births and those for twin births. Twin birth rates decreased in Denmark, the Netherlands, and Norway, increased slightly in Finland, Sweden, and Northern Ireland, and increased further in the other countries (Figure 4.2). The 3 countries that experienced a decrease had the highest twinning rates in 2004.

KEY POINTS

Very preterm multiple births impose considerable costs on health services, families, and societies. High rates due to either delayed childbearing or subfertility management raise questions about the need for policies to encourage earlier childbearing and to prevent multiple pregnancies in assisted conception (see recommended indicator R13). The decrease in twinning rates in some countries may be the result of these policies.[6] In the absence of data about ovarian stimulation and assisted conception, age-specific multiple birth rates can provide an indication of the extent of their use.[1]

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Figure 4.1 Multiple birth rates per 1000 women with live births or stillbirths by number of fetuses in 2010

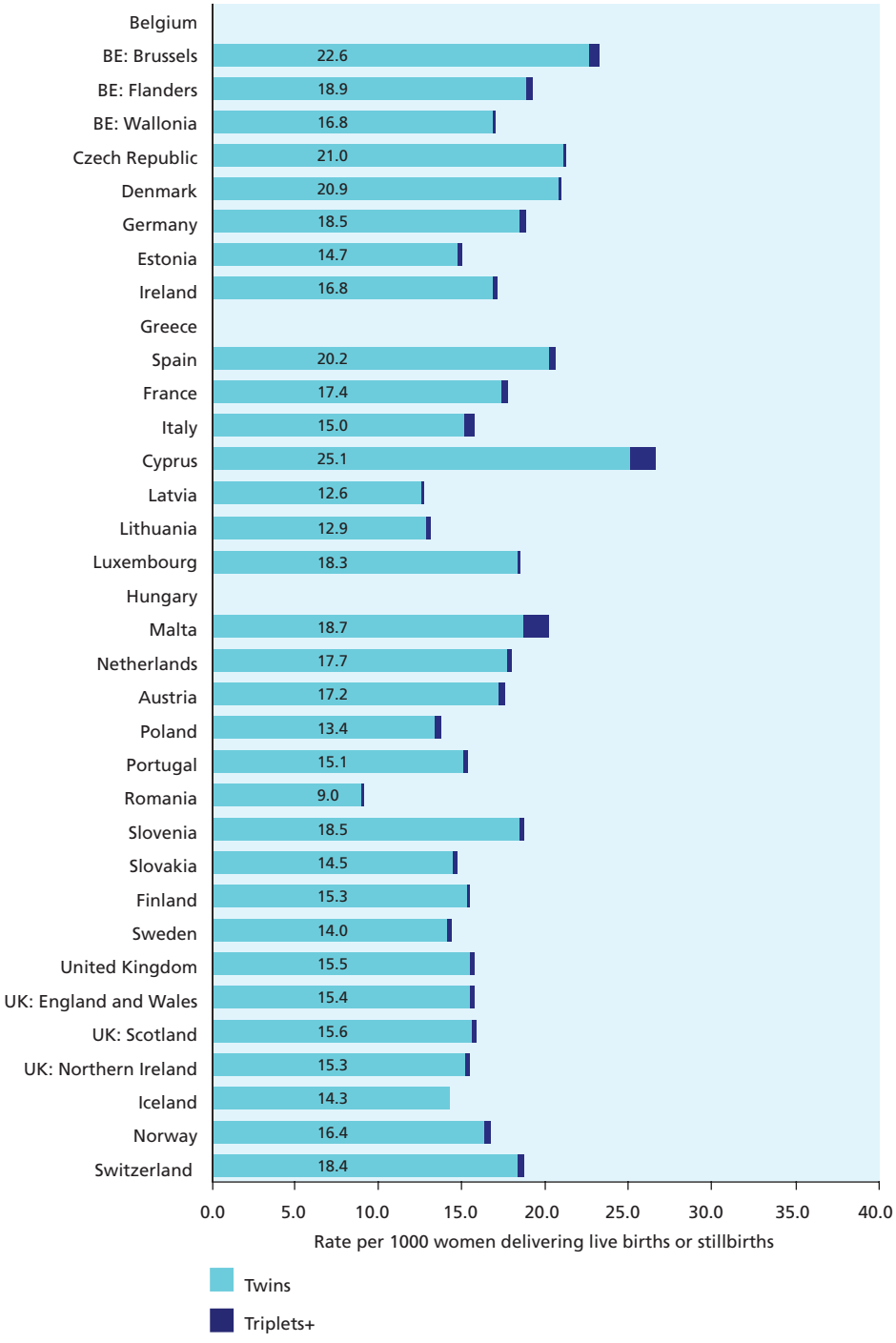
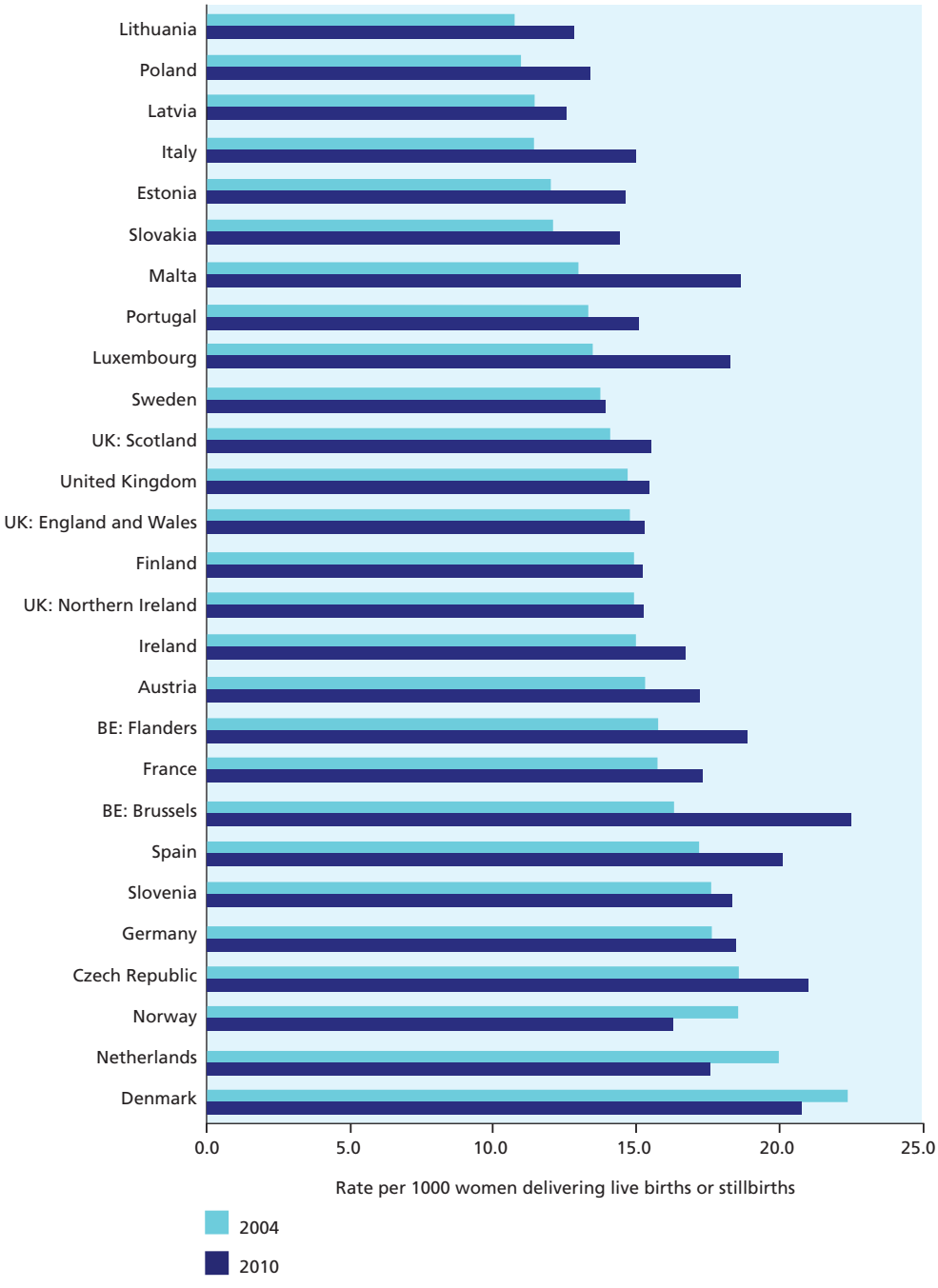


Figure 4.2 Twin birth rates per 1000 women in 2004 and 2010



NOTE: Countries ordered by ascending twin birth rates in 2004.

C8 MATERNAL AGE AT DELIVERY

JUSTIFICATION

Both early and late childbearing are associated with higher than average rates of preterm birth, growth restriction, and perinatal mortality.[1-4] Younger mothers are more likely to have low social status, and they have increased risks of unwanted or hidden pregnancy, inadequate antenatal care, and poor nutrition. Older mothers have a higher risk of multiple births (see C7) and a higher prevalence of pregnancy complications, including some congenital anomalies, hypertension, and diabetes. Older and younger women are at higher risk of maternal mortality and morbidity. Older mothers are more often delivered by caesarean section. Because of the association between maternal age and perinatal health outcomes and because the age at which women in European countries bear children differs widely, the maternal age distribution should be taken into account in comparisons between countries. Furthermore, mothers are increasingly having children later in life throughout Europe, and this likely affects trends in perinatal health outcomes. Policy issues include the orientation of antenatal surveillance towards the needs of older pregnant women and the provision of information about the risks associated with delayed childbearing. The prevention of teenage pregnancy is a policy concern in many countries.[5] Younger mothers may be exposed to less favourable social conditions and more vulnerable in times of economic crisis.

DEFINITION AND PRESENTATION OF INDICATOR

This indicator is defined as the distribution of age in years at delivery for women delivering a liveborn or stillborn baby. The recommended presentation is: 10-14, 15-19, 20-24, 25-29, 30-34, 35-39, 40-44, and 45 and older. This summary presentation focuses on the extremes of the childbearing distribution, defined as younger than 20 years and as 35 years and older.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THIS INDICATOR

Some civil registration systems record the age the mother reaches during the year of birth and not her age at delivery. In some situations, age may be recorded during antenatal visits but not updated at delivery. These data are presented in relation to total births in Hungary and Romania, while Euro-Peristat recommends consideration of the total number of women giving birth instead. However, the differences between these 2 numbers are due to multiple births, which are a relatively small proportion of total births even among women aged 35 or more, so this is not a major problem.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

All countries were able to provide this indicator, although Belgium did not have national data.

RESULTS

The percentage of mothers aged younger than 20 varied from 1.1 in Switzerland to 10.6 in Romania. Latvia, Malta, Hungary, Slovakia, and the UK, all with about 5% of mothers in this age group, are in an intermediate position (Figure 4.3). The percentage of older mothers, defined as women giving birth at 35 years or older, ranged from 10.9 in Romania to 34.7% in Italy. The group of women aged between 25 and 34 years, who have the lowest perinatal risks, is proportionally largest in Slovenia and Flanders (about 70%) because both younger and older women represent a small proportion of the women giving birth in these countries. On the contrary, the proportion of births to women aged 25-34 is relatively small in Romania (54%) because of the high proportion

of women under 25, and in Italy (55%) because of the high proportion of births to women aged 35+.

Figures 4.4 and 4.5 display the geographical distribution of high and low maternal age at childbirth; these figures illustrate the higher prevalence of births to women under 20 in eastern European countries. Older childbearing is less common in eastern Europe as well, but has a heterogeneous geographic pattern elsewhere.

Having children later in life is a general trend in Europe (Figure 4.6). Only Finland experienced a decrease between 2004 and 2010 in the proportion of women aged 35 years or more. The increase was relatively small in the countries of the UK, and very large in Italy, Estonia, Hungary, the Czech Republic, and Spain.

KEY POINTS

In more than half of EU countries or regions, births to teenaged mothers account under 3% of all deliveries. The proportion of women bearing children later in life varies substantially but in 40% of countries or regions, at least 20% of births were to women aged 35 years or more, and the proportion of births in this age group increased substantially in almost every country. This is a concern in countries which already had a high proportion of childbearing women in this age group. Policies should be developed to inform young women of the consequences of having children late in life so that they can make informed choices about when to have their children. Encouraging earlier childbearing may also require policies to support young parents and working mothers.

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Figure 4.3 Age distribution of women delivering live births or stillbirths in 2010

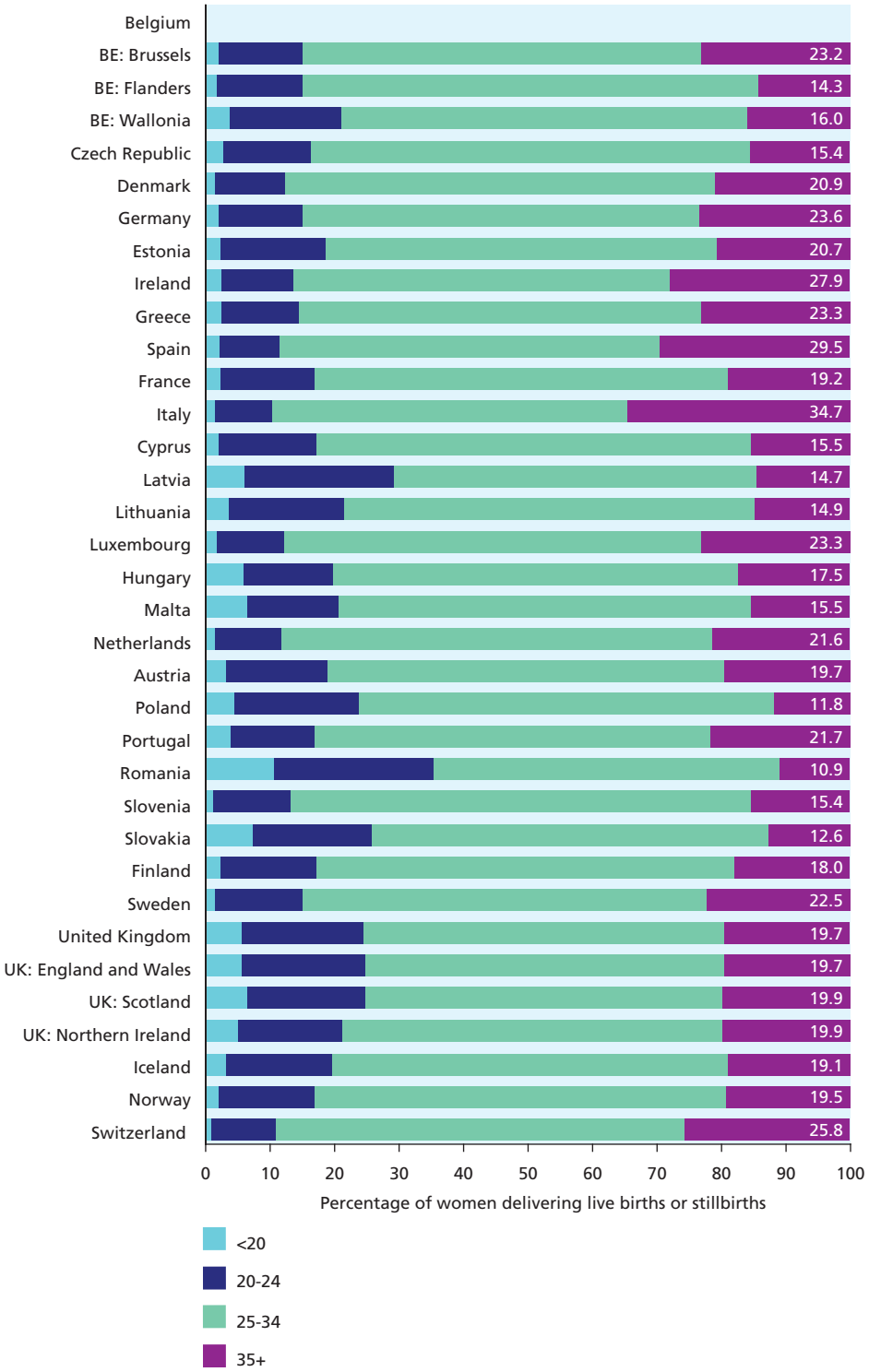
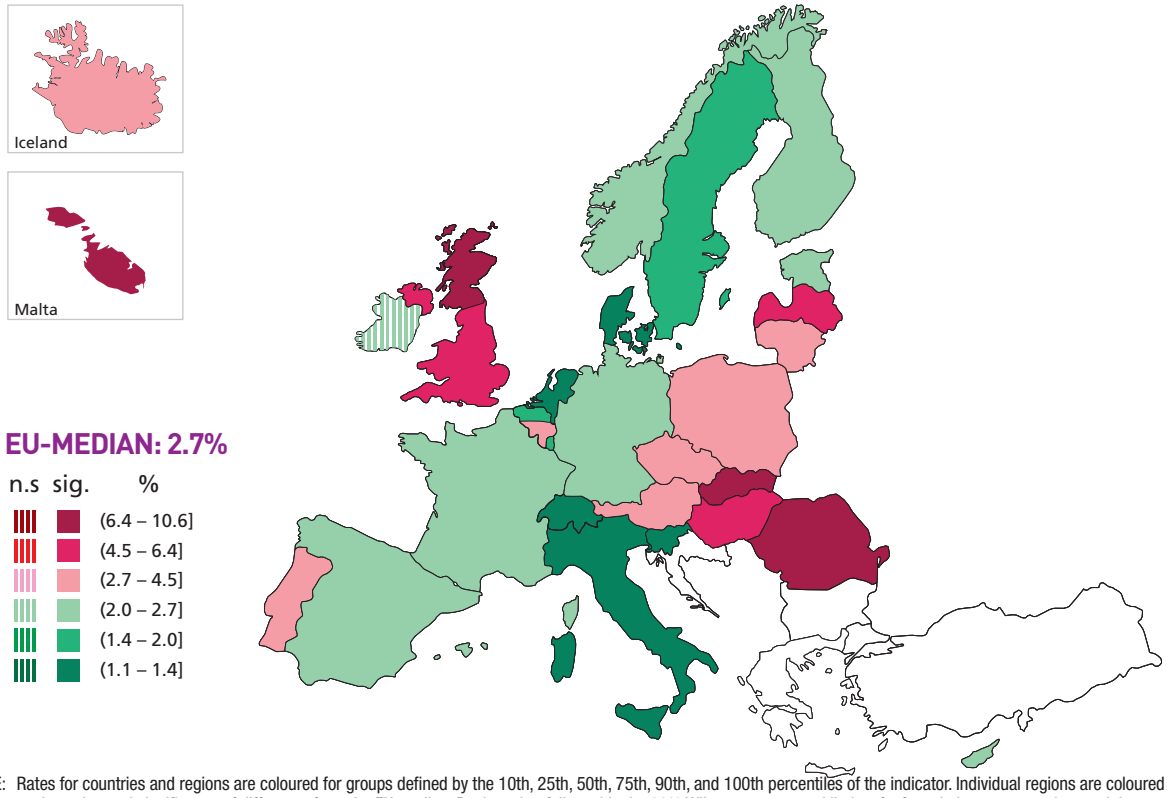
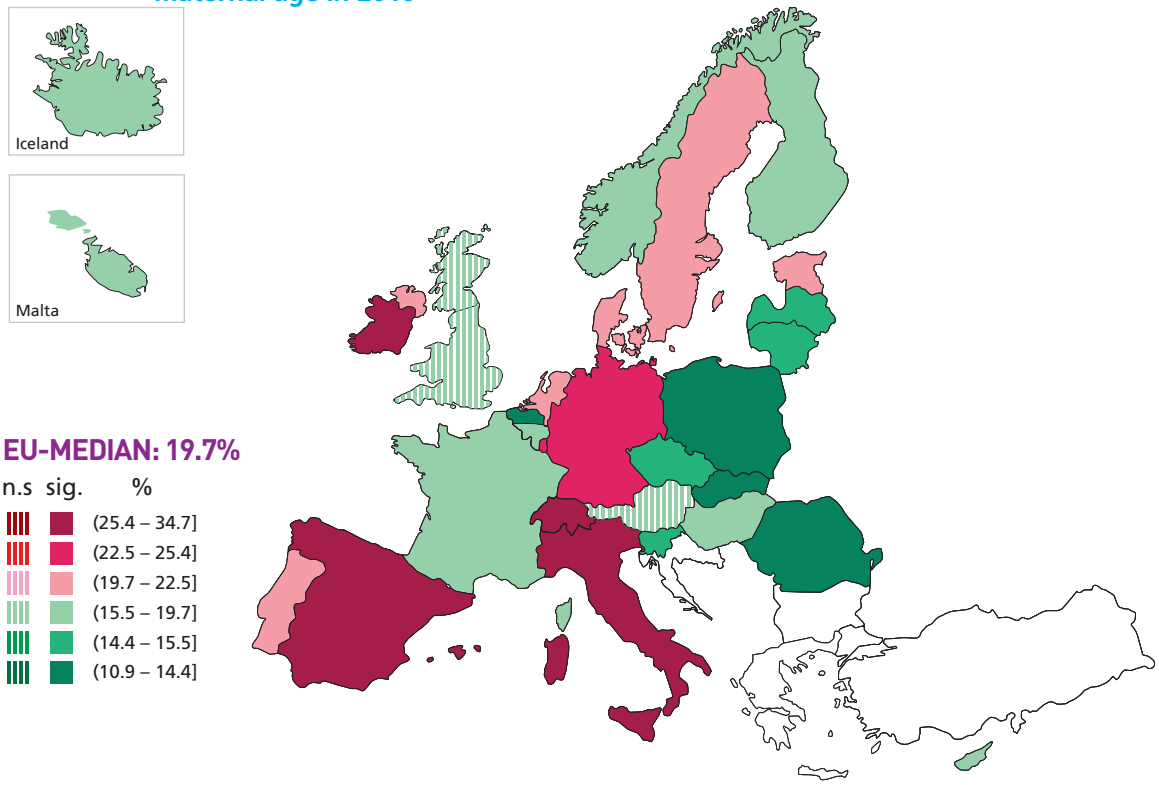


Figure 4.4 Mothers aged younger than 20 years as a percentage of all pregnancies with known maternal age in 2010



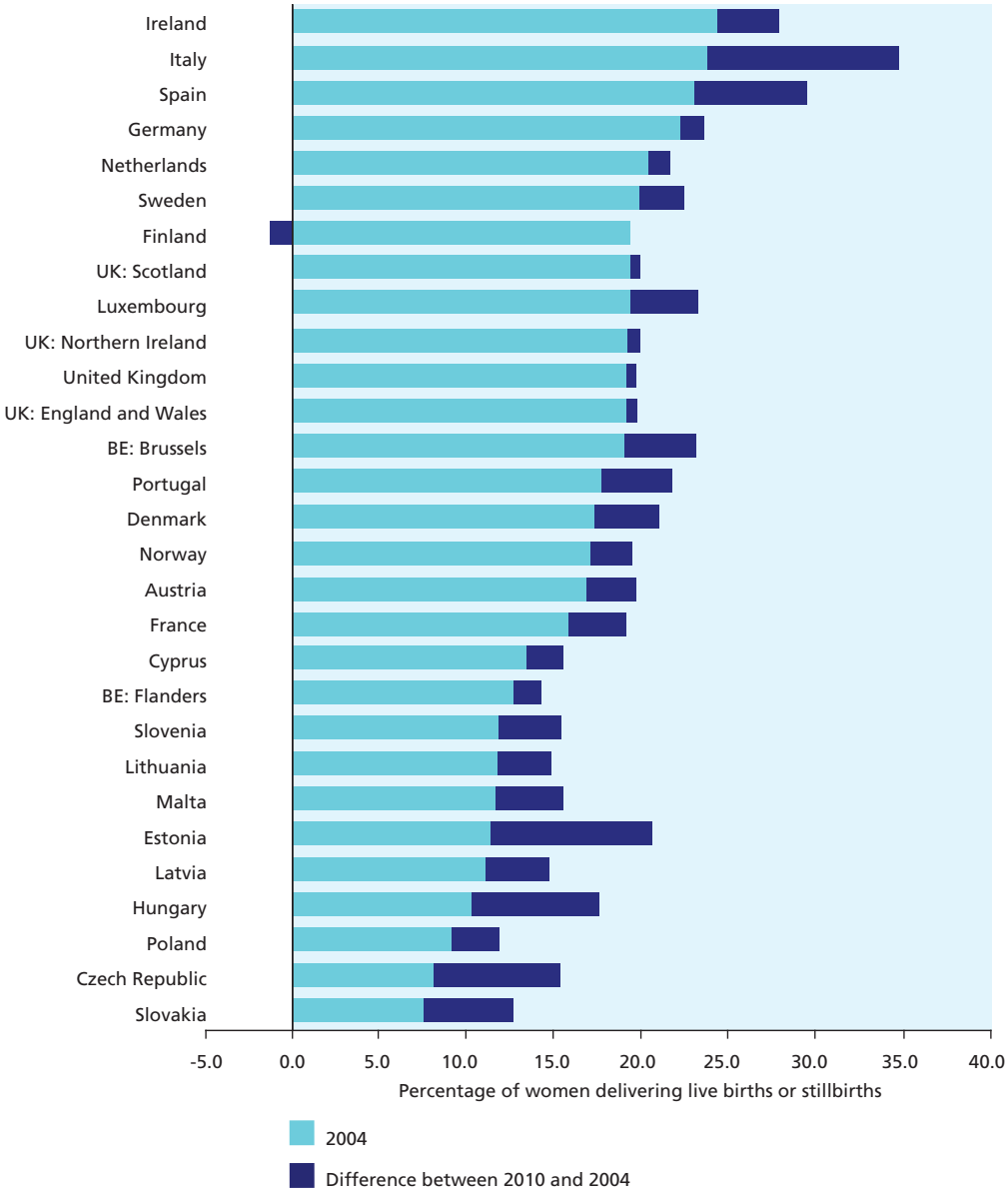
NOTE: Rates for countries and regions are coloured for groups defined by the 10th, 25th, 50th, 75th, 90th, and 100th percentiles of the indicator. Individual regions are coloured to show sign and significance of difference from the EU median. Regions that fall outside the 99% Wilson-score control limits of a funnel plot constructed around the EU-median against population size differ significantly (sig) and are shown as solid colours. Regions within the control limits (n.s.) are displayed with vertical hatching.

Figure 4.5 Mothers aged 35 years and above as a percentage of all pregnancies with known maternal age in 2010



NOTE: Rates for countries and regions are coloured for groups defined by the 10th, 25th, 50th, 75th, 90th, and 100th percentiles of the indicator. Individual regions are coloured to show sign and significance of difference from the EU median. Regions that fall outside the 99% Wilson-score control limits of a funnel plot constructed around the EU-median against population size differ significantly (sig) and are shown as solid colours. Regions within the control limits (n.s.) are displayed with vertical hatching.

Figure 4.6 **Percentages of mothers aged 35 or older in 2004 and differences between 2010 and 2004**



NOTE: Countries ordered by proportion of older mothers in 2004.

C9 DISTRIBUTION OF PARITY

JUSTIFICATION

The incidence of maternal conditions such as hypertension and preeclampsia differs by parity, as do use of services and interventions during pregnancy, labour, and delivery, as well as health behaviour.[1-3] Primiparous women (ie, those giving birth for the first time) are at above average risk of adverse outcomes compared with multiparous women (those with at least one previous delivery). Their stillbirth and neonatal mortality rates, for example, are higher. They also have

higher rates of caesarean sections.[4] Risks are also higher for women of higher parity who have had many previous births (grand multiparous women).[5]

DEFINITION AND PRESENTATION OF INDICATOR

Parity is defined as the number of previous total live births and stillbirths (0, 1, 2, or 3+ births). Figure 4.7 shows the distribution of parity as a percentage of women with live births and stillbirths.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

Most countries were able to provide data on parity. Romania provided data on parity at the level of the child (number of live births and stillbirths) rather than the mother.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Many civil registration systems do not count previous stillbirths as a birth in the computation of parity (for instance, Switzerland). Attention should also be paid to the recording of previous multiple births. WHO defines a woman who had twins as having 2 previous births. The proportion of missing cases is high in Italy (5%) and in England and Wales (19%), where parity was derived from hospital and community data, respectively, because up to April 2012 parity was recorded only for births to married couples and excluded any births before marriage in civil registration data (19%). In England, numbers were extrapolated to deal with the large number of missing values. Missing data are probably imputed in many countries.

RESULTS

The percentages of women having their first birth ranged from 39% in Iceland and Slovakia to 50-53% in Spain, Italy, Malta, Poland, Portugal, Romania, Slovenia, Wales in the UK, and Switzerland; the percentages of women with 3 or more previous births ranged from 3% in Spain, Italy, Portugal, Slovenia, and Switzerland to 9% or higher in Brussels (Belgium), Ireland, Finland, Slovakia, and the UK.

KEY POINTS

As fertility is rather low in Europe, attention is paid to women having their first birth and the associated risks rather than to women with many previous births. Demographic patterns of childbearing differ within Europe, but the increase in fertility rates in some countries[6] may result in a decrease in their proportion of women having first births and a trend towards more homogeneity in the distribution of parity.

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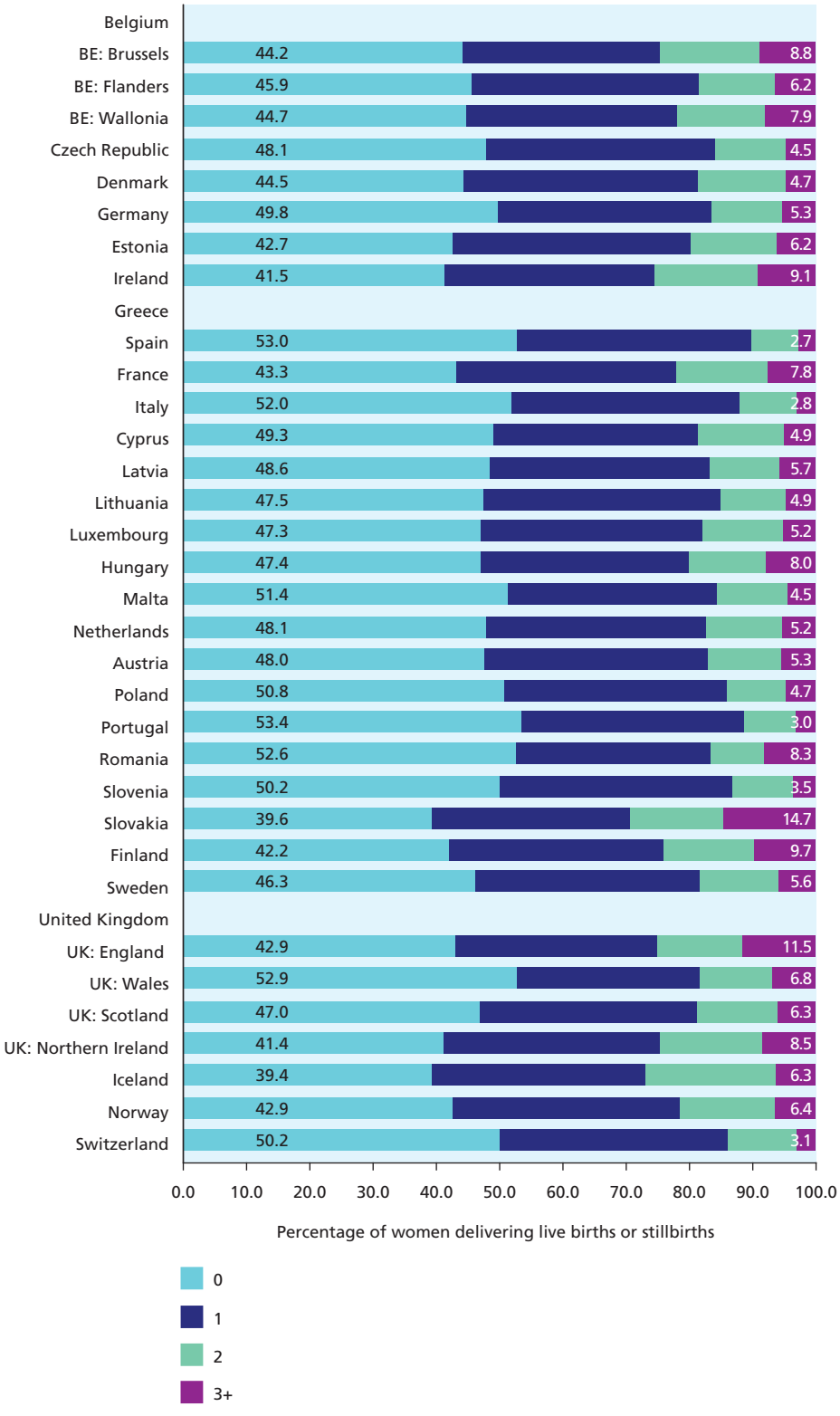
Figure 4.7 Distribution of parity for women delivering live births or stillbirths in 2010



R8 SMOKING DURING PREGNANCY

JUSTIFICATION

Maternal smoking during pregnancy is a well-established risk factor for adverse perinatal outcomes. It can impair normal fetal growth and development and thus increase the risk of low birth weight, preterm birth, intrauterine growth restriction, and some congenital anomalies.[1-4] Maternal smoking not only influences outcomes during the perinatal period but probably has long-term and lifelong consequences. Although not all of these have yet been recognised, they are known to include obesity later in childhood,[5] neurobehavioural and cognitive deficits,[6] and impaired lung function, including wheezing and asthma.[7] Over the past 2 decades, smoking among pregnant women has declined by about 60–75% in developed countries.[1] It nonetheless continues to account for a substantial proportion of fetal and infant morbidity and mortality.[8] Maternal smoking may be considered the most important preventable factor associated with adverse pregnancy outcome.[9] Smoking cessation is one of the most effective interventions for improving mothers' and children's health[10] and thus serves as an indicator of the quality of antenatal preventive healthcare services.

DEFINITION AND PRESENTATION OF INDICATOR

Smoking during pregnancy was defined as the proportion of women who smoked during pregnancy among those with liveborn or stillborn babies. When possible, data were collected for 2 time periods: an earlier (ideally, first trimester) and a later (ideally, third trimester) phase.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

The data were provided by 23 countries or regions. Some countries or regions provided data based on routine surveys (France, the Netherlands, Valencia, and the UK). The UK data come from the infant feeding survey conducted every 5 years. In Spain, data come from the region of Valencia and are based on a representative sample of pregnant women, excluding women with high risk pregnancies.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

To be able to compare countries or regions or to evaluate time trends, a common time frame is essential. This is important because many women stop smoking during pregnancy. If a single measure is the most practical option, it should relate to the last trimester of pregnancy so that the length and timing of exposure can be taken into account. Differences in the type of data (antenatal care records, medical records in maternity units, and birth surveys including interviews with mothers before and after birth) and the questions asked are additional sources of potential bias. Accordingly, the quality of the information is variable. Some data sources may record a woman as a non-smoker if smoking is not recorded in medical records. The rate of missing data varied from 0% (the Czech Republic, Germany, Latvia, Lithuania, Malta, and Slovenia) to 6% (Poland) and 17% (Norway). Finally, there is evidence that some women may under-report smoking, as they know that they should not be smoking during pregnancy. Misclassification and inaccurate estimates of smoking may thus result. Many of the data providers expressed reservations about the quality of these data because they were based on self-report, and missing data were not well recorded. Data were not collected on amount smoked, so these data include women who smoked daily and those who smoked occasionally.

RESULTS

Table 4.1 presents information on the time periods covered by the data and the proportions of smokers during both periods. Data on smoking in the second period (during pregnancy or in the last trimester) varied from under 5% in Lithuania and Sweden to 14.0% in Catalonia, 15% in Northern Ireland, 16% in Wales, 17.1% in France, and 19% in Scotland. When prevalence was available for 2 periods, the percentage of smokers was always lower closer to delivery.

Countries that had data points for 2004 and 2010 reported slightly lower proportions of smokers in the last trimester in 2010 — by about 1-3%. In France, the Netherlands, and the UK, the decrease was more pronounced.

KEY POINTS

In many European countries, more than 10% of women smoke during their pregnancy. Not all countries could provide data on maternal smoking during pregnancy, and standardised collection procedures are necessary to improve comparability for those countries that did. Tobacco use during pregnancy is insufficient to assess the effectiveness of preventive policies during pregnancy, as this use is largely influenced by habits before pregnancy. Given the adverse effects of smoking on fetal and infant health and since pregnancy care is considered an ideal setting for intervention, having high quality and comparable information on smoking before and during pregnancy should be a priority.

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Table 4.1 Estimates of proportion of women smoking during pregnancy in routine data, according to period for which data are collected in 2010

Time Period			Smokers in 2010		2004
Countries	Period 1	Period 2	Period 1 %	Period 2 %	Latest period %
Belgium					
Czech Republic		During pregnancy		6.2	6.1
Denmark		During pregnancy		12.8	16.0
Germany		During pregnancy		8.5	10.9
Estonia	1st trimester	During pregnancy	9.1	7.8	9.9
Ireland					
Greece					
Spain					
ES: Catalonia	Before pregnancy	3rd trimester	36.7	14.4	
ES: Valencia	1st trimester		15.8		19.6
France	Before pregnancy	3rd trimester	30.6	17.1	21.8
Italy					
Cyprus	1st trimester		11.5		
Latvia		During pregnancy		10.4	11.3
Lithuania	Before pregnancy	During pregnancy	7.0	4.5	4.8
Luxembourg		3rd trimester		12.5	--
Hungary					
Malta	1st trimester		8.2		7.2
Netherlands	1st trimester	After 1st trimester	10.5	6.2	13.4
Austria					
Poland	Before pregnancy	3rd trimester	24.6	12.3	--
Portugal					
Romania					
Slovenia		During pregnancy		11.0	10.9
Slovakia					
Finland	1st trimester	After 1st trimester	15.5	10.0	12.4
Sweden	1st trimester	3rd trimester	6.5	4.9	6.3
United Kingdom	Before or during	During pregnancy	26.0	12.0	17.0
UK: England	Before or during	During pregnancy	26.0	12.0	17.0
UK: Wales	Before or during	During pregnancy	33.0	16.0	22.0
UK: Scotland		During pregnancy		19.0	24.9
UK: Northern Ireland	Before or during	During pregnancy	28.0	15.0	18.0
Iceland					
Norway	1st trimester	3rd trimester	18.6	7.4	11.1
Switzerland					

R9 MOTHERS' EDUCATIONAL LEVEL

JUSTIFICATION

Social disadvantage remains a major determinant of poor perinatal outcome and requires effective action.[1] Many perinatal health indicators, including maternal mortality, preterm birth, and duration of breast feeding, are inversely related to variables measuring social disadvantage, such as education, occupation, and income. Because there are no universally agreed-upon measures of social disadvantage, researchers use a wide variety of different indicators, sometimes individually and sometimes combined: occupation, educational level, income and other measures of wealth, housing conditions, lack of access to health care, and others. The Euro-Peristat group initially chose to use maternal educational level as its marker of social status. Because some countries do not collect data on education, our recent update of our indicator list (see Chapter 2) also added parental occupation, which captures different dimensions of social status. Much of the research on perinatal health has studied maternal educational level and has shown that it is correlated with perinatal outcomes, even after adjustment for lifestyle factors such as smoking and obesity;[2] these associations are observed in many different settings.[3]

As an indicator for international comparisons, educational level has the additional advantage that UNESCO has established an international classification, the International Standard Classification of Education (ISCED), which has also been adopted by the EU Directorate General for education and culture.[4]

DEFINITION AND PRESENTATION OF INDICATORS

For the present data collection, we asked countries to provide the ISCED classification when they used it and, if not, to provide their local classifications. These were then coded to match the ISCED definitions. The ISCED classification contains the following categories:

- Level 0 - Preprimary education
- Level 1 - Primary education or first stage of basic education
- Level 2 - Lower secondary or second stage of basic education
- Level 3 - (Upper) secondary education
- Level 4 - Postsecondary non-tertiary education
- Level 5 - First stage of tertiary education
- Level 6 - Second stage of tertiary education.

We further grouped these data into 3 basic categories:

√ Primary school completed, or started, or no formal education (levels 0, 1)

√ Any secondary (levels 2, 3)

√ Any postsecondary (levels 4, 5, 6).

DATA SOURCE, AVAILABILITY, AND METHODOLOGICAL ISSUES

Twenty-six countries or regions provided information on the educational level of childbearing women. As mentioned earlier, education is one indicator of social position among others; in some countries, it is not the preferred indicator. Concerns about its use include: possible selection bias in missing data, poor comparability of the educational level classifications inside Europe, and difficulties classifying women with low professional training. Another concern is the fact that some countries report that no women are in the category of primary education or less. This is surprising because all European countries have migrant women from regions of low literacy,

who belong to this category. However, some countries, such as Finland, do not register primary education because it is assumed that everyone has it.

RESULTS

Figure 4.8 describes the distribution of maternal education level in European countries according to the classification described above. Depending on the country, missing values (educational level not reported) varied from less than 1% to more than 25% of women. For the women for whom information on educational level was available, the largest group in most countries — 37 to 72% — had secondary education as their highest level. Nonetheless, the proportion with postsecondary education was also high, ranging from 22 to 61%. Mothers with a primary school education or less accounted for 0 to 18% of the population. Some of this variation may be related to the differences in the manner that educational level is measured.

KEY POINTS

The distribution of educational level varies widely between the European countries that provided data for this indicator. Many countries cannot provide data on educational level, which is one of the reasons that Euro-Peristat has added a second indicator of social status, parental occupation, to its list of indicators. Further research will be required into the possibility of effectively comparing educational level and occupational class as it seems unlikely that the countries that do not collect education will do so in the near future. However, even if educational and occupational levels are not comparable, collecting these data — either or both, according to availability — will make it possible to compare fetal and neonatal mortality outcomes between these groups within countries and call attention to the differences related to social factors. These analyses are underway for 2010 and will be issued shortly.

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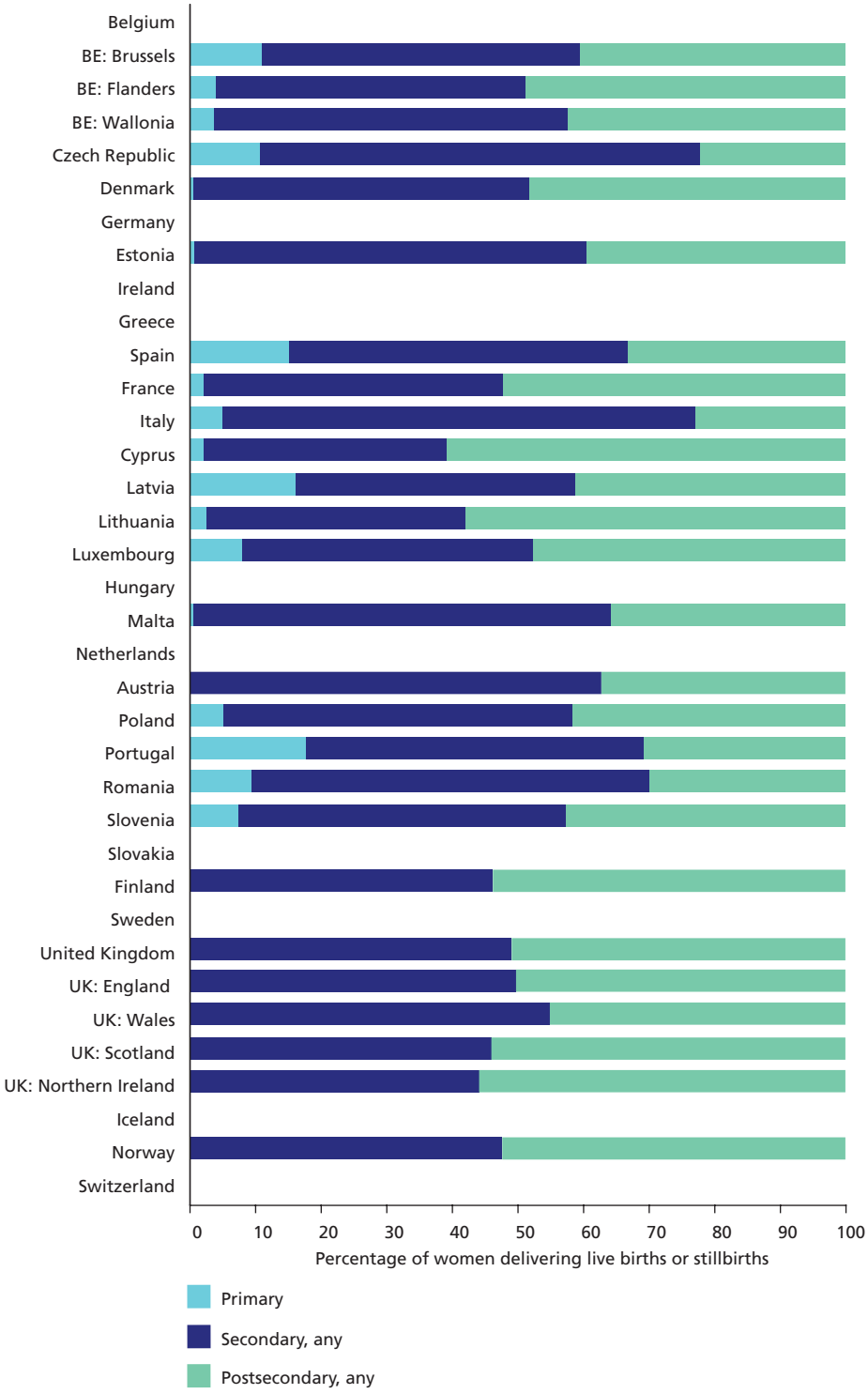
Figure 4.8 Distribution of mothers' education in 2010



R10 PARENTS' OCCUPATIONAL CLASSIFICATION

(new indicator – to be published in October, see discussion in R9)

R11 MOTHERS' COUNTRY OF BIRTH

JUSTIFICATION

International migration to industrialised countries may be accompanied by health disparities in perinatal outcomes between migrants and women born in receiving countries and also between groups of migrants. Some studies have shown poorer medical care,[1] higher rates of maternal complications,[2,3] and worse perinatal health outcomes for migrants, including increased rates of obstetric interventions,[4] perinatal mortality, low birth weight, and preterm birth.[5] In other cases, migrants' outcomes are as good and sometimes better than those of the host population. This has been described as a "healthy migrant" effect, meaning that migrants tend to be more healthy than the general population because unhealthy people are less likely to migrate. Outcomes vary both by the migrant's country of origin and by receiving country.[6] Comparing the health of and care provided to migrant women in diverse settings can help to identify factors associated with suboptimal care. These factors may include more limited access to care during pregnancy and differences in care related to language limitations and cultural differences. This indicator represents one social measure of subpopulations of women and children potentially at risk for adverse outcomes in the perinatal period. Euro-Peristat has collaborated with the ROAM (Reproductive Outcome and Migration: an international collaboration) project to study this question in detail and to develop international indicators.[7]

DEFINITION AND PRESENTATION OF INDICATOR

The ROAM collaboration and Euro-Peristat recommend using the mother's country of birth as the primary indicator and presenting it in 2 ways: (1) geographic regions, classified according to the UN list of world macro regions and components, with Europe further subdivided into EU27 and non-EU27, and (2) regions grouped by income level, as classified by the World Bank.[7] Many European countries do not record the country of birth, but record related data, which have been used to construct this indicator. In Belgium, nationality (citizenship) at birth is used. Some east European countries use a mix of ethnicity and nationality, as women can be classified as either. In the UK, data are collected on ethnicity, but information can also be provided on mothers' country of birth. For the UK and its constituent countries, the percentages of mothers born outside the UK are shown in Tables 4.2 and R11.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES; METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Most countries were able to provide information on country of birth or ethnicity or another indicator of maternal origin, more than those providing other Euro-Peristat indicators of social circumstances: educational level and occupation. When countries provided data, they were complete with few missing. Not all countries collect data by individual country of birth, which makes it difficult to standardise reporting categories according to the ROAM recommendations. For this report, we show the proportions of women born outside the country. It should be borne in mind that these groups include privileged as well as disadvantaged populations. For instance, in Brussels, foreign-born women include civil servants for the EU or other international institutions but also asylum seekers and undocumented persons from low and middle income countries. In Portugal, foreign-born women include a sizeable proportion of Portuguese women whose parents migrated out of Portugal.

RESULTS

Table 4.2 describes the availability of data about country of birth and its distribution in Europe. The percentage of foreign-born mothers ranged from 3% or less (the Czech Republic) to 66% (Luxembourg) and the proportion of women with a foreign nationality from 1.0% in Poland and Iceland to 30.2% in Latvia. The rates of foreign-born or foreign-nationality mothers in most countries in western Europe exceeded 25%. Countries provided this information with different levels of detail. In many countries, however, it should be possible to classify women by region of birth, as recommended.

KEY POINTS

In many European countries, a sizeable proportion of births are to women born outside of the country. Data are available in many countries to permit an analysis of health outcomes by mothers' countries or regions of birth.

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Table 4.2 Proportion of women with live births or stillbirths who were of foreign origin (or nationality or ethnicity) as defined by country of birth in 2010

Country/coverage	Country of birth %	Nationality %	Ethnicity %	Other %
Belgium				
BE: Brussels	66.2			
BE: Flanders	23.2			
BE: Wallonia	25.2			
Czech Republic	2.6			
Denmark	15.2			
Germany			16.9	
Estonia			24.9	
Ireland	24.6			
Greece				
Spain	23.6			
France	18.3			
Italy		19.0		
Cyprus	32.7			
Latvia		30.2		
Lithuania		12.8		
Luxembourg	66.0			
Hungary				
Malta		9.2		
Netherlands				21.1[1]
Austria	29.3			
Poland		0.04		
Portugal	19.0			
Romania				
Slovenia				
Slovakia				
Finland	6.2			
Sweden	24.4			
United Kingdom	24.0			
UK: England and Wales	25.2			
UK: Scotland	13.9			
UK: Northern Ireland	13.5			
Iceland		12.1		
Norway	24.8			
Switzerland	41.1			

NOTES (1) Country or nationality at birth or ethnicity.

R12 DISTRIBUTION OF MATERNAL PREPREGNANCY BODY MASS INDEX (BMI)

JUSTIFICATION

Women's weight before and during pregnancy affects the course of pregnancy, its outcome, and the health of offspring. Mothers who are underweight before pregnancy have a higher probability of delivering growth-restricted babies,[1] with all the consequences that entails for their adult life. On the other hand, obese mothers have higher risk of gestational diabetes mellitus and preeclampsia.[2,3] The relative risk of stillbirth[4] or a baby with a neural tube defect, spina bifida, or some other congenital anomalies is also higher in this group and increases with the level of obesity.[5,6] As well, macrosomia (birth weight ≥4500 g) and caesarean sections are 2-3 times more common among women who are obese or severely obese.[6,7]

DEFINITION AND PRESENTATION OF INDICATOR

This indicator is defined as the percentage of women delivering live births or stillbirths by their prepregnancy body mass index (BMI). This distribution is presented as follows: <18.5 (underweight), 18.5-24.9 (normal), ≥25.0 (overweight and obese). Overweight and obese women can be subdivided as pre-obese (BMI 25.0-29.9), obese class I (BMI 30.0-34.9), obese class II (BMI 35.0-39.9), and obese class III (BMI ≥40.0).

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

This indicator is available in the 3 regions of Belgium (Brussels, Flanders, and Wallonia), Denmark, Germany, France, Malta, Poland, Slovenia, Finland, Sweden, Scotland, and Norway.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

In most countries for which data are available, prepregnancy BMI is recorded at the first antenatal visit, which may slightly overestimate the mothers' BMI before pregnancy. When data are reported directly from women, as it is for instance in France, BMI may be underestimated as women tend to report their weight as being lower than it actually is. Seven countries or regions reported a proportion of missing data less than 10% (Flanders, Denmark, France, Poland, Slovenia, Finland, and Sweden); the frequency of missing data was higher in the other countries.

RESULTS

Figure 4.9 shows that women with a low prepregnancy BMI accounted for 2.5 to 8.7% of mothers delivering in countries for which data are available; the highest proportions were in Poland (8.7%), France (8.3%), and Wallonia (7.1%), and the lowest in Sweden (2.5%), Scotland (2.6%), Finland (3.6%), and Germany (3.6%). The proportion of overweight or obese women was typically about 30-37% with the exception of Poland (25.6%), France (27.2%), and Slovenia (27.8%), where lower percentages were reported, and of Scotland, where it reached 48.4%. Obese women accounted for 7.1 (Poland) to 20.7% (Scotland) of all pregnant women.

KEY POINTS

Maternal weight before and during pregnancy affects the course of pregnancy, its outcome, and the offspring's lifelong health. BMI before pregnancy is one of the simplest indicators of maternal nutrition, and it is not available in most European countries. Countries for which data are available report high variability of the proportion of both underweight and obese women, although in most countries, more than 10% of childbearing women are obese. This indicator of maternal weight should be monitored in more European countries in view of the possible changes in proportions of underweight, overweight, and obese women in the upcoming generations of women of childbearing age and the impact of these changes on perinatal health outcomes.

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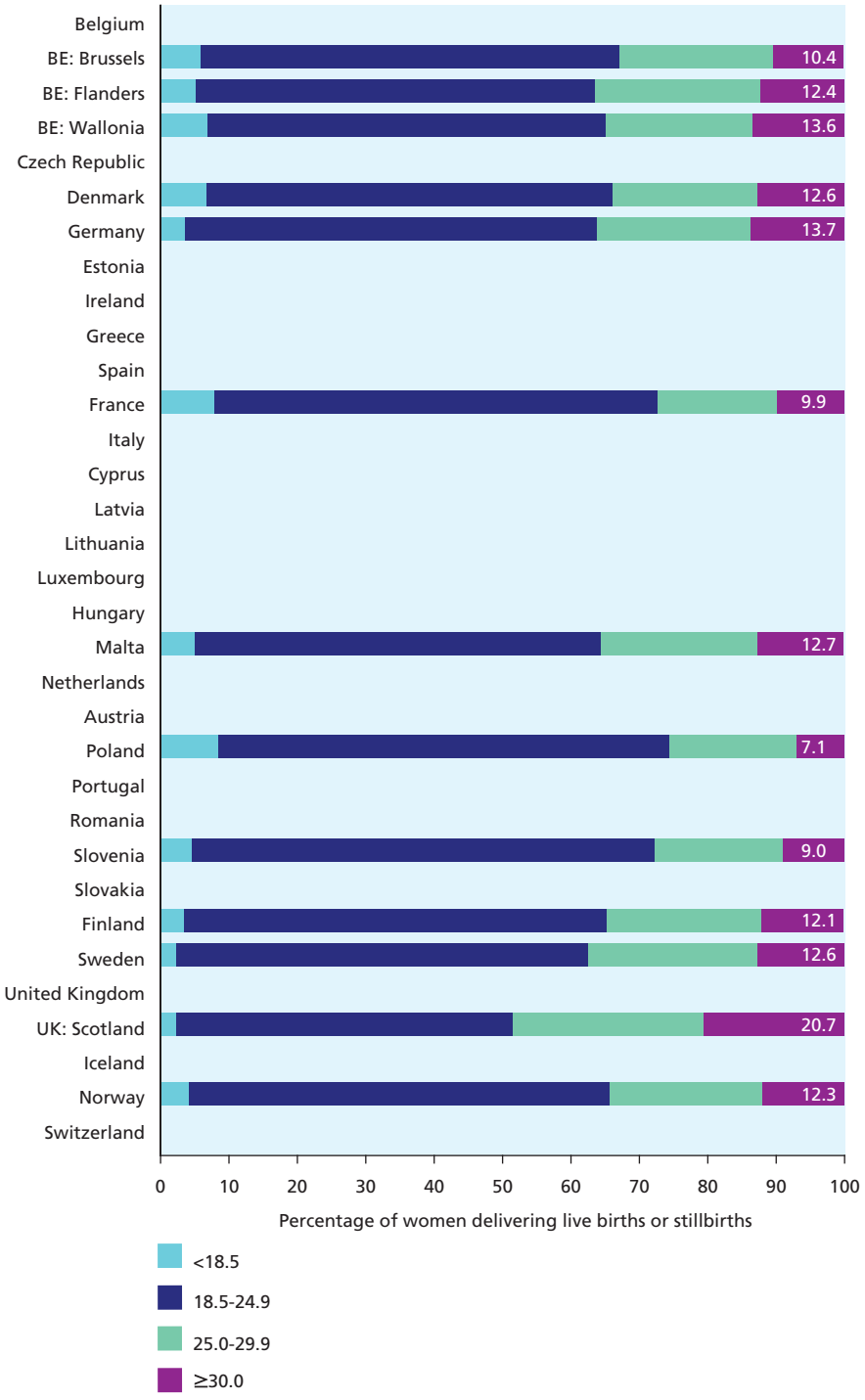
Figure 4.9 Distribution of maternal prepregnancy body mass index (BMI) in 2010



5

THE CARE OF PREGNANT WOMEN AND BABIES DURING PREGNANCY AND THE POSTPARTUM PERIOD

5. THE CARE OF PREGNANT WOMEN AND BABIES DURING PREGNANCY AND THE POSTPARTUM PERIOD

CORE

Mode of delivery according to parity, plurality, presentation, previous caesarean section, and gestational age (C10)

RECOMMENDED

Percentage of all pregnancies following treatment for subfertility (R13)
Distribution of timing of first antenatal visit (R14)
Distribution of births by mode of onset of labour (R15)
Distribution of place of birth by volume of deliveries (R16)
Percentage of very preterm births delivered in units without a NICU (R17)
Episiotomy rate (R18)
Percentage of births without obstetric intervention (R19)
Percentage of infants breast fed at birth (R20)

The development of systematic reviewing and the promotion of the concept of evidence-based health care in the field of maternity care began in the late 1980s. The tradition of evaluating medical practices and working to find a balance between insufficient or excess intervention might have been expected to lead to similarities between the patterns of maternity care in Europe. However, Euro-Peristat and other European projects have documented wide diversity in approaches to providing care during pregnancy and the postpartum period. The indicators in this section were devised to allow comparison of key components of care for mothers and babies in order to document these differences and make it possible to relate them to health outcomes. The indicator on births without obstetric intervention will be issued when the full Euro-Peristat tables are released in October as this indicator requires more detailed subgroup analyses.

This section contains one core indicator and 8 recommended indicators. The core indicator is presented first, while the recommended indicators are organised following the chronological pathway through pregnancy, delivery, and the postnatal period. Since the previous report, we have separated the indicator on trauma to the perineum into 2 indicators, one, classed under maternal health, relates to tears to the perineum and the other, presented in this section, pertains to episiotomies, which are obstetric interventions rather than health outcomes.

Pregnancy is not an illness, but a physiological process associated with health risks for some women and babies. When all pregnant women have access to comprehensive prenatal care and deliveries are attended by qualified medical personnel, as is the case in European countries, most women and newborns will not experience complications. A major concern is to guarantee an adequate level of medical safety for this group while avoiding overmedicalisation of the pregnancy and, in particular, procedures with side effects. In addition to data on care for babies at highest risk (R17 on births in units without a NICU), the indicators in this section provide information about the care of the general population of pregnant women and babies. By collecting data on interventions by subgroups defined by levels of risk, we aim to provide more relevant data for evaluating practices with respect to the current scientific evidence about effectiveness.

C10 MODE OF DELIVERY

JUSTIFICATION

The substantial rise in obstetric intervention since the 1970s in most developed countries is a long-standing and continuing cause for concern.[1-3] Consequences of the rise in caesarean rates in both high and middle income countries include elevated risks of placenta accreta, placenta praevia, placental abruption, and stillbirth in subsequent pregnancies. Data from the Organisation for European Co-operation and Development (OECD) show a continuing rise in caesarean rates in most member countries, despite signs of flattening in a few countries with high rates.[3] Several factors have been cited as possible explanations for this increase, including fear of litigation, financial incentives related to methods of payment,[4] women's requests for caesarean births,[5] and the perception that a caesarean section is a safe procedure.[6]

Countries also vary in their use of operative vaginal delivery, either with forceps or vacuum extraction.[2] In addition to wide variations between countries, operative delivery rates also vary by parity, previous caesarean section, presentation, and plurality, so comparisons of methods of delivery according to each of these factors can be informative. Because operative delivery, especially caesarean section, may increase the risk of repeated operative delivery in subsequent pregnancies, it is useful to compare caesarean section rates among primiparous women, especially as their complication rates are higher than those of women who have already given birth.

In some specific situations, the need for intervention is clear. For others there is ongoing debate, for example, about the use of caesarean section for breech presentation, multiple births, and women with a previous caesarean section. This lack of consensus means it is useful to highlight differences in practices by comparing rates of operative delivery by presentation and plurality, as well as rates of repeat caesarean sections.

DEFINITION AND PRESENTATION OF INDICATOR

This indicator was defined as the percentage distribution of all births, live born and stillborn, by method of delivery for all women and then subdivided by parity, previous caesarean section, presentation, and plurality. Data were also requested for caesarean sections as a percentage of births at grouped weeks of gestational age. Summary tables presented in this report are restricted to overall rates. Rates by subgroup will be made available when the full set of tables is issued on the Euro-Peristat website.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Countries differ in the ways that they classify caesarean sections. Some countries subdivide them according to whether they were undertaken before or during labour. Others use the subdivision into elective caesarean sections, which include all those planned before the onset of labour and thus include a few that take place after labour has started, and emergency or unplanned caesarean sections. Sometimes, as in the Scottish Audit of Caesarean Section, emergency caesarean sections include those performed before the onset of labour in response to a clinical emergency.[7] In Poland, Portugal, England, and Wales, rates were reported per woman. This may result in slight underestimates of operative deliveries, as multiple births to one woman are counted only once.

DATA SOURCES AND AVAILABILITY OF INDICATOR

Method of delivery was available for everywhere except Greece. Data about whether caesarean sections took place before labour or were elective were not available for Ireland, Spain, Catalonia, Lithuania, Luxembourg, Hungary, Austria, Poland, Portugal, Iceland, Slovakia or Switzerland. In Spain, national data refer to public hospitals only.

RESULTS

Cyprus had the highest overall caesarean rate, at 52.2%, followed by Italy with 38.0%, Romania with 36.9%, and Portugal with 36.3%, as Figure 5.1 shows. In Spain, data came from public hospitals. The inclusion of private hospitals increased the national total from 22.2% to 25.3%; however, data on instrumental deliveries were not available for public and private hospitals combined. Germany, Hungary, Luxembourg, Malta, Poland, and Switzerland also had rates of 30% or higher. Everywhere else, rates were below 30%. Only the Netherlands, Slovenia, Finland, Sweden, Iceland, and Norway had rates below 20%. There was no clear inverse correlation with rates of instrumental vaginal delivery. These exceeded 10% in Ireland, Flanders, Spain, France, Luxembourg, the Netherlands, Portugal, Wales, England, Scotland, Northern Ireland, and Switzerland. In contrast, they accounted for fewer than 2% of deliveries in the Czech Republic, Latvia, Lithuania, Poland, and Romania, and at least 2% but fewer than 5% in Estonia, Italy, Cyprus, Malta, Slovakia, and Slovenia.

For the countries with available data, caesarean section rates were subdivided into those undertaken or at least planned before labour and those decided upon and undertaken, or simply undertaken, after the onset of labour; they are shown in Figure 5.2. Rates of caesarean sections that were planned or undertaken before labour varied less between countries, except in Cyprus and Italy where nearly 40% and 25% of births, respectively, were elective caesareans. Romania had the highest rate of caesarean sections performed during labour.

Figure 5.3 displays the geographic distribution of caesarean section rates, illustrating similarities in practice between neighbouring countries, as in eastern Europe (higher rates) and the Nordic countries (lower rates).

CHANGES FROM 2004 TO 2010

Apart from a slight reduction in Finland and Sweden, caesarean section rates rose everywhere between 2004 and 2010, as shown in Figure 5.4, which orders countries by their 2004 rates. We see that increases occurred among countries with both high and low levels of caesareans in 2004. Increases ranged from under 0.2% in Italy to over 7% in Lithuania, Slovakia, and Poland. In general, increases were most marked in the countries of eastern Europe and in Germany and Austria.

KEY POINTS

Data about mode of delivery show marked variations, with relatively low levels of interventions in Slovenia, the Nordic countries, and the Netherlands, and higher levels in the more southern countries, most notably Cyprus, as well as Italy, Malta, Portugal, and Romania. There were considerable differences in the relative contribution of caesarean sections and operative vaginal deliveries to the overall rate of operative births. Equally marked differences were apparent between rates of caesarean sections where the decision was made or the caesarean undertaken before labour. These differences in practices raise questions about clinical effectiveness and the role of evidence.

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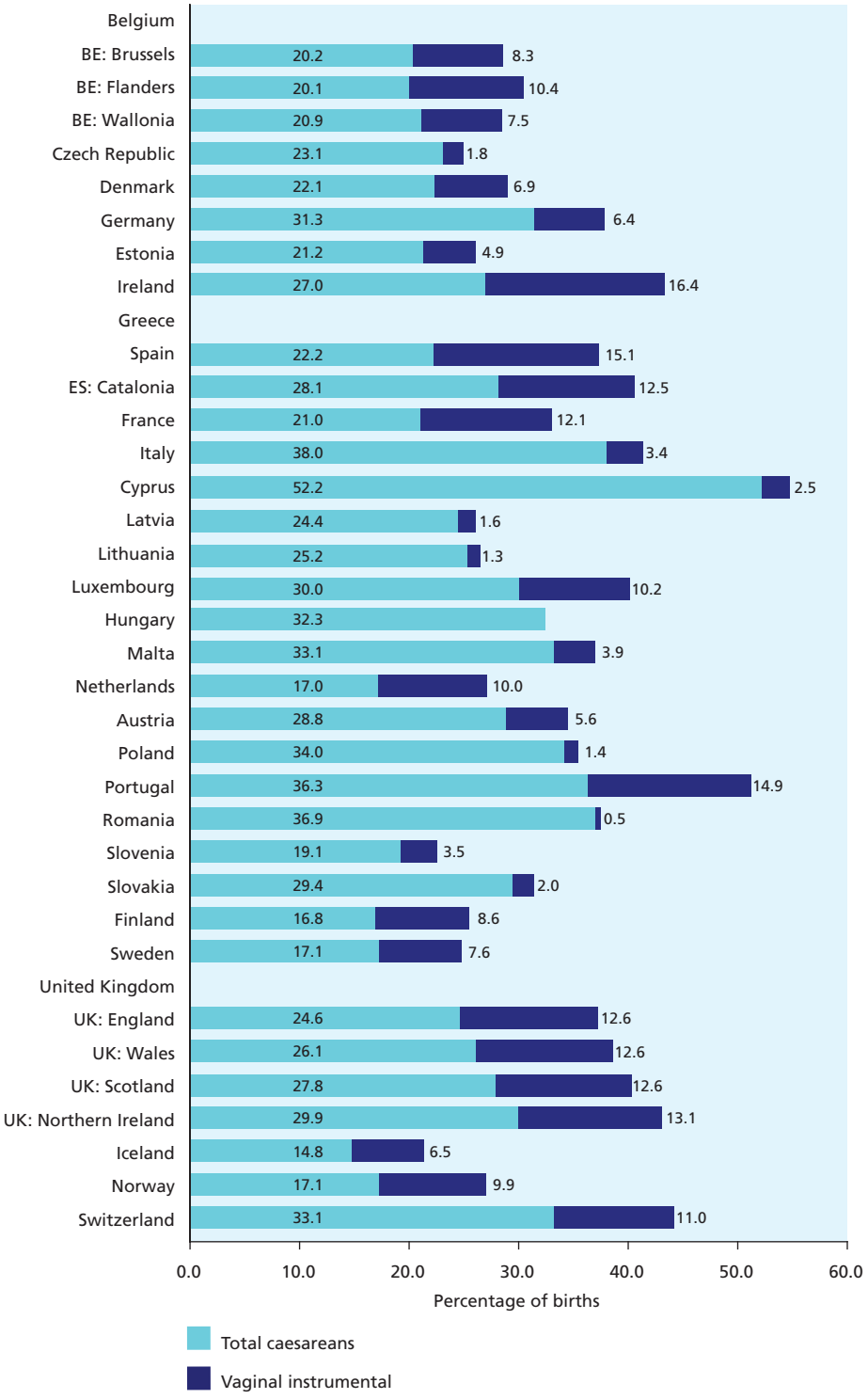
Figure 5.1 Percentage of births by mode of delivery in 2010



NOTE: for Spain, percentages refer to public hospitals only.

Figure 5.2 Percentage of births by type of caesarean section in 2010

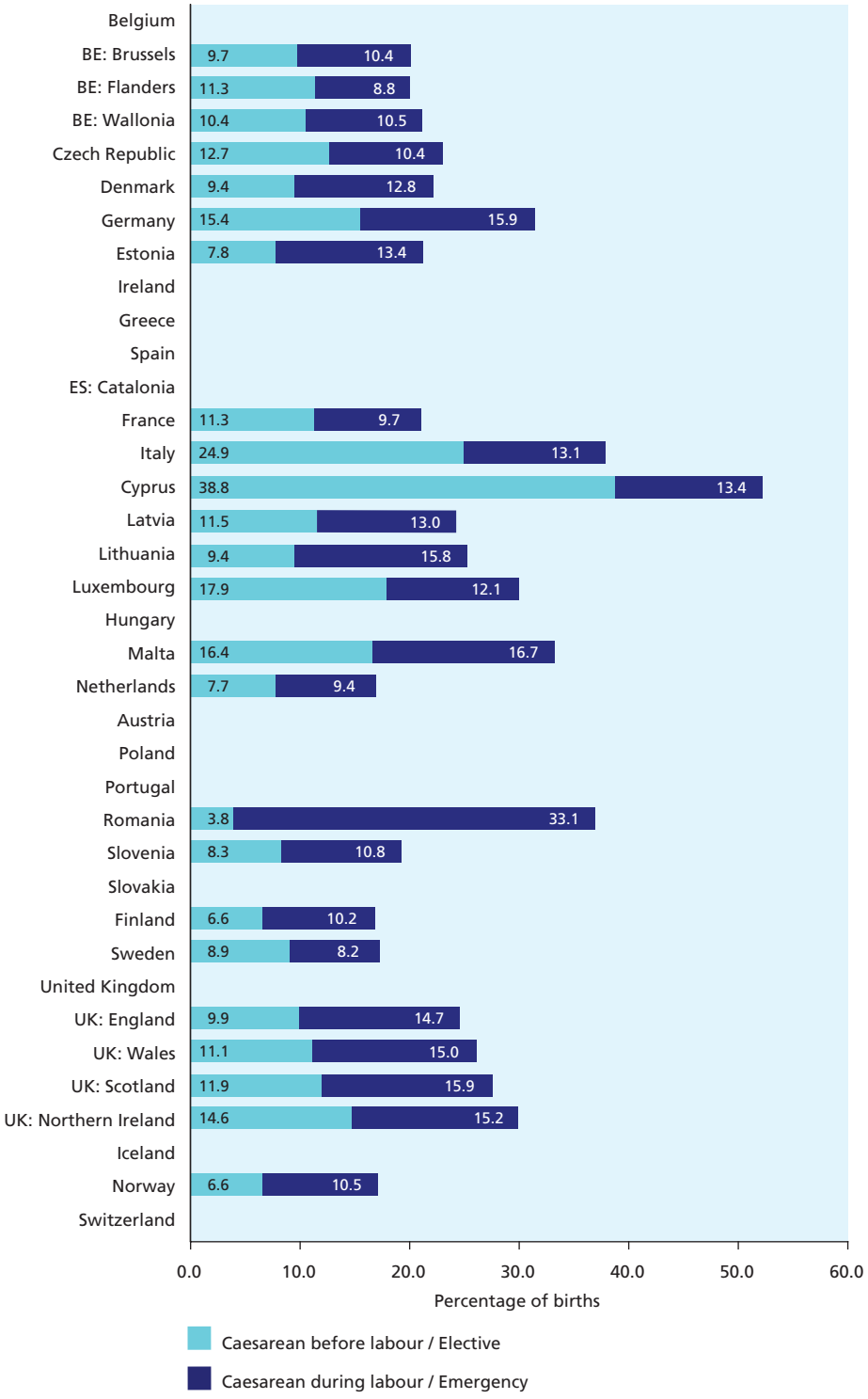
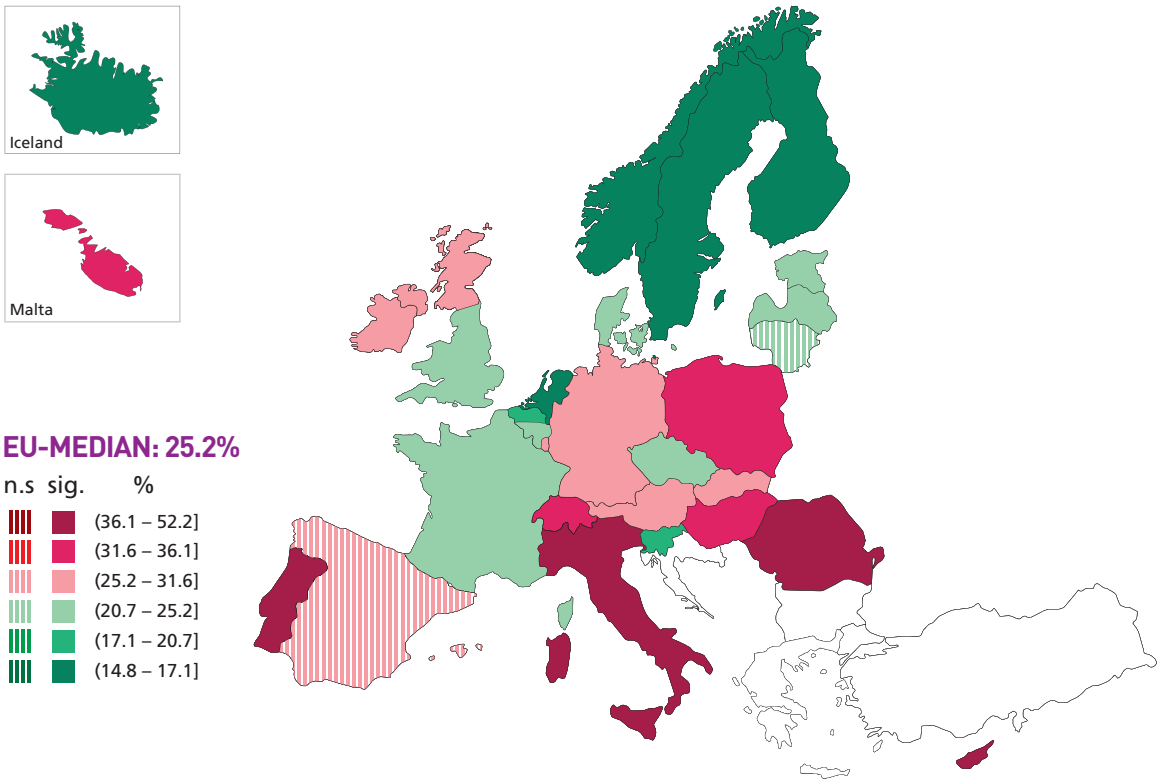
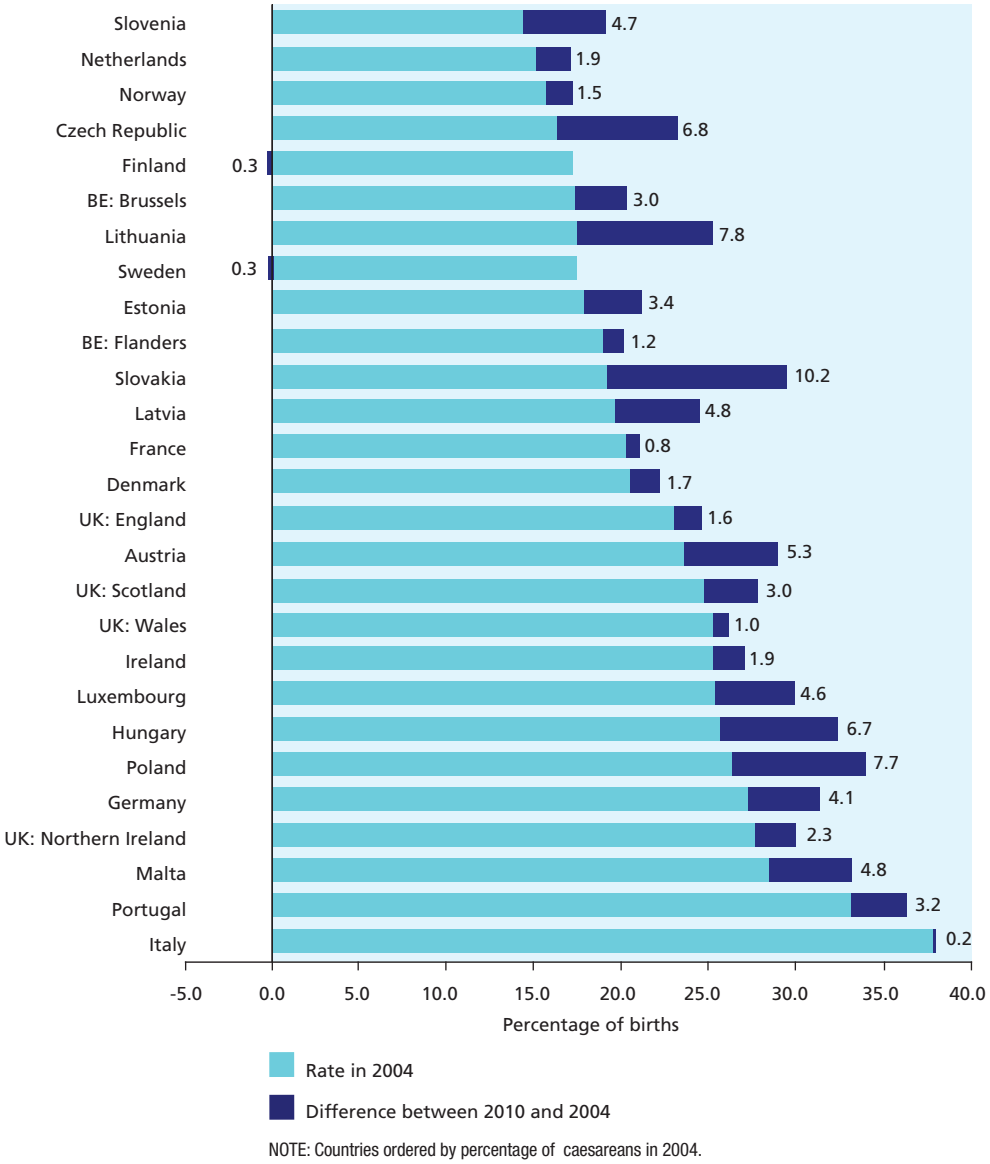


Figure 5.3 Caesareans as a percentage of all births in 2010



NOTE: Rates for countries and regions are coloured for groups defined by the 10th, 25th, 50th, 75th, 90th, and 100th percentiles of the indicator. Individual regions are coloured to show sign and significance of difference from the EU median. Regions that fall outside the 99% Wilson-score control limits of a funnel plot constructed around the EU-median against population size differ significantly (sig) and are shown as solid colours. Regions within the control limits (n.s.) are displayed with vertical hatching.

Figure 5.4 Percentage of births by caesarean section in 2004 and change 2004-2010



NOTE: Countries ordered by percentage of caesareans in 2004.

R13 PREGNANCIES FOLLOWING SUBFERTILITY TREATMENT

JUSTIFICATION

Although the percentage of all births that result from the use of assisted reproductive techniques (ART) is low, these births are the subject of great interest in many countries. This percentage is likely continue to increase as a result of demographic changes, notably the rising age at childbirth as a consequence of delayed childbearing (see C8), and of new developments in ART. Children conceived using ART have a higher risk of some adverse outcomes compared with children conceived spontaneously.[1-3] They tend to have higher rates of perinatal death, preterm birth, low birth weight, and congenital anomalies.[1-5] These techniques are also more likely to result in multiple pregnancies, unless single embryo transfer is used (see C7).[1,5] It is still unclear whether the observed higher rates of adverse outcome are associated with factors related to the

assisted conception procedures themselves, to factors related to the parents' subfertility, or to a combination of both.[6,7]

DEFINITION AND PRESENTATION OF INDICATOR

ART are defined as: (i) ovulation induction, (ii) intrauterine insemination with or without ovulation induction; or (iii) in vitro fertilisation (IVF), which may include intracytoplasmic sperm injection, in vitro maturation, and frozen embryo transfer. Figure 5.5 presents the numbers of women with live births or stillbirths after ART as a percentage of all women with liveborn or stillborn babies.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

Nineteen countries and regions were able to provide some data for this indicator. Sixteen countries or regions provided data for IVF, 7 for intrauterine insemination, 11 for ovulation induction, and one region for intrauterine insemination and ovulation induction combined. Cyprus and Malta provided combined data for all treatments. Only France, Luxembourg, the Netherlands, Slovenia, Finland, and the United Kingdom had data for all types of assisted reproduction.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

The data for France came from a representative survey where all women were asked a question about the use of these techniques. In other countries, this item is included in some medical birth registers, which probably contributes to lower estimates. Few countries have specialist registers to cover all or some ART. Where they do exist, as in the United Kingdom, links with data recorded at birth may be limited.

The major problem with this indicator is that it is difficult to know whether the relevant information is systematically collected for all pregnancies or is noted only when the birth attendants are aware that ART were used. This problem is particularly acute for the less invasive procedures, such as ovulation induction or intrauterine insemination, because the midwife or the obstetrician managing the delivery is less likely to be aware of them. When women are asked about these procedures at delivery, they may be hesitant to report their use. A related problem is the proportion of missing data. Brussels, France, and Cyprus reported missing data rates between 5% and 10%, and the Netherlands a rate of 29.4%. Seven countries reported no missing data. The absence of missing data might indicate either that data were recorded for all women or that women without this information were assumed not to have used ART. Only 4 countries and regions rated their data as good (Estonia, Finland, Flanders, and France), 12 had concerns with the quality of their data (Brussels, Cyprus, Germany, Hungary, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Norway, Slovenia, and Switzerland).

RESULTS

In all, 5.7% of women giving birth in Flanders, 5.2% in France, 4.1% in Luxembourg, 4.0% in the Netherlands, 3.5% in Finland, and 2.8% in Slovenia became pregnant after some form of ART. In Belgium, the proportion of IVF children was about 3.5 to 3.8% in the 3 regions. In Iceland, this proportion was 3.6%. The proportion was between 2% to 3% in Norway, Luxembourg, Slovenia, Finland, France, and Estonia, and between 1% and 2% in Switzerland, the Netherlands, and the UK. For Hungary and Latvia, this proportion fell to below 1%. For all countries and regions with comparable data in 2004 and 2010, the proportion of IVF children increased by 0.4% (Slovenia and France) to 1.4% (Estonia), excluding the Netherlands which showed a decrease of 0.1%, most likely due to under-reporting.

The percentage of births following intrauterine insemination was 0.9 to 1.3% in the Netherlands, France, and Luxemburg, 0.6% in Finland, 0.3% in Italy, and 0.1% in Slovenia. The percentage of OI births following ovulation induction was 2.3% in France and 1.2% in the Netherlands, between 0.6% and 1% in Brussels, Luxembourg, and Finland, and below 0.5% in Lithuania, Slovenia, Wallonia, and Norway.

KEY POINTS

Up to 5 to 6% of births in some countries may occur after use of some form of ART, although the use of the less invasive procedures appears to be under-reported in most data systems. Births after IVF account for 2 to 4% of all births. These data corroborate the volume of ART services as collected by the European Society of Human Reproduction and Embryology (ESHRE) from fertility clinics. The number of treatments started in 2008 was highest per woman of reproductive age in Belgium, the 5 Nordic countries, and the Czech Republic, above the European average in Estonia, the Netherlands, and Germany, and under the European average in the United Kingdom, Italy, Austria, Portugal, and Romania.[6]

To evaluate health services provided to couples with difficulties conceiving, member states should consider implementing population-based systems to record all types of subfertility management including the numbers of couples/women, the management and procedures they undergo, and the outcomes in terms of clinical pregnancies, live births, and stillbirths.

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Figure 5.5 Percentage of women with live births and stillbirths in 2010 following treatment for subfertility.

NOTE: In Flanders, ovulation induction and intrauterine insemination+ovarian induction combined. Cyprus data combines all available treatments.
The Netherlands had serious concerns about the quality of this data.
IVF: in vitro fertilisation; ICSI: intracytoplasmic sperm injection; IVM: in vitro maturation; FET: frozen embryo transfer.

R14 TIMING OF FIRST ANTENATAL VISIT

JUSTIFICATION

Promoting antenatal care and defining its content are central components of maternal and child health policy in all European countries. They all cover the costs of a prenatal care package and some include incentives for pregnant women to use these services. The aim is to screen for potential complications in the pregnancy and to prevent and treat them. However, the evidence base concerning the optimal quantity and content of antenatal care is far from clear. In Europe, despite enormous variability in what constitutes basic prenatal care during pregnancy,[1,2] there is a general consensus that it should begin early. Ideally, when the pregnancy is planned, a preconceptional visit is considered desirable, to ensure folic acid supplementation and counselling or any necessary treatment. It allows for identification of specific medical conditions, such as previously unknown diabetes, social or mental health problems (such as intimate partner violence), and addictions to smoking or other substances in time for effective intervention. This preconceptual visit is being promoted systematically in some EU countries, including Hungary, Belgium, the Netherlands, and possibly more.[3] With or without preconceptional care, an early first antenatal visit has become the accepted standard for antenatal care.[4] It includes the items described in the preconception visit, accurate dating of gestational age, and information for women. Timing of the first antenatal visit is an indicator of access to antenatal care, which can be influenced by both maternal social conditions and organisation of care.[5] It is less likely to be affected by policy differences between member states than the recommended number of antenatal visits, which varies.

DEFINITION AND PRESENTATION OF INDICATOR

The indicator shows the distribution of timing of the first antenatal visit by trimester of pregnancy for all women with liveborn or stillborn babies. Trimesters are defined as follows: the first trimester is the period up to 14 weeks, the second trimester 15-27 weeks, and the third from 28 weeks to delivery. Summary Table R14 presents the distribution of the trimester of the first antenatal visit per 100 women with liveborn or stillborn babies; the distribution also includes women who received no antenatal care.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES; METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Nineteen countries and regions were able to provide information about trimester of initiation of antenatal care, as shown in Figure 5.6. Data were complete with few missing. It is not known what the content of this first visit might be. It is also possible that the first recorded visit may refer to the first visit with the mainstream antenatal care system, rather than the first health provider seen about the pregnancy. It might also refer to the "booking visit" or to the first ultrasound scan. Some countries provide data by trimesters that do not coincide with the Euro-Peristat definition.

RESULTS

Figure 5.5 describes the availability of data about the timing of the first antenatal visit and its distribution in European countries. Missing values vary between countries from 0% to 19%. Although the vast majority of women begin antenatal care during the first trimester, care begins in the second or third trimester for between 2% (Poland) and 33% (Malta) of all women. The largest number of countries reported between 4 and 7% of women with care after the first trimester (10 out of 19). The percentage of women with no antenatal care at all ranges from 0

to 2.8%. Some of this variation may be related to the differences in the manner that timing of antenatal care level is assessed. In particular, it is unclear how different countries count foreigners or recent immigrants who were not booked in their countries, arrived just around the time of birth, but did have antenatal care in their own country.

KEY POINTS

It is difficult to collect data about the first antenatal visit with medical birth registers because of the potential confusion between the first consultation with a health professional and the first visit to a hospital or maternity unit. Whether these first visits are recorded may also depend on the organisation of maternity care in the country. In general, recall bias is possible where data are recorded retrospectively. It is therefore important to record this information accurately during pregnancy. Between 2 and 36% of women begin care after the first trimester. Given the importance of starting care early in pregnancy, this raises questions about whether the most vulnerable women in each country have access to appropriate health care. Using this indicator in conjunction with educational level and country of birth could provide a useful basis for comparing the ability of healthcare systems to provide access to care for all pregnant women.

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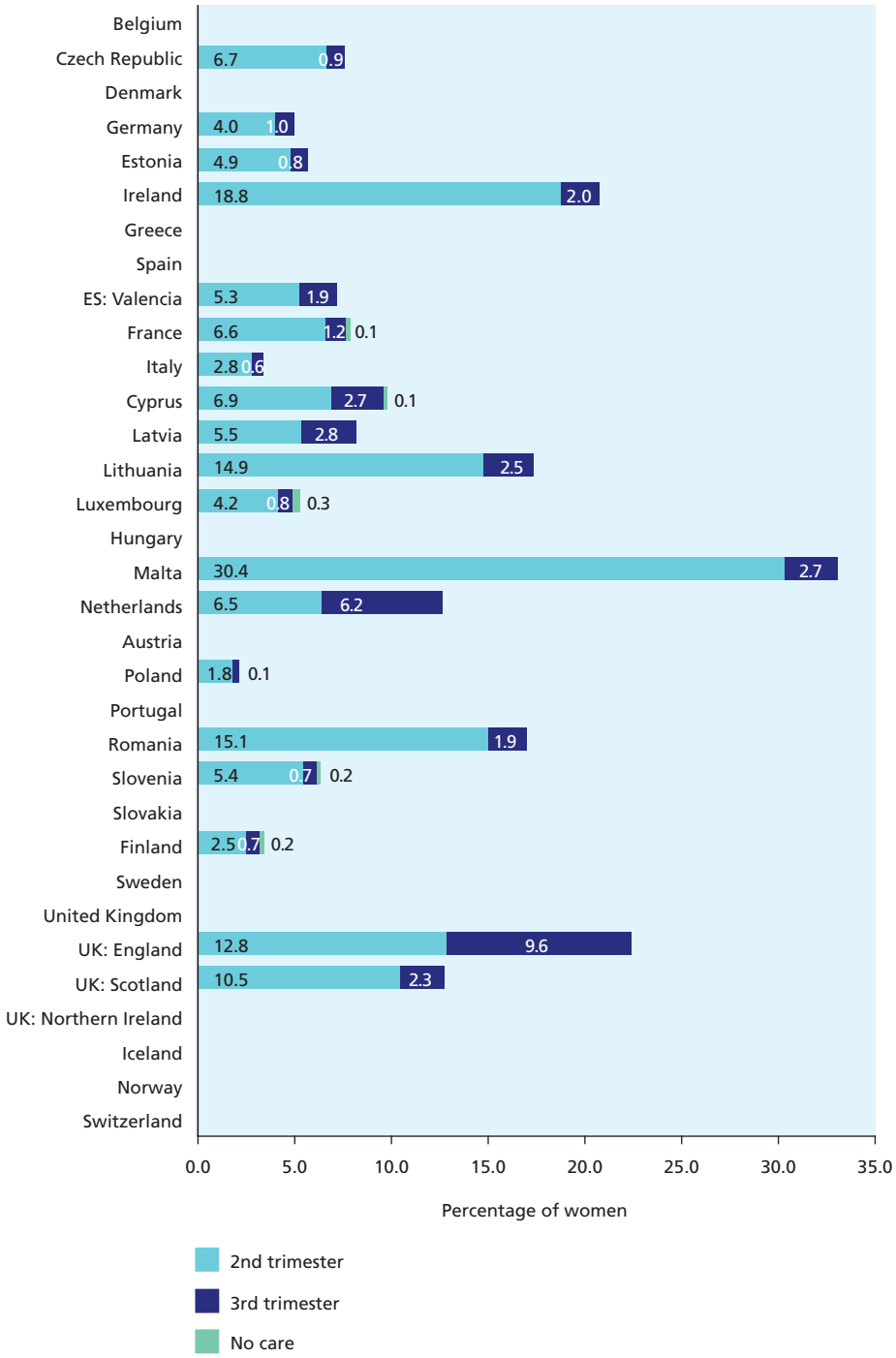
Figure 5.6 Distribution of initiation of antenatal care after the first trimester of pregnancy in 2010



NOTE: Data from Latvia refer to 2nd and 3rd trimesters combined.

R15 MODE OF ONSET OF LABOUR

JUSTIFICATION

There is widespread concern about the high rates of obstetric intervention, including inductions and caesarean sections, during labour and delivery; there is also growing pressure by women to avoid their unnecessary use. In the year 2000, about half of all caesarean sections in the 15 EU member states were planned or undertaken before the onset of labour.[1] Although these decisions were taken in the belief that they would benefit mothers and their babies, they might have had unintended side effects and may have led to subsequent interventions in labour and delivery. There is no evidence that a high rate of induction of labour increases the risk of delivery by caesarean section, either among term or post-term deliveries,[2,3] provided, however, that they are undertaken in accordance with good practice guidelines.[4] Data about the onset of labour are essential to the interpretation of data about mode of delivery (see C10).

DEFINITION AND PRESENTATION OF INDICATORS

Mode of onset of labour is described by the numbers of babies (per 100 live births and stillbirths) born after spontaneous onset of labour, induced labour, and caesarean section, either planned or undertaken before labour. Countries differ in the ways that they classify caesarean sections. Some countries subdivide them according to whether they were undertaken before or during labour. Others use the subdivision into elective caesarean sections, which include all those planned before the onset of labour and thus include a few that take place after labour has started, and emergency or unplanned caesareans.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

Mode of onset was available for 25 countries or regions. Records from Spain come from Valencia, and include data about induction only. There were some inconsistencies with data provided about mode of delivery. For some countries, such as Lithuania and Scotland which record caesarean section as elective versus emergency, this is due to inclusion of emergency caesarean sections in the no-labour category in addition to elective caesareans. Other countries which use the classification of elective-vs-emergency do not collect data on whether emergency caesareans were done before labour. Data about mode of onset of labour were collected for singletons and twins and by gestational age; data were not collected for triplets in some countries, nor for cases with missing gestational age data. Accordingly, the numbers of total births differ slightly from those reported for indicator C10.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

The definition of induction may vary between countries or even between maternity units within the same country, according to the use and timing of the procedures. In some places, induction includes the use of drugs for cervical ripening and oxytocin for induction. In other places, including Malta, Norway, England and Wales, and Scotland, artificial rupture of membranes is also included. These differences may have a significant impact on rates: in England, in the financial year 2010-11, labour was induced with oxytocics in 16.8% of cases, and in a further 4.5% by artificial rupture of the membranes alone.[5] There is also some uncertainty about whether these data include other uses of oxytocics, including for augmentation of labour. This misclassification can occur if augmentation is not recorded separately.

Countries also differ in the ways that they classify caesarean sections. Some subdivide them according to whether they were undertaken before or during labour. Others use the definition of elective caesarean section, which include all those planned before the onset of labour and

thus include a few that take place after labour has started. For example, the Scottish Audit of Caesarean Sections in 1994 explained that caesarean sections that had been scheduled as elective but were carried out as an emergency after the woman went into labour unexpectedly were still categorised as elective. This answer was intended to clarify why some elective caesareans were done at night as about 5% of all elective caesarean sections were undertaken between 18.00 and 9.00.[6]

RESULTS

Figure 5.7 shows that the rate of caesarean sections planned or undertaken before labour varied widely, ranging from under 7% in Finland and Iceland to over 17% in Italy, Estonia, Lithuania, Luxembourg, and Cyprus. Variations in the rate of induced labour were also wide, ranging from 6.8% in Lithuania and 8.3% in Latvia to 33.0% in Wallonia, with rates under 10% in the Baltic countries and the Czech Republic to over 27% in Brussels (Belgium), Malta, and Northern Ireland (UK). Only 3 of the 25 regions or countries for which complete data were available had spontaneous onset of labour in more than 75% of cases.

KEY POINTS

The fact that most countries record the onset of labour points to the importance attached to this indicator in Europe. The impact of the difference between caesarean section before labour and elective caesarean section seems small compared to the substantial differences between countries in their overall caesarean section rates. Decisions taken before labour about caesarean sections are therefore likely to have a strong influence on the overall rate, as there is no evidence in Figure 5.2 or elsewhere that high rates of planned or prelabour caesarean section are offset by low rates of caesareans during labour.[7] The definition of induction must be harmonised within and across countries, and induction and augmentation should be clearly distinguished to improve the rigour of comparisons between countries, especially in cases of inductions without well-established indications.

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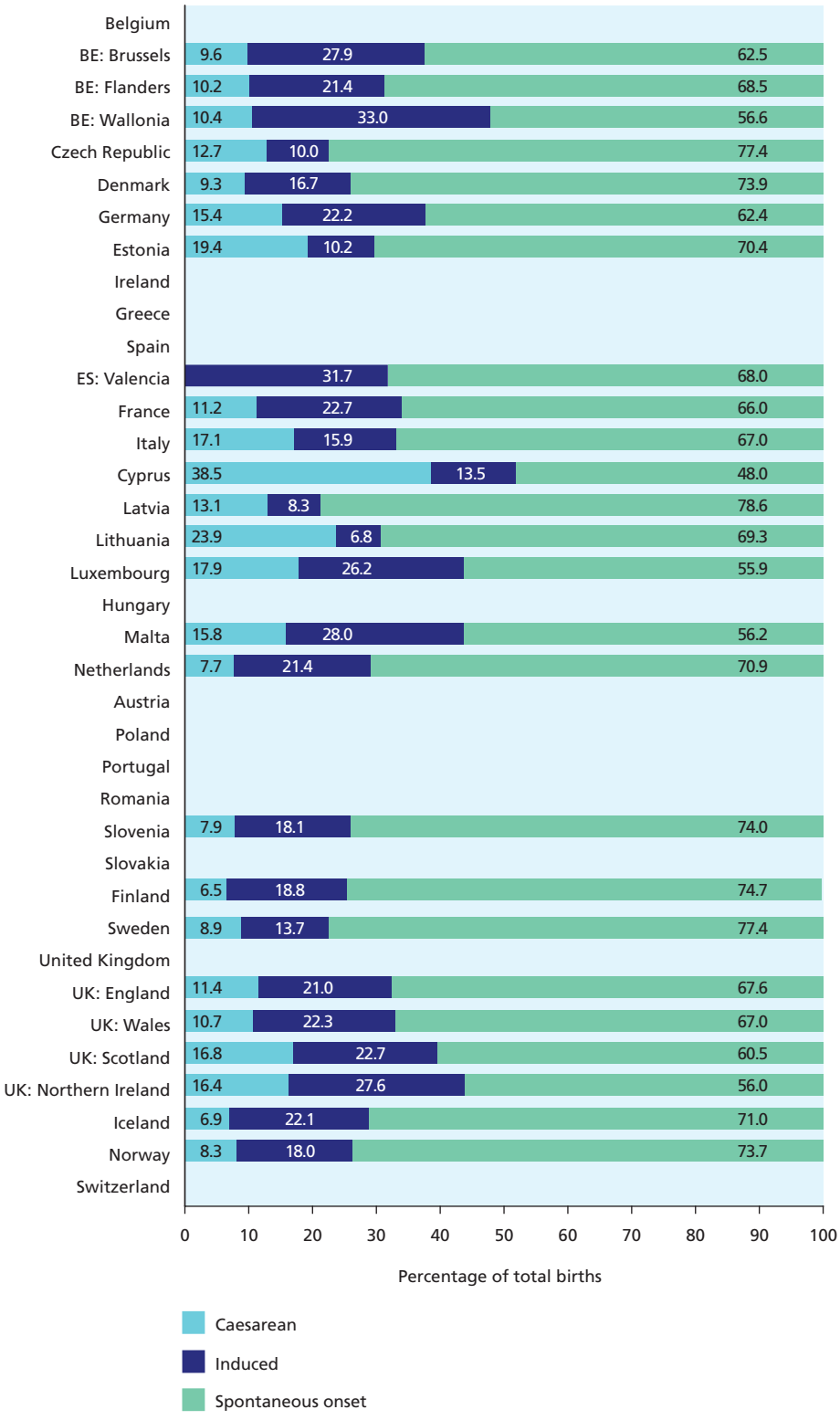
Figure 5.7 Distribution of mode of onset of labour in 2010



NOTE: Valencia in Spain did not have data on caesareans before labour.

R16 PLACE OF BIRTH BY VOLUME OF DELIVERIES

JUSTIFICATION

An indicator presenting data on the number of births per maternity unit is important for monitoring the impact of maternity reconfigurations and unit closures, which are occurring throughout Europe. Further, differences in the size of populations and population density affect the organisation of maternity services. There is also an ongoing debate about the association between the size of maternity units and quality of care, although it can be misleading when it ignores the types of care offered. In contexts where small units provide midwife-led care for women at low risk of obstetric complications within an organisation that has facilities for transfer to units providing the full range of obstetric care if complications arise, results appear positive; that is, there is a growing body of evidence that midwife-led units provide similar outcomes for babies combined with lower levels of obstetric intervention and morbidity for their mothers, compared with units offering obstetrician-led care.[1-3] However, these units depend on a well organised referral system as transfers during delivery for unexpected complications are common.[1]

On the other hand, the low volume of deliveries in very small units offering obstetric care may lead to suboptimal care for women with obstetric complications. For women and babies with complications, data about sizes of units should be interpreted in the light of information about regionalisation of care and arrangements for dealing with emergencies.[4,5] Very large units may offer better access to facilities for dealing with complications but may be unwieldy and impersonal. The concentration of births into larger units may also lead to longer travel time for pregnant women and thus possibly increase numbers of unintended out-of-hospital deliveries.[6,7] Units that provide care for a higher proportion of high-risk pregnancies may also mean more obstetric interventions for women without complications, although this has not been found everywhere.[1-3, 8-10] Other factors may be more important than size, however. For example, there is a tendency for intervention rates to be higher in the private sector, irrespective of hospital size.[11]

This indicator also includes information on home births. Although these are rare in most European countries, they are offered in the Netherlands and in the United Kingdom to women who are at low risk of complications.

DEFINITION AND PRESENTATION OF INDICATOR

This indicator describes the number of births occurring at home or in maternity units of various sizes and is defined by the total number of births in the same year at home, and in hospitals that had a total number of births in 2010 of less than 300, 300-499, 500-999, 1000-1499, 1500-1999, 2000-2999, 3000-3999, 4000-4999, or 5000 and over. These groups have been amalgamated in Figure 5.7 to illustrate the range of unit sizes. More detailed data on the distribution over the entire spectrum of unit sizes can be found in the summary tables in Appendix B. It was also possible to include births in an *other* category, which some countries used to classify births that take place in different types of structures. In the Netherlands and Switzerland, this category was used to describe midwife-led units.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

This information comes from birth registers, hospital discharge data, and perinatal surveys. Twenty-nine countries or regions provided data for this indicator. In the Czech Republic, data were provided for all units with 3000+ deliveries without distinction by size over this limit.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

When data collection systems are hospital-based, home births may not be included, so they may be undercounted. In some countries, such as Portugal and the United Kingdom, private maternity units do not contribute to data collection systems, although up to now the private sector has been very small in the UK. In England, Scotland, and Northern Ireland, data from civil registration are a source of data for births occurring at home, but they do not mention the initial intentions of women who planned to give birth at home but transferred to hospital in labour. Where systems cover the entire population, this indicator should be readily available and of good quality but must be interpreted, within the context of the referral system and levels of care, which are specific to each country (see R14 and R17). For instance, obstetric units may differ substantially in the level of services for pregnant women and babies with complications and in the choices they provide for women, for example, the availability of midwife-led units on main hospital sites.

RESULTS

Figure 5.8 presents the distribution of births by number of births in the unit as well as the proportion of home births. Overall, few births occurred in maternity units with fewer than 500 births in 2010, but this varied considerably by country. In Cyprus, 61.9% of births took place in units of this size, while in 10 countries, from 10 to 20% of births did. In Flanders, Wallonia, Germany, and Switzerland, over half of all births took place in units with 500-1499 births, and over a third of births in a further 6 countries took place in units of this size. At the other end of the size spectrum, more than a quarter of births in Denmark, Sweden, and England took place in units with more than 5000 births, while Slovenia, Latvia, Scotland, and Ireland had even larger proportions of births in units with more than 5000 births; in 14 countries or regions, more than a third of births took place in units with 3000 or more births.

Many countries reported that less than 1% of births took place at home. In England, this figure was 2.7%, in Wales 3.7%, in Iceland 1.8%, and in Scotland 1.4%. In the Netherlands, where home births have been a usual option for women with uncomplicated pregnancies, 16.3% of all births occurred at home. This is, however, a substantial change from 2004, when this proportion exceeded 30%. Women in the Netherlands now also have the option of giving birth in a birth centre (a homelike setting) under care of the primary midwife; there are 26 birth centres in the country and 11.4% of births occurred in them (corresponding to the *other* category in Figure 5.7). Almost all birth centres are adjacent to or in hospitals. In many regions where women can choose such a centre, it is no longer possible to give birth in the hospital under the care of a primary midwife. The *other* category also refers to birthing homes in Switzerland.

CHANGES SINCE 2004

Figure 5.9 shows changes between 2004 and 2010 in the percentage of births occurring in maternity units with 3000 or more births per year. In most countries, with the exception of Finland, the Valencia region of Spain, and Spain as a whole, births in large maternity units rose over this period. In France, Denmark, and Northern Ireland, these changes were substantial in relation to the initial levels of births in large units.

KEY POINTS

The organisation of maternity services varies greatly throughout Europe. Data for this indicator are available in most countries and can thus be used to monitor trends over time, but other contextual information is needed to interpret data about births in small units.
Comparisons of health outcomes, health practices, and costs of care in these contexts would provide insights into the advantages and disadvantages of the diverse models of organisation found in Europe.

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Figure 5.8 Distribution of births by maternity unit volume of deliveries in 2010

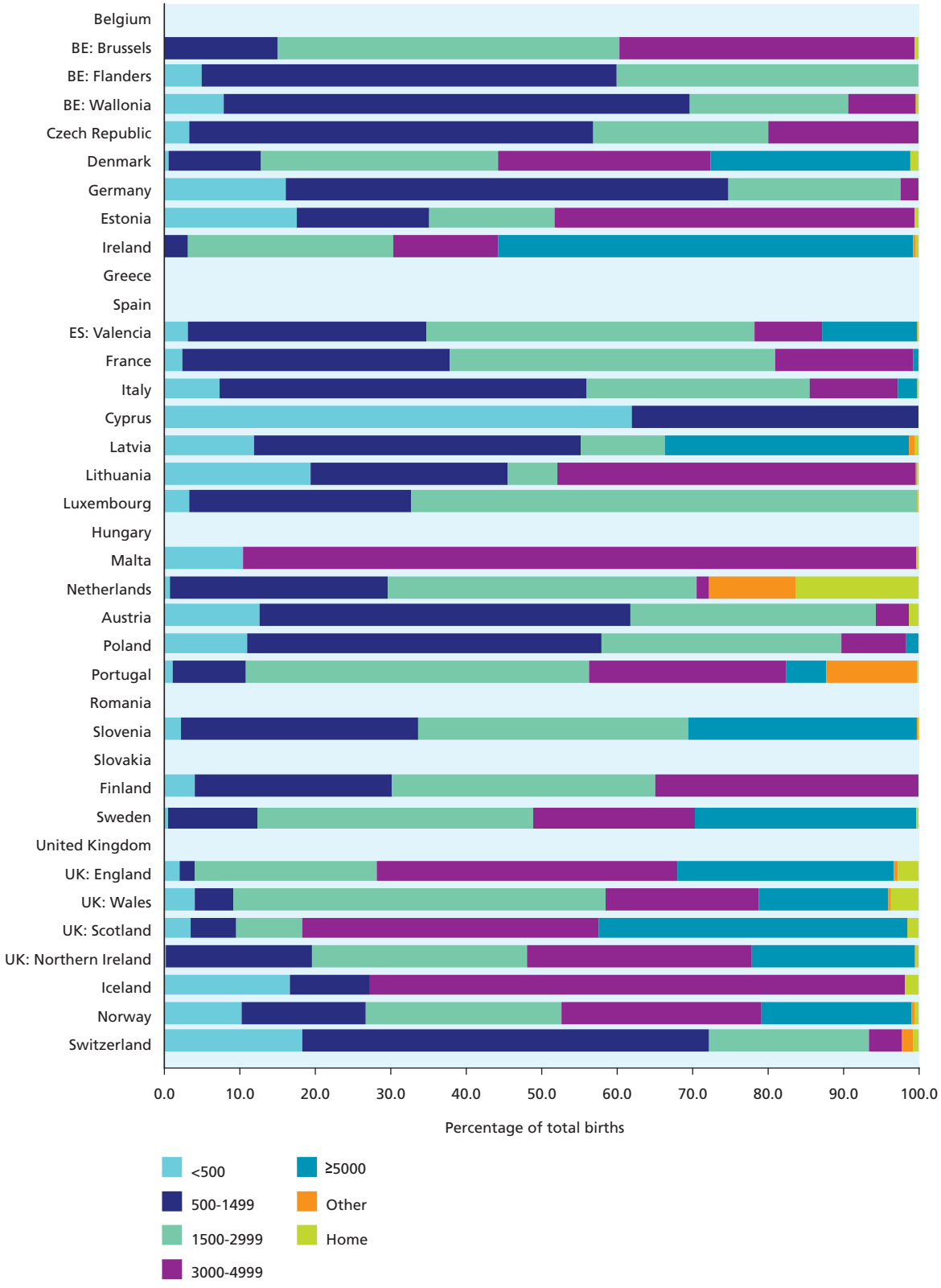
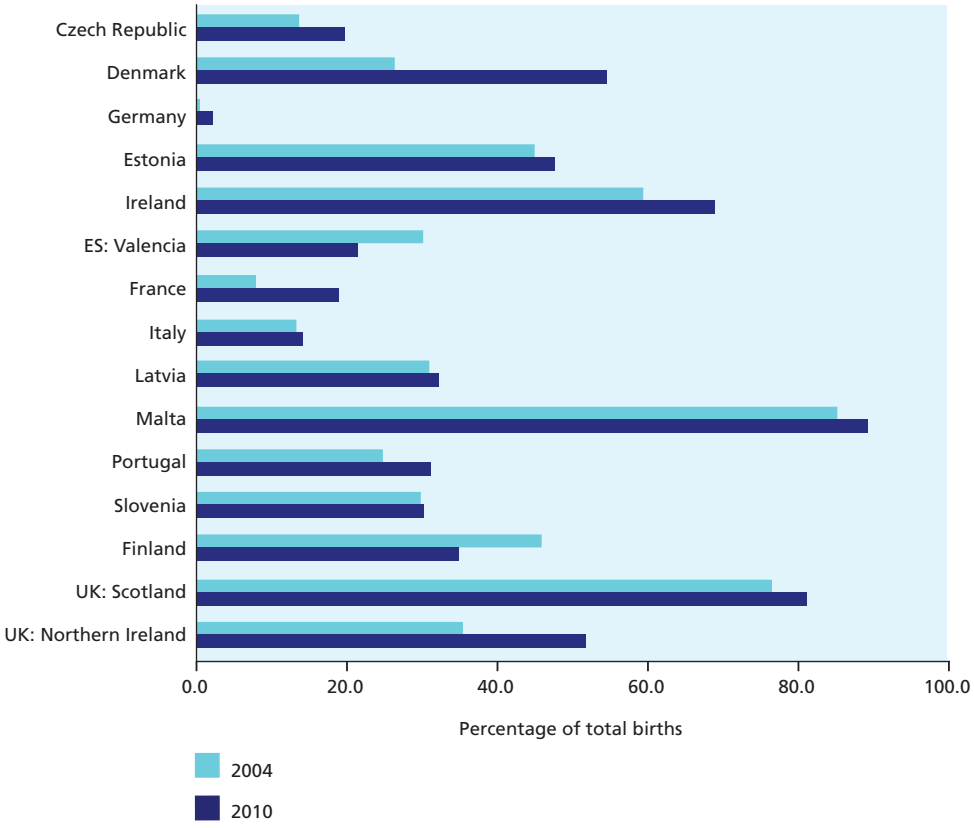


Figure 5.9 Percentage of births in units with 3000 or more births per year in 2004 and 2010



R17 VERY PRETERM BIRTHS DELIVERED IN MATERNITY UNITS WITHOUT AN ON-SITE NEONATAL INTENSIVE CARE UNIT (NICU)

JUSTIFICATION

About 1 to 1.5% of all births are very preterm, but these infants account for one third to one half of all neonatal deaths; between 5 and 10% of survivors develop cerebral palsy,[1] and babies without severe disabilities face risks of developmental, cognitive, and behavioural difficulties in childhood at least twice as high as babies born at or closer to term.[2] The delivery of these infants in maternity units with on-site neonatal intensive care (called level III units) is associated with lower mortality.[3,4] The organisation of care for these infants varies greatly in Europe, and these factors affect the proportion of deliveries that occur in these units.[5,6]

DEFINITION AND PRESENTATION OF INDICATOR

This indicator is defined as the proportion of all births (live born and stillborn) between 22 and 31 weeks of gestation delivered in units without an on-site NICU. Because there is no consensus definition of an "on-site neonatal intensive care unit", we collected and present these data based on local classifications of units.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES:

Sixteen countries were able to provide some data about this indicator, although in the UK and Belgium, coverage was not national. The 2 principal reasons for this failure are: 1) there is no agreed-upon classification for maternity units, and it is thus impossible to know what type of care they provide to very preterm babies, and 2) data are unavailable. In Germany, for instance, there are 4 levels of care (Level I perinatal centre, which corresponds to level III internationally, Level II perinatal centre, obstetric unit with perinatal focus, other obstetric unit), but a breakdown of births by these centres is not at present available on a national basis. The situation is similar in Poland.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

The principal difficulty in interpreting this indicator is the absence of a common definition of levels of neonatal care. While it is easy to agree on what constitutes a tertiary or regional centre with full neonatal intensive care facilities, many countries have intermediate levels of care which provide care to many, but not all, high-risk infants. These facilities are very heterogenous.

RESULTS

Table 5.1 provides information on the classifications of maternity units in European countries. This indicator makes it possible to determine whether countries have policies to define maternity units appropriate for the care of very preterm babies and whether information is routinely collected for evaluating these policies. Many countries have official classifications for specialised maternity units that provide on-site neonatal care. There is, however, significant variability in the classifications, especially the number of levels of care. In some countries, all maternity units appear to have a neonatal ward, but in others there are maternity units without on-site neonatal units. Some countries also have "intermediate" levels that provide some neonatal care for high-risk babies. Classifications of levels of care, even when they use similar labels (such as level I, II, and III), are probably not comparable, and the structures classified as most specialised undoubtedly have quite different characteristics in different countries.[6] This may explain in part the wide variation in the proportion of very preterm babies born in the highest level of care. This percentage ranged from about 20% to 100%.

KEY POINTS

Many, but not all, countries in Europe have clearly designated levels of care that make it possible to define specialised maternity units where high-risk babies should be born. Most of these countries also have data on their place of birth. The proportion of very preterm babies born in the most specialised units varies widely. It would be useful to develop a common European classification for maternity and neonatal units to facilitate monitoring the care of these high-risk babies. Whether these classifications exist or not, it is important for countries to be able to monitor where these high risk infants are delivered.

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Table 5.1 Percentage of very preterm babies born in the most specialised units as defined by national classifications of levels of care in 2010

	Classifications of levels of care					
Country/coverage	**Lowest level**	**I**	**II**	**Highest level**	**Number of births 22-31 weeks GA (N)**	**% born in Highest level**
Belgium						
BE: Brussels			Level II	Level III (MIC NIC)	338	93.5
BE: Flanders			Level II	Level III	910	77.6
BE: Wallonia			Level II	Level III (MIC NIC)	314	83.4
Czech Republic	Other hospital		Intermediate care perinatal Centre	Regional perinatal centre	1236	82.1
Denmark						
Germany						
Estonia	General hospital	Specialised hospital	Central hospital	Regional hospital	200	22.5
Ireland						
Greece						
Spain						
ES: Valencia	Without NICU			With NICU	452	88.1
France	Level 1	Level 2A	Level 2B	Level 3	219	69.9
Italy	Maternity, no neonatal unit		neonatal unit	NICU	5833	83.1
Cyprus (2007)	Non-NICU			NICU	114	24.6
Latvia	Level I	Level II		Level III	256	44.1
Lithuania		Level IIA without NICU	Level IIB- regional	Level III-university	345	75.7
Luxembourg	Maternity without NICU			Maternity with NICU	92	63.0
Hungary						
Malta	Maternity without NICU			Maternity with NICU	41	97.6
Netherlands	Home	In hospital, under midwife supervision	Maternity without NICU	Maternity with NICU	2582	65.8
Austria						
Poland						
Portugal		Level II-private	Level II – Perinatal support hospital	Level III – Differentiated perinatal support hospital	893	92.5
Slovenia		Level 2 no NICU, all other facilities		Level 3 with NICU	335	91.0
Slovakia						
Finland	Other hospital	Regional hospital	Central hospital	University hospital	559	84.3
Romania						
Sweden						
United Kingdom						
UK: Scotland	Community maternity unit with medical support+ GP Obstetrics	Community maternity unit	Obstetrician + co-located midwife-led unit	Obstetrician-led unit	809	55.0
Norway	Home/planned delivery	Midwife-led unit	Emergency obstetric care unit	University hospital	687	69.3
Switzerland						

NOTES: MIC: maternal intensive care; NICU: neonatal intensive care unit;
Portugal - number of deliveries of a live birth, not known for private level I units;
Unplanned deliveries out of hospital have not been included in this table;
Data from Cyprus are from 2007, and data from Greece from 2009.
In Italy, data do not include spontaneous fetal deaths under 26 weeks of gestation or TOPs.

R18 EPISIOTOMY RATE

JUSTIFICATION

The aim of an episiotomy is to prevent severe perineal tears. Its use became more common in the first half of the 20th century, with the move from home to hospital births and the greater involvement of obstetricians in maternity care.[1] Policies of routine episiotomy were instituted in some settings, particularly in the United States and Latin America, but also in Europe. This policy was called into question by a midwife-led trial in West Berkshire, England, in the early 1980s[2,3] and by others conducted elsewhere.[1] The routine use of episiotomies has also been questioned by women who want a more "normal" birth.

A Cochrane review to assess the effects of restrictive compared with routine use of this procedure during vaginal birth concluded that restrictive episiotomy policies appeared to have a number of benefits compared to its routine use.[1] It therefore seemed appropriate to compare the rates of episiotomy in Europe (see also indicator R7).

DEFINITION AND PRESENTATION OF INDICATORS

This indicator is defined as the percentage of women who delivered vaginally and had an episiotomy.

DATA SOURCES AND AVAILABILITY OF INDICATORS IN EUROPEAN COUNTRIES

Most of the data came from hospital databases. Episiotomy data were available for 26 countries or regions. Many countries have no missing data, but some data providers noted that it is not possible to distinguish between missing information and no episiotomy.

RESULTS

As shown in Figure 5.10, episiotomy rates varied widely: roughly 70% of vaginal deliveries in Cyprus, Poland, Portugal, and Romania, 43-58% in Wallonia, Flanders, the Czech Republic, and Spain, 16-36% in Wales, Scotland, Finland, Estonia, France, Switzerland, Germany, Malta, Slovenia, Luxembourg, Brussels, Latvia, and England. Rates were lowest in Denmark (4.9%), Sweden (6.6%), and Iceland (7.2%).

Between 2004 and 2010, for countries where comparable data were available, as shown in Figure 5.11, episiotomy rates decreased in many countries except the UK and the Netherlands. In general, countries where episiotomy rates were higher in 2004 experienced decreases over this period, whereas those with increases had lower rates in 2004.

KEY POINTS

The wide variation in the use of episiotomy illustrates the variability in medical practices that exists between the countries in Europe and raises questions how scientific evidence is integrated into clinical decisions. Episiotomy rates have fallen or stayed the same in many countries with data from 2004, with the exception of England, Scotland, and the Netherlands.

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Figure 5.10 Percentage of women who had episiotomies among women with vaginal deliveries in 2010

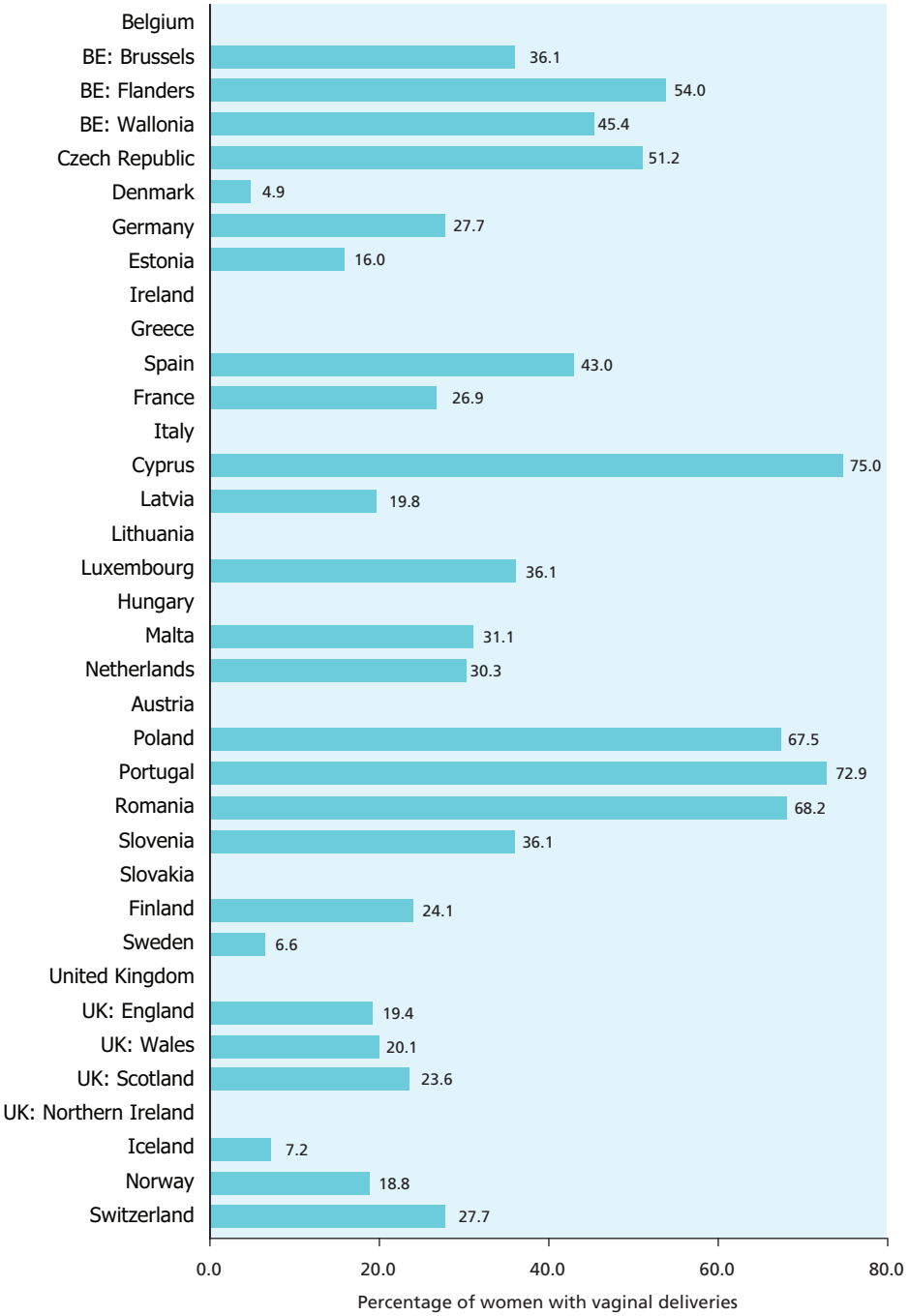
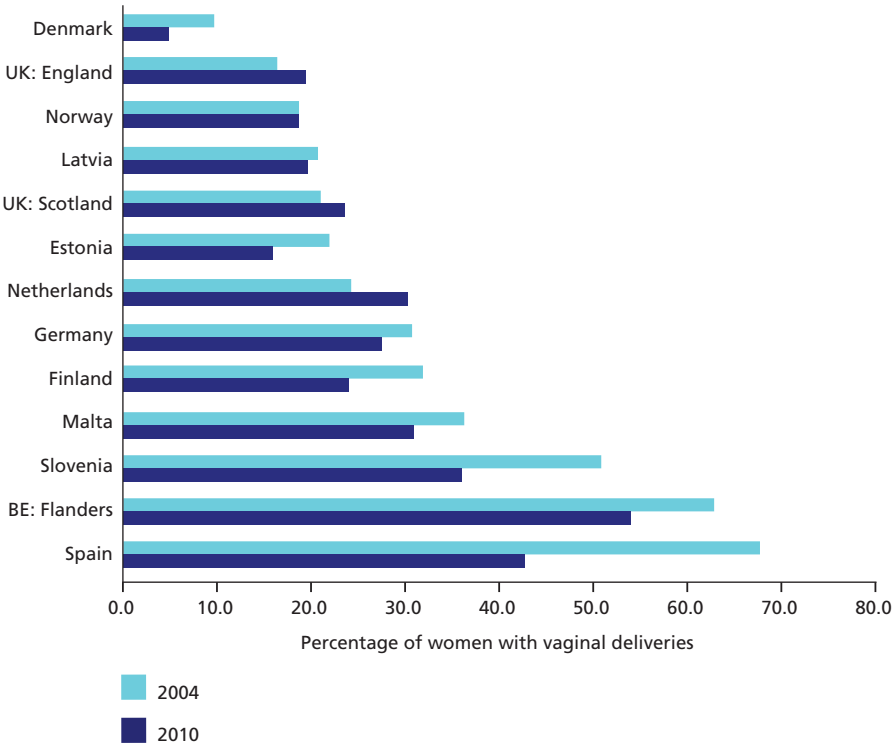


Figure 5.11 Episiotomy rates in 2004 and changes between 2010 and 2004 among women with vaginal deliveries



NOTE: Countries ordered by ascending episiotomy rates in 2004.

R19 BIRTHS WITHOUT OBSTETRIC INTERVENTION

(new indicator – to be published in October)

R20 BREAST FEEDING IN THE FIRST 48 HOURS AFTER BIRTH

JUSTIFICATION

Breast feeding is considered to provide benefits for mothers and babies including important nutritional advantages and improved resistance to infections for the latter. Breast feeding may also contribute to improved cognitive development and protect against chronic disease in adulthood.[1,2] Although recommendations about the length of time that breast feeding should continue vary substantially between and within countries, there is general agreement about its benefits for babies and thus about the importance of the initial postpartum intake.[3] Success of breast feeding during the first 48 hours after birth depends on public health policies and healthcare practices during pregnancy and in the immediate postpartum.[4-6]

DEFINITION AND PRESENTATION OF INDICATOR

Babies breast fed in the first 48 hours after birth are defined as: (i) the number of newborn babies who are exclusively breast fed (baby receives breast milk and is allowed to receive drops and syrups) or (ii) the number of newborn babies who receive mixed food (baby receives breast milk and is allowed any food or liquid including non-human milk), or it can be defined as its opposite (iii) the number of newborns who are not breast fed throughout the first 48 hours of age as a percentage of all newborn babies.[7]

Breast feeding in the first 48 hours after birth is presented as a percentage of all newborns. The summary table shows 3 percentages: percentage of babies who are exclusively breast fed, those who are mixed breast fed, and all babies who are either exclusively or mixed breast fed during the first 48 hours.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

Data on breast feeding at birth are available from 19 countries or regions, as shown in Figure 5.12; the Spanish data come from the Catalonia and Valencia regions. These data come mostly from population-based surveys and hospital discharge data, but some countries use health surveys after birth to collect these data. In Poland, data were obtained through a health survey in 2009, by home interviews. In Portugal, data were derived from a breastfeeding observatory that was set up recently and does not yet have widespread coverage; 55% of public hospitals are participating, and it covers term newborns from July 2010 to June 2011. In Switzerland, data come from the Baby Friendly Hospital Initiative and only include healthy term newborns in participating hospitals and birthing homes; the coverage rate is 38% of the live births and data refer to feeding during the hospital stay. In the UK, data for all 4 countries separately and for the UK as a whole came from the Infant Feeding Surveys carried out in 2005 and 2010. In the Netherlands, data came from a routine survey that asked only about exclusive breast feeding during the first 48 hours. In Poland, no distinction was made between exclusive and mixed feeding. Ireland provided data on type of feeding recorded at the hospital discharge or by a midwife attending a home birth.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

There may be differences in the period of breast feeding considered, even though the indicator specified feeding status in the first 48 hours. As data were derived from birth register or hospital statistics, statistics refer to status before discharge and may vary by length of stay before discharge. France and Cyprus provided data on breast feeding collected from an interview in the postpartum ward, which was not precisely 48 hours after birth. It is unclear how these differences in the time period at which the data are recorded affect estimates of breast feeding at birth. In addition the meaning of exclusive vs mixed breast feeding may differ between countries, as the first 48 hours is a period when lactation is established and non-human milk may be given as a supplement in this period.

RESULTS

Figure 5.13 illustrates the large differences in rates of breast feeding in Europe. More than 90% of babies received some breast milk at birth in the Czech Republic, Latvia, Portugal, and Slovenia. Rates were lowest in France, Cyprus, Ireland, Malta, and Scotland. In countries with very high rates of breast feeding, exclusiveness varied: almost all babies are exclusively breastfed in the Czech Republic and Latvia, whereas in Portugal and Switzerland mixed feeding is more common. In Switzerland, data come from hospitals participating in the Baby Friendly Hospital Initiative, so these may be an overestimate of national rates. The last representative study, in 2003, found a breastfeeding rate of 94%.

Some countries that could not provide the data required for this indicator have other statistics which suggest high rates of breast feeding in the first 48 hours; in Denmark, in the first *European Perinatal Health Report*, it was reported that data on breast feeding were not collected because over 95% of all newborns were breast fed exclusively for at least the first 48 hours; in Estonia, 87% of infants under one year who are monitored in primary healthcare centres are breast fed for at least 6 weeks; in Hungary 97% of infants are breast fed at 3 months

KEY POINTS

Many countries were unable to provide data on breast feeding, despite the importance of this indicator of child health and care at birth. When almost all newborns in a country receive some breast milk at birth, collecting data on that indicator during the first 48 hours may be less important. In those countries that provide data, rates of breast feeding in the first 48 hours and the distribution between exclusive and mixed breast feeding varied. These differences may show variations in the priority given to breast feeding in the public health policies; it can also express differences in the way data are collected, or differences in medical practices about the use of formula supplementation in the first days when there are maternal or infant problems.[7] Data collection in every country and greater precision and consistency in defining the modes of breast feeding are necessary to assess the efficacy of national policies and to know to what extent the recommendations in favour of breast feeding are achieved.[8]

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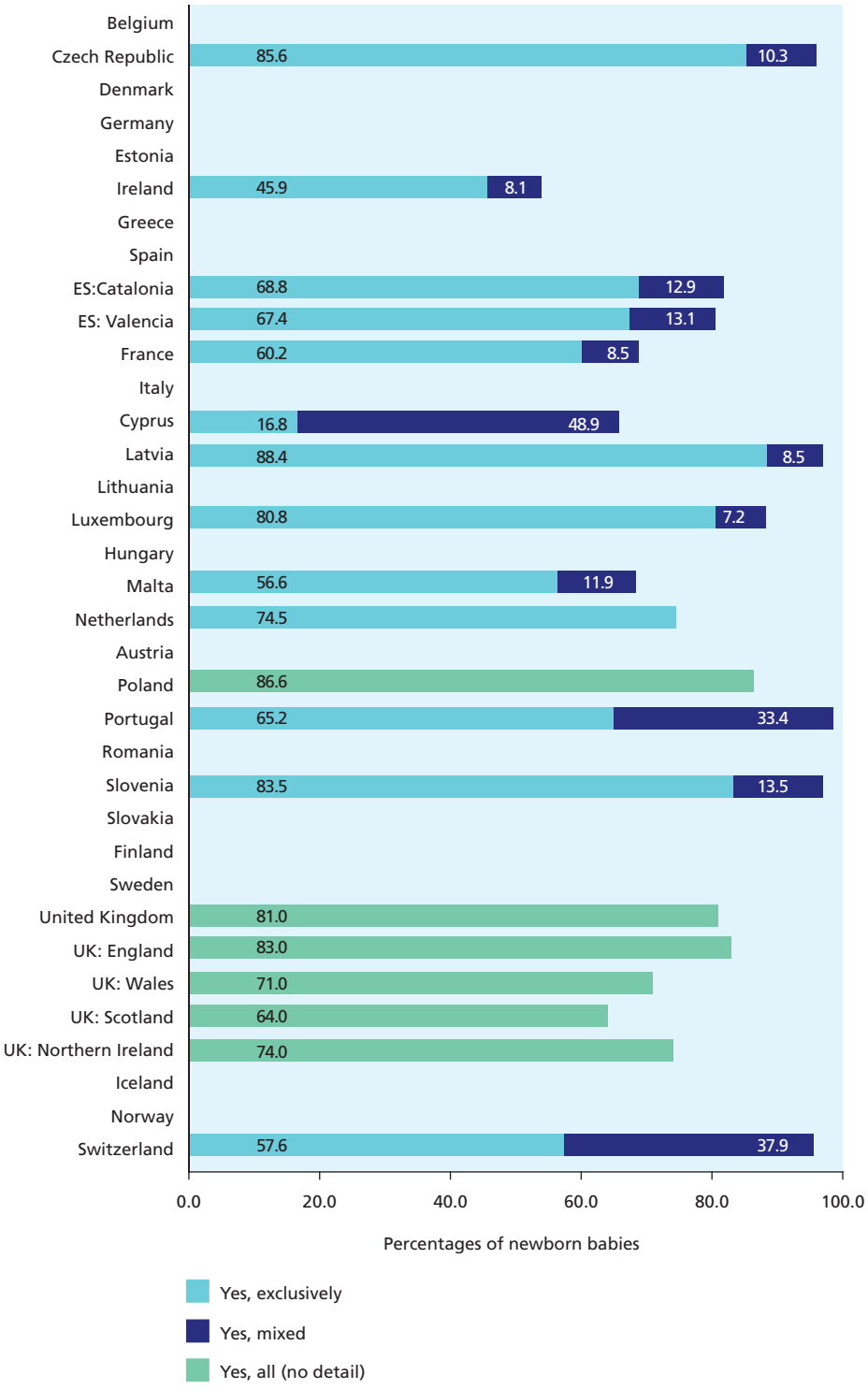
Figure 5.12 Distribution of exclusive and mixed breast feeding for the first 48 hours in 2010



NOTES:
Cyprus: Perinatal Survey in 2007
The Netherlands, no data on mixed feeding
Poland: National Health Survey in 2009
Portugal: National breastfeeding registry which was set up recently; coverage rate: 55% of public hospitals; includes term newborns from July 2010 to June 2011
Switzerland: includes healthy term newborns in hospitals and birthing homes participating in Baby Friendly Hospital Initiative; coverage rate: 38%
UK: no question on mixed feeding, only intended mixed feeding

6

MOTHERS' HEALTH: MORTALITY AND MORBIDITY ASSOCIATED WITH CHILDBEARING

6. MOTHERS' HEALTH: MORTALITY AND MORBIDITY ASSOCIATED WITH CHILDBEARING

CORE

Maternal mortality ratio (C6)

RECOMMENDED

Maternal mortality by cause of death (R5)
Incidence of severe maternal morbidity (R6)
Incidence of tears to the perineum (F7)

Each year more than 5 million women give birth in the EU. Another 2 million have failed pregnancies — spontaneous and induced abortions as well as ectopic pregnancies. Maternal mortality is a major marker of health system performance, and overall each year from 335 to 1000 women die in Europe during and because of pregnancy or delivery. Maternal mortality results from severe obstetric complications and conditions that occur more frequently but without such catastrophic results. This maternal morbidity is not adequately measured, however, mainly because there is no international agreement about the definition of the conditions and thus about methods for estimating their prevalence. In high income countries, maternal health has received less scientific attention in recent years than the health of babies. The Euro-Peristat group nonetheless agreed that indicators of maternal health were indispensable, and we included them in this project.[1]

This category includes 4 indicators of maternal mortality and morbidity. The 2 indicators of maternal mortality, that is, maternal mortality ratios and obstetric causes of death, are well constructed. The situation is very different for severe maternal morbidity — an indicator that has no widely agreed definition. It has nonetheless come to be seen in recent years as highly informative and important.[2] The Euro-Peristat project has developed a definition of this indicator and assessed the feasibility of collecting the relevant data. Although few countries can provide good quality data about this indicator,[3] it has been retained in the Euro-Peristat list and ongoing work is exploring the extent to which hospital discharge data can be used to improve national capacities for reporting the specific conditions and procedures that are included in our indicator. Finally, this chapter also includes an indicator on tears to the perineum; third- and fourth-degree tears are associated with substantial morbidity, and variations in this indicator are considered to reflect, in part, the quality of care during delivery.[4]

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C6 MATERNAL MORTALITY RATIO

JUSTIFICATION

Although maternal mortality in Europe has decreased to a very low level, healthy young women are dying from obstetric causes, up to half of which are potentially avoidable. The maternal mortality ratio (MMR) — the number of maternal deaths per 100 000 live births — is a proxy for the probability that a woman will die during a single pregnancy. Although numbers are low in smaller countries, maternal deaths in Europe are sentinel events that raise questions about the administration of effective care and the avoidance of substandard care.[1]

Beyond providing statistics, studying the circumstances that surround maternal mortality and the chain of events that led up to each death helps to prevent these avoidable deaths in the future. These investigations serve as a powerful tool for identifying weaknesses in the provision of care and recommending improvements to health policy makers.[1-3] Routine statistics and confidential enquiries are essential for estimating the frequency of maternal deaths, as sentinel events, and for investigating the circumstances of each. All European countries have routine statistics from national civil registration and cause-of-death data systems, but fewer have designed confidential enquiries or enhanced systems. Confidential enquiries into maternal deaths are conducted in some European countries, with especially strong traditions in the United Kingdom, France, and the Netherlands.[2-4]

Enhanced systems for reporting maternal deaths are necessary because routine systems generally underestimate the numbers of maternal deaths.[5,6] Some enhanced systems improve on routine systems by linking data sources, for example, deaths with births, for a more complete ascertainment of deaths associated with pregnancy. In the 2010 Euro-Peristat data collection exercise, information was requested from routine systems as well as from confidential enquiries and other enhanced systems, where they exist.

DEFINITION AND PRESENTATION OF INDICATOR

Maternal death is defined as the death of a woman while pregnant or within 42 days of the termination of pregnancy, irrespective of the duration and site of the pregnancy, for any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. The MMR is thus the number of all maternal deaths from direct and indirect obstetric causes per 100 000 live births. Our definition of maternal death is that published by WHO: a special chapter (10.3) of the 10th revision of the International Classification of Diseases (ICD-10) is devoted to the obstetric causes of death.[7] Because the number of deaths each year is so low in most countries, we used data covering a 5-year period (2006 to 2010).

DATA SOURCES AND AVAILABILITY

Data came from routine and enhanced systems for recording maternal deaths.

- Routine systems are those most generally available in each member state or country; the data are generally extracted from national civil registration and cause-of-death data systems, in which deaths are coded according to ICD-10. All EU countries except Greece, Ireland, and Norway contributed data, as did Iceland and Switzerland. In the Czech Republic, data come from a register of parturients only and therefore maternal deaths in pregnancy or after delivery are not included.
- Enhanced systems vary by country and may use different inclusion criteria from routine systems and from each other. Data were provided by Estonia, France, the Netherlands, Portugal, Slovenia, and the United Kingdom.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

The first major difficulty in reporting maternal mortality is that maternal deaths are generally under-reported, so much so that WHO has proposed systematically weighting the official statistics reported by developed countries by a factor of 1.5.[8] In Europe, underestimation of maternal deaths varies from 30% to 50%, depending on the initial level recorded in the routine national cause-of-death records.[5] Because the WHO coefficient assumes the same level of under-reporting everywhere, we do not apply it. Instead, we provide data from enhanced systems as well as published studies, where these exist, to illustrate the extent of under-reporting. In some cases, however, enhanced systems have wider inclusion criteria, especially for indirect and late maternal deaths. For example, data from the UK confidential enquiry system suggest that there is minimal under-reporting of direct maternal deaths in the routine system, but the confidential enquiry has a wider remit in investigating indirect and late maternal deaths.[2]

A second difficulty comes from the small numbers recorded and the resulting statistical variation. To address the difficulties related to the low numbers of deaths, maternal mortality ratios were calculated with data for the 5 years 2006-2010 and 95% confidence intervals are presented to illustrate the uncertainty arising from the small numbers of deaths in some countries. Even with data for 5 years, however, the numbers of deaths are still very low in the smallest countries. For example, only 2 deaths were registered in Malta in the years 2006-2010. It has about 4000 live births a year, for a MMR of 9.9 per 100 000 live births. This does not necessarily mean that Malta has a high maternal mortality ratio or even that its ratio has risen; if Malta had the average European MMR — about 6.2 per 100 000, we would expect 0.5 maternal deaths per year or one every 2 years. There is a high probability that no maternal deaths would occur at all in any given year or even in any 2-year period. This was the case in 2003-2004, the period covered in the last Euro-Peristat report when no death was recorded in Malta.

Finally, since obstetric causes can be attributed to deaths occurring after the 42-day limit specified in the definition, data provided by some countries to Euro-Peristat may include late maternal deaths more than 42 days after delivery but coded as having an obstetric cause. There may well be differences in the extent to which indirect maternal deaths are included.

RESULTS

The total number of maternal deaths officially recorded in routine systems varied from none in Iceland and less than 1 per year in Cyprus, Estonia, Luxembourg, and Malta to more than 40 in France, Romania, and the United Kingdom, as shown in Figure 6.1. Among the countries reporting data for 5 years, the highest ratios were observed in Latvia with 24.5 per 100 000 live births and Romania with 21.0 compared with 2.5 in Italy, 2.6 in both Austria and Estonia, and 2.9 in Poland. All these ratios differ significantly from the overall level of 6.2 per 100 000 for all participating countries combined (Figure 6.1).

Six countries provided data from enhanced systems (Figure 6.2). These showed wide differences in enhanced MMRs, some of which may have been due to differences in inclusion criteria, especially for indirect and late maternal deaths. In 2 of them, Estonia and Slovenia, the maternal mortality ratios reported from the enhanced systems were identical to those from the routine systems. In contrast, enhanced ratios were higher than those from routine systems in the United Kingdom, the Netherlands, Portugal, and France. The Portugese data for the enhanced system are from 2003-2007; over this period the routine MMR was 5.4 per 100 000 live births. Other countries

have undertaken studies to investigate the completeness of their maternal mortality ratios and have also found them to be substantially higher than those reported in routine systems: 5.9 per 100 000 over the period 1988-2007 in Sweden,[9] 8.0 per 100 000 for the period 2002-2006 in Denmark,[10] and 11.8 per 100 000 between 2000 and 2007 in a set of Italian regions.[11] The EURO-PERISTAT project used its 2004 data to conduct a review of results from the enhanced systems and specific studies (including those from Italy, Austria, and Finland); this study confirmed that routine systems ascertained fewer deaths.[5] It also found that countries with enhanced systems had higher maternal mortality ratios reported from routine systems, probably reflecting greater awareness of the problems of recording these deaths.

Compared to the ratios from the 2003-2004 data from routine systems in the previous EURO-PERISTAT report, those for 2006-2010 were lower in 14 countries (including Flanders, the Czech Republic, Estonia, and Spain), but the decreases were not statistically significant. The maternal mortality ratios increased in 8 countries. The overall level of 6.2 per 100 000 live births for the EU as a whole was the same.

Figure 6.3 presents MMRs by maternal age group (2003-2004 and 2006-2010). In view of the small numbers, we pooled the data from contributing countries and focused on 3 age groups: younger than 25 years, 25-34 years, and 35 years and over. This figure illustrates the association between maternal age and maternal mortality. The MMR for women aged 35 years or older is about twice as high as that for women aged 25-34 years and 3 times higher than for those younger than 25.

KEY POINTS

The MMR is low (less than 10 per 100 000) in the majority of countries, but this is generally an underestimation. There is good evidence that maternal deaths derived from routine statistical systems are under-reported, and this must be suspected particularly where ratios are very low. Confidential enquiries and record linkage are recommended to obtain complete data on pregnancy-related deaths and also to make it possible to understand how these deaths happened and to make recommendations to prevent the recurrence of those that could have been prevented.

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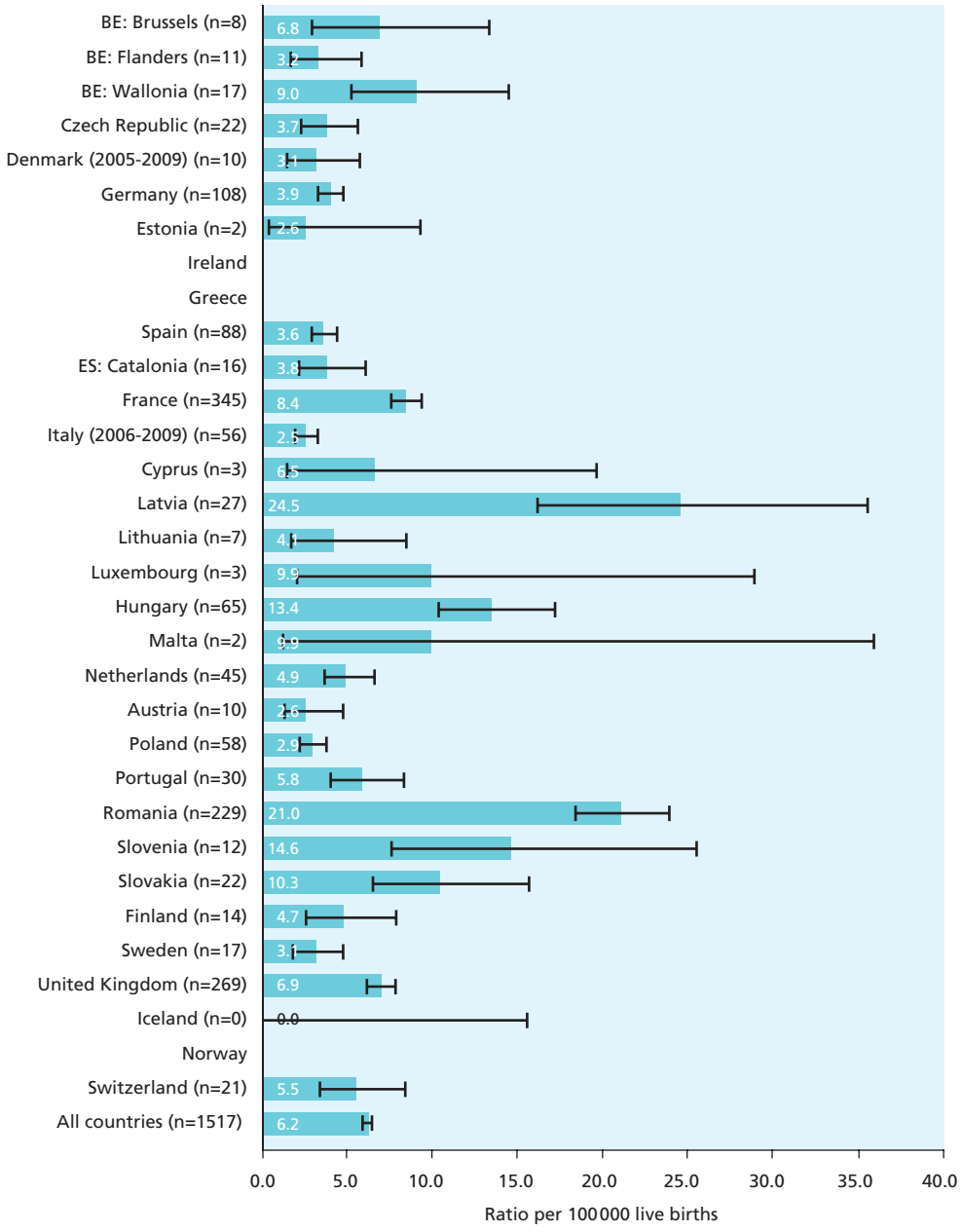
Figure 6.1 Maternal mortality ratio, 2006-2010



NOTE: ratios provided with 95% confidence intervals

Figure 6.2 Maternal mortality ratios from routine statistics and from enhanced systems, 2006-2010

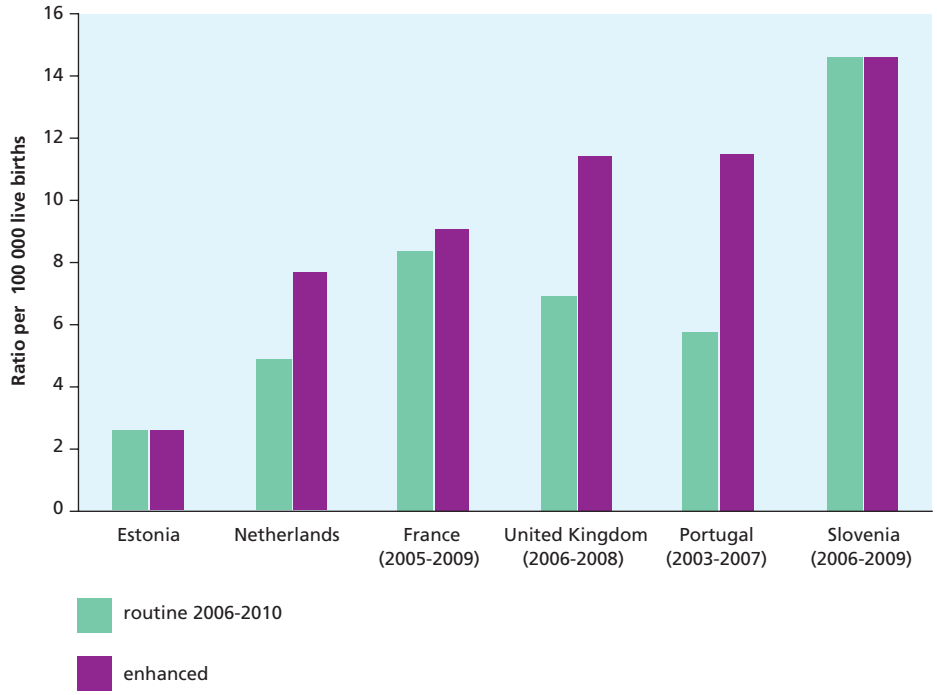
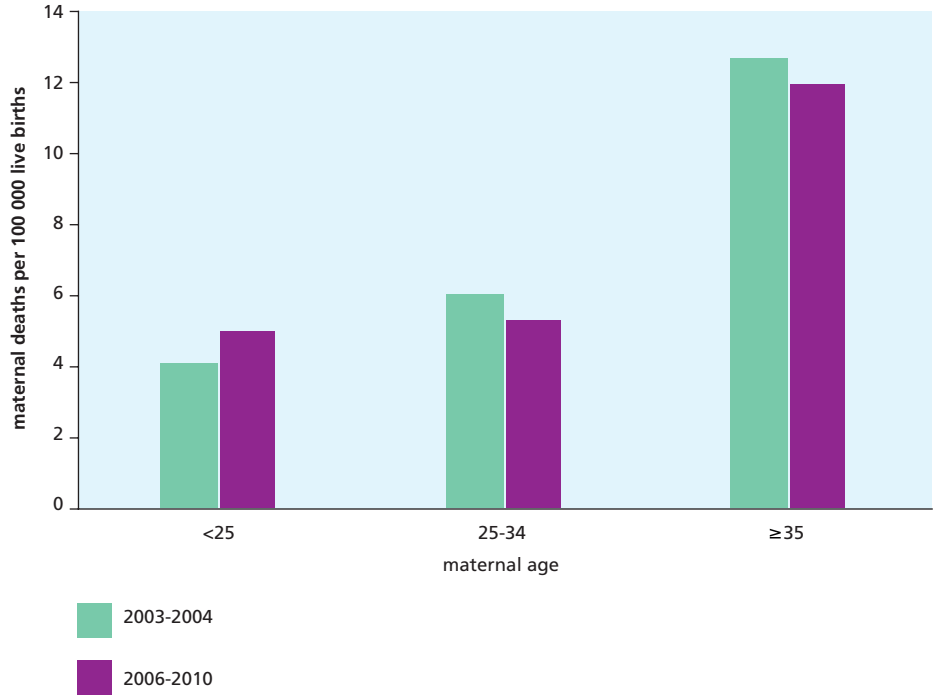


Figure 6.3 Maternal mortality ratios by maternal age in Europe in 2003-2004 and 2006-2010



R5 MATERNAL MORTALITY BY CAUSE OF DEATH

JUSTIFICATION

In addition to differences in the rates of mortality, causes of these deaths can vary across countries. An earlier European study, the European Concerted Action on Mothers' Mortality and Severe Morbidity (MOMS), found that patterns of causes and timing of death as well as age-specific mortality ratios varied between countries with different levels of MMR.[1] In countries with higher MMRs, a higher proportion of deaths resulted from haemorrhages and infections, whereas hypertensive disease and indirect obstetric deaths formed a higher proportion of the deaths in countries with lower MMRs. Deaths from infections and haemorrhages were more often associated with substandard care.

DEFINITION AND PRESENTATION OF INDICATORS

Because of the small number of deaths in each country, we did not compute MMRs by individual causes of death. Instead we calculated the proportion of each specific cause by taking the number of deaths attributed to each category of causes as a percentage of total maternal deaths. Countries were asked to report the number of deaths that corresponded to the ICD-10 codes for the following causes: abortions, ectopic pregnancy, hypertension, haemorrhages, chorioamnionitis/sepsis, amniotic fluid embolisms, other thromboembolic causes, anaesthesia complications, uterine ruptures, other direct obstetrical causes, indirect circulatory causes, other indirect obstetrical causes, and unknown causes. We also computed the specific maternal mortality ratios by causes at the European level from the national data provided (Figure 6.4).

DATA SOURCES AND AVAILABILITY

The availability of the data generally depends on the information written on death certificates and how it is coded by the organisation responsible for processing data from them. There are 2 sorts of limitations: firstly, the under-reporting of deaths associated with pregnancy described above and, secondly, a specific problem of application of the coding rules recommended by the WHO in the ICD. A maternal death is usually the consequence of a series of unexpected obstetric complications and possibly also adverse social circumstances that in combination lead to the death of a woman who is generally young and in good health. As a result, the choice of the underlying cause and therefore its coding to the appropriate digit code of the ICD is not easy and differs from one country to another.[2] For example, before 1998 in France, maternal deaths from pulmonary embolisms were classified in the ICD chapter on respiratory diseases and not in the chapter on complications of pregnancy. Studies have shown coding differences between some European countries.[3,4] A recent study from Sweden confirmed the existence of coding mistakes, in particular, related to pre-existing diseases; if information about pregnancy is not taken into account, the death cannot be coded as an indirect obstetric cause.[5]

Confidential enquiries are considered the best approach for improving the quality of information about the circumstances surrounding these events and thus the accuracy of the diagnosis and coding of the underlying cause of the death.[5-8]

RESULTS

Appropriate interpretation of the causes of maternal deaths requires particular attention to the proportion of unknown causes. The cause of maternal death was listed as unknown in 4% of EU cases, a decrease since the preceding report (16.4% in 2003-2004). But countries varied dramatically in their attribution of cases to this category, as seen in Summary Table R5. Nine

countries reported unknown causes: Estonia 50% (1/2), Germany 1% (1/89), Denmark 10% (1/10), Wallonia 18% (3/17), France 7% (24/345), Spain 3% (2/74), Sweden 6% (1/16), Romania 3% (6/229), and the United Kingdom 0.8% (2/266).

The general European profile of known direct obstetric causes of death, as presented in Figure 6.4, shows patterns similar to those in 2003-2004 and a general decrease in the specific ratios by cause, except for complications of the first trimester (0.18 for ectopic pregnancies and 0.45 for abortions) and hypertensive disorders (0.72 per 100 000, compared with 0.63 in 2004). Among direct obstetric causes, haemorrhage continues to contribute most to the MMR in the EU (0.87 per 100 000 live births), slightly less than in 2003-2004 (0.91), followed by hypertensive disorders. The change since 2004 is that third place is occupied by deaths due to first-trimester complications. This is the direct consequence of the high proportion of maternal deaths in Romania due to abortion — 20% (see Summary Table for R5 for breakdown by country). All other causes declined between the 2 periods, including indirect obstetrical causes (ratio of 1.08 per 100 000).

Among indirect causes, circulatory diseases ranked high, with a ratio of 0.42 per 100 000 live births. Of direct causes, haemorrhage accounted for around 15% of maternal deaths in participating countries, ranging from 4% in the Czech Republic to more than 30% in several countries. Complications of hypertension accounted for an average of 12% and amniotic fluid embolisms 7%. "Other direct obstetric causes" were reported as the cause of 19% of the maternal deaths in the EU.

KEY POINTS

In Europe today, maternal deaths occur in relatively small numbers, but an analysis of their causes is essential for developing strategies to prevent them. Surveillance of maternal mortality by conducting confidential inquiries helps to improve our understanding of healthcare systems and how they perform so that we can make recommendations to prevent these tragic events. Better and more uniform coding and recording of the causes of maternal deaths in European countries would facilitate comparisons between countries and improve our understanding of the sequences of events that can lead to maternal death.

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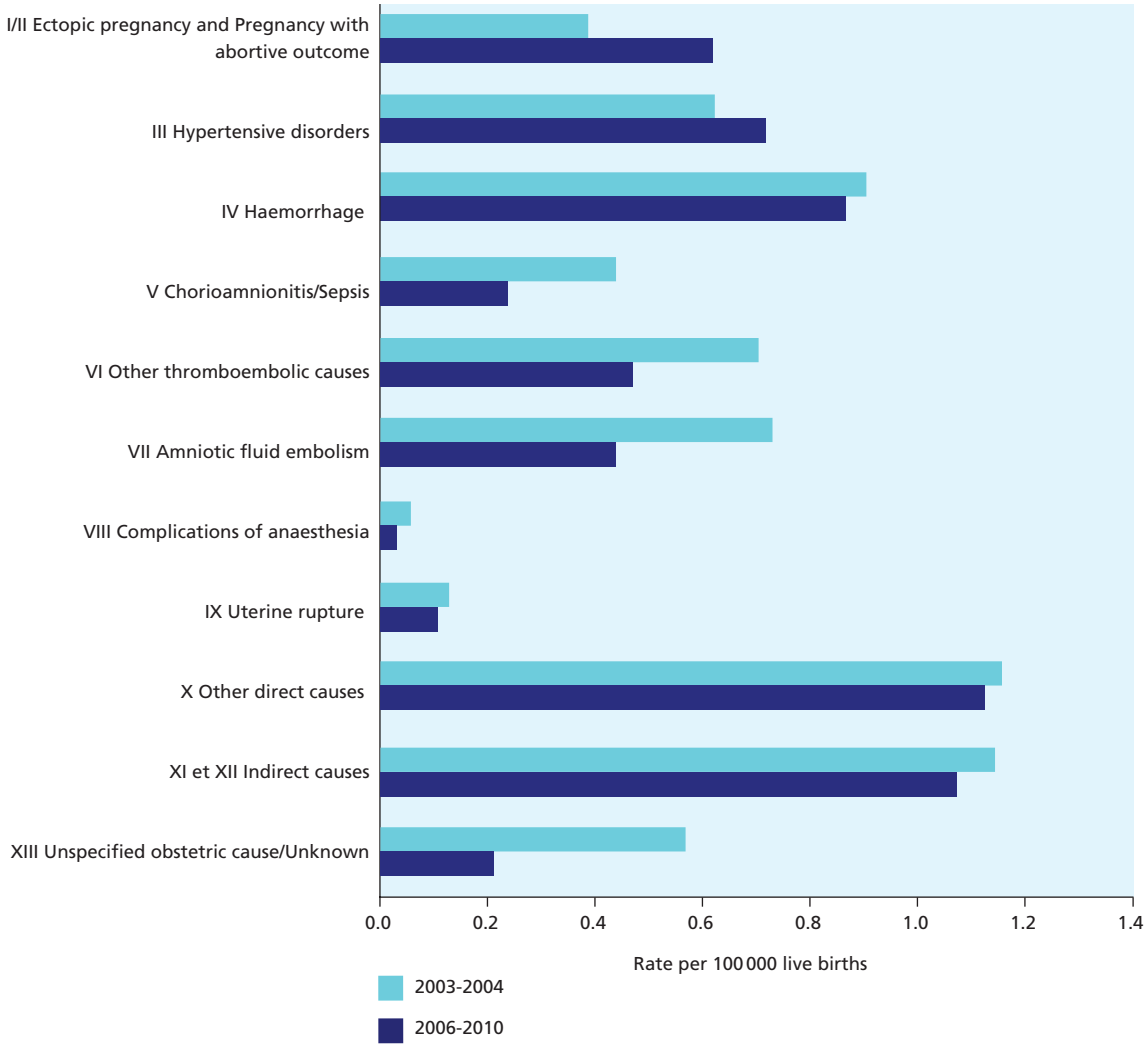
Figure 6.4 **Maternal mortality ratios by obstetric causes, data pooled from all national data provided for 2003-2004 and 2006-2010**



R6 INCIDENCE OF SEVERE MATERNAL MORBIDITY

JUSTIFICATION

Maternal mortality is the measure traditionally used to evaluate the status of women's health in pregnancy, but the welcome decline in mortality has given rise to concerns about the statistical power and validity of studies based on such small numbers. The rarity of maternal death in developed countries does not mean that pregnancy is a safe condition. For every maternal death, there are many serious, even life-threatening episodes of pregnancy complications. Severe maternal morbidity has been estimated to occur at rates ranging from 9.5 to 16 cases per 1000 deliveries throughout Europe, the United States, Canada, and Australia[1-5] and may be increasing over time.[2,5] There are no widely accepted definitions or inclusion criteria for defining severe maternal morbidity. The Euro-Peristat study set up a working group to conduct a review of potential maternal morbidity indicators, to propose a definition for Euro-Peristat, and to assess the availability of data to construct these morbidity indicators from hospital systems in participating countries. The definition adopted during the first phase of the project was made up of 4 indicators (eclampsia, hysterectomy, blood transfusion, and ICU admission). Embolisation was subsequently added as a fifth indicator.

Since Euro-Peristat began, maternal morbidity has become the focus of several research projects in Europe and elsewhere. An international network now links obstetric surveillance surveys (International Network of Obstetric Survey Systems, INOSS). A WHO working group proposed an international definition of severe maternal complications and life threatening events, and various approaches have been tested.[6,7] Nevertheless, for purposes of surveillance and despite problems with data availability and quality, routine hospital data can provide valuable information about severe maternal morbidity and efforts should continue to validate the data and improve their quality.[8]

DEFINITION AND PRESENTATION OF INDICATOR

The proposed Euro-Peristat indicator includes both management-based and disease-specific criteria. It is defined as the number of women experiencing any one of eclamptic seizures, caesarean hysterectomy, embolisation, blood transfusion, or a stay of more than 24 hours in an intensive care unit as a percentage of all women with liveborn and stillborn babies.

DATA AVAILABILITY

We had expected that these data about the incidence of embolisation, eclampsia, blood transfusion, and hysterectomy for postpartum haemorrhage would be easy to collect through hospital discharge systems. We know that most member states have financial systems that allocate funding to hospitals delivering care and consequently systems for recording the number of patients with conditions such as those included in our definition of severe maternal morbidity. Unfortunately data on these complications are not now routinely available from most of these systems.

RESULTS

Twenty-two countries or regions provided at least one of the components of the maternal morbidity indicator (see Summary Table for R6 in Appendix B). Only 5 provided information for all the categories, however. These were France, Germany, Poland, Norway, and Switzerland.

Eclampsia appears to be the condition which is most widely recorded. Twenty countries provided data, and only 5 have definitions which differed from our specification, but some countries had concerns about the accuracy of the data provided. The ratios range from 0.1 per 1000 women delivered (Finland, Sweden, and Scotland) to 0.9 (Latvia and France). Seventeen countries or regions provided data about hysterectomies, most with the same definition, although some were not able to separate hysterectomies associated with pregnancy and delivery from those related to other circumstances. The ratios ranged from 0.0 and 0.1 per 1000 women delivered (Wales and Sweden) to 1.2 and 1.3 per 1000 women (Latvia and Estonia). Data about transfusion were provided for 12 countries; embolisation for 12, and ICU admission for 8. Figure 6.5 presents rates for eclampsia and hysterectomy, the 2 complications most frequently reported by countries. It shows wide disparities between countries in these rates. Further investigation is required to understand these differences.

KEY POINTS

This is the third time that an attempt has been made to gather information about severe maternal morbidity at a European level from routine data collection systems. The only previous attempt to compare maternal morbidity in Europe involved a European Concerted Action that was limited to 14 countries and used a specific survey.[2] Our objective here was to make use of existing routinely collected hospital data, but our results show that these systems require further development before a comparable measure of maternal morbidity can be included in routine reporting at a European level.

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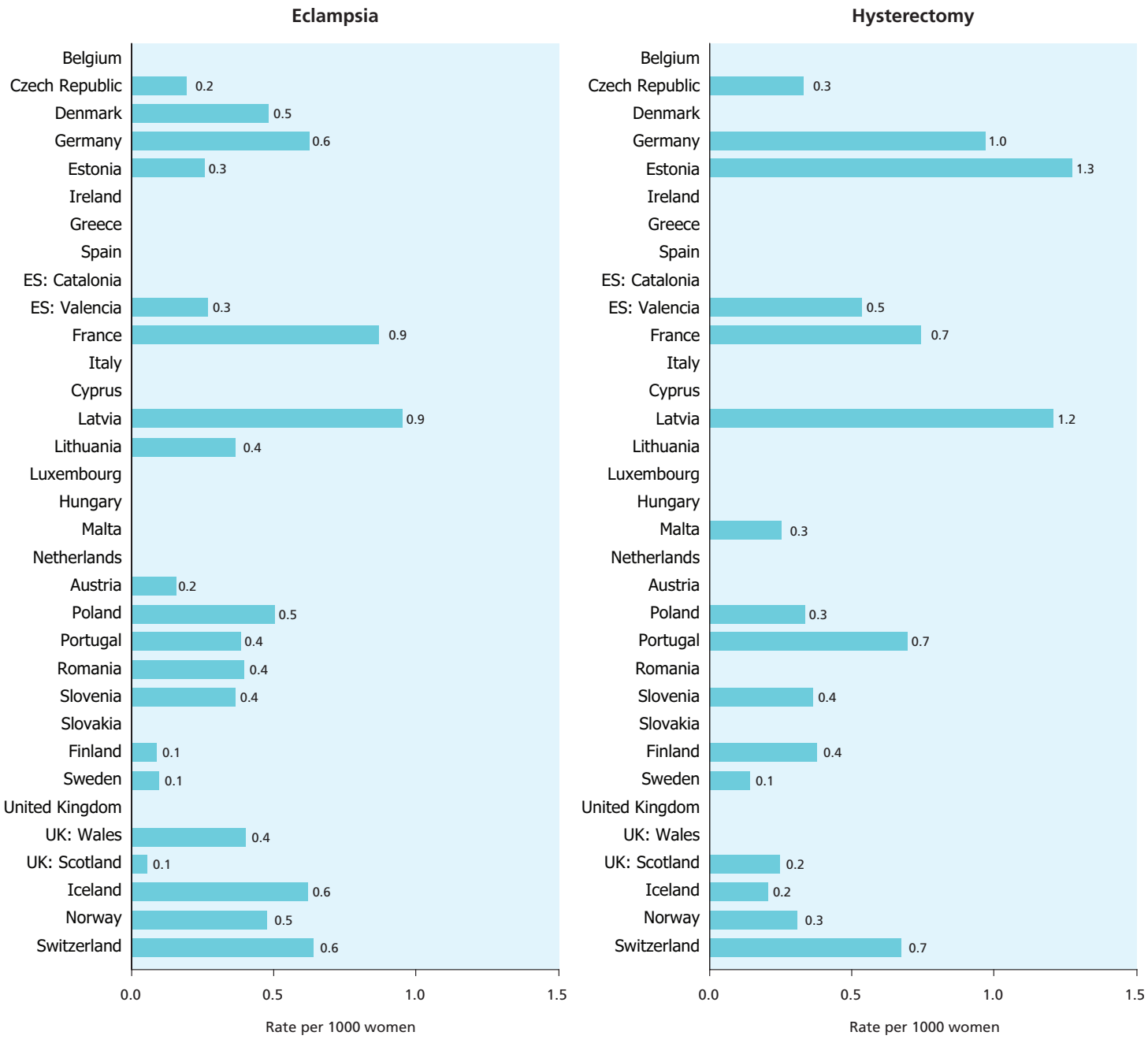
Figure 6.5 Maternal morbidity: rates of eclampsia and of hysterectomy for postpartum haemorrhage in 2010



R7 INCIDENCE OF TEARS TO THE PERINEUM

JUSTIFICATION

Vaginal births can be associated with some form of trauma to the genital tract, either as a consequence of tears or of episiotomy. The morbidity associated with perineal trauma is significant in the case of third- and fourth-degree tears.[1] Although policies of routine episiotomy have been advocated for reducing the incidence of severe vaginal tears, the evidence suggests that policies restricting use of episiotomy are more beneficial.[2] This indicator is designed to monitor the proportions of women with tears by degree of severity.

DEFINITION AND PRESENTATION OF INDICATORS

This indicator is defined as the percentage of women who delivered vaginally and had a tear, by its degree of severity.

DATA SOURCES AND AVAILABILITY OF INDICATORS IN EUROPEAN COUNTRIES

Most of the data came from hospital databases. Data about tears were available for Denmark, Germany, Estonia, the Valencia region of Spain, France, Cyprus, Latvia, Luxembourg, Malta, the Netherlands, Austria, Poland, Portugal, Romania, Slovenia, Finland, Sweden, England, Wales, Scotland, Iceland, Norway, and Switzerland. Some of these did not have the full range of data requested. The data for Malta were restricted to the proportion of women with no tear, while Estonia, the Netherlands, and Sweden did not have data about first- and second-degree tears. Data for Estonia, France, Latvia, the Netherlands, and Norway were for third- and fourth-degree tears combined.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Although the percentage of vaginal deliveries with third- and fourth-degree tears is a well established indicator of the quality of maternity care, there are questions about variations in the completeness of reporting.[3] Although techniques have been developed to prevent third- and fourth-degree tears, the issues involved are complex, as factors including birthing positions, individual tissue quality, and the speed of labour all play a part.[1,4] Higher rates of tears are associated with operative vaginal delivery, compared to spontaneous vaginal delivery. These operative vaginal rates vary considerably between countries, as indicator C10 shows. Finally, this indicator applies only to women having vaginal deliveries, a percentage that ranges from only 47.8% of deliveries in Cyprus to 85.2% in Iceland (see C10).

RESULTS

The percentage of women with vaginal deliveries and reported to have no tear varied from over 95% in Estonia, the Netherlands, Austria, Poland, and Finland, to around half in England, Wales, Scotland, Malta, Norway, and Switzerland. The percentage of women with first- and second-degree tears ranged from 4% in Finland to 58% in Iceland. The proportion of women reported to have third- or fourth-degree tears ranged from 0.1% in Poland and Romania and 0.2% in Slovenia to over 4% in Denmark, the Netherlands, and Iceland.

Only Denmark, Germany, Estonia, Slovenia, Finland, England, Wales, and Scotland contributed data about vaginal tears in both 2004 and 2010. The proportions of women reported to have tears by degree of severity did not differ markedly. There were small increases in the proportions of women with severe tears, as in the countries of the UK, but these could reflect fuller reporting.

KEY POINTS

There were differences between countries in the percentage of women reported to have tears. These differences should be interpreted with caution as they are likely to be a consequence of variations in completeness of recording of tears, especially for first- and second-degree tears. Third- or fourth-degree tears were reported in from under 1% to over 4% of all deliveries in participating countries and can sometimes be associated with significant short or long-term problems for the woman. Although techniques have been developed to prevent third- and fourth-degree tears, the issues involved are complex, as factors including birthing positions, individual tissue quality, and the speed of labour all play a part.[1,4.]

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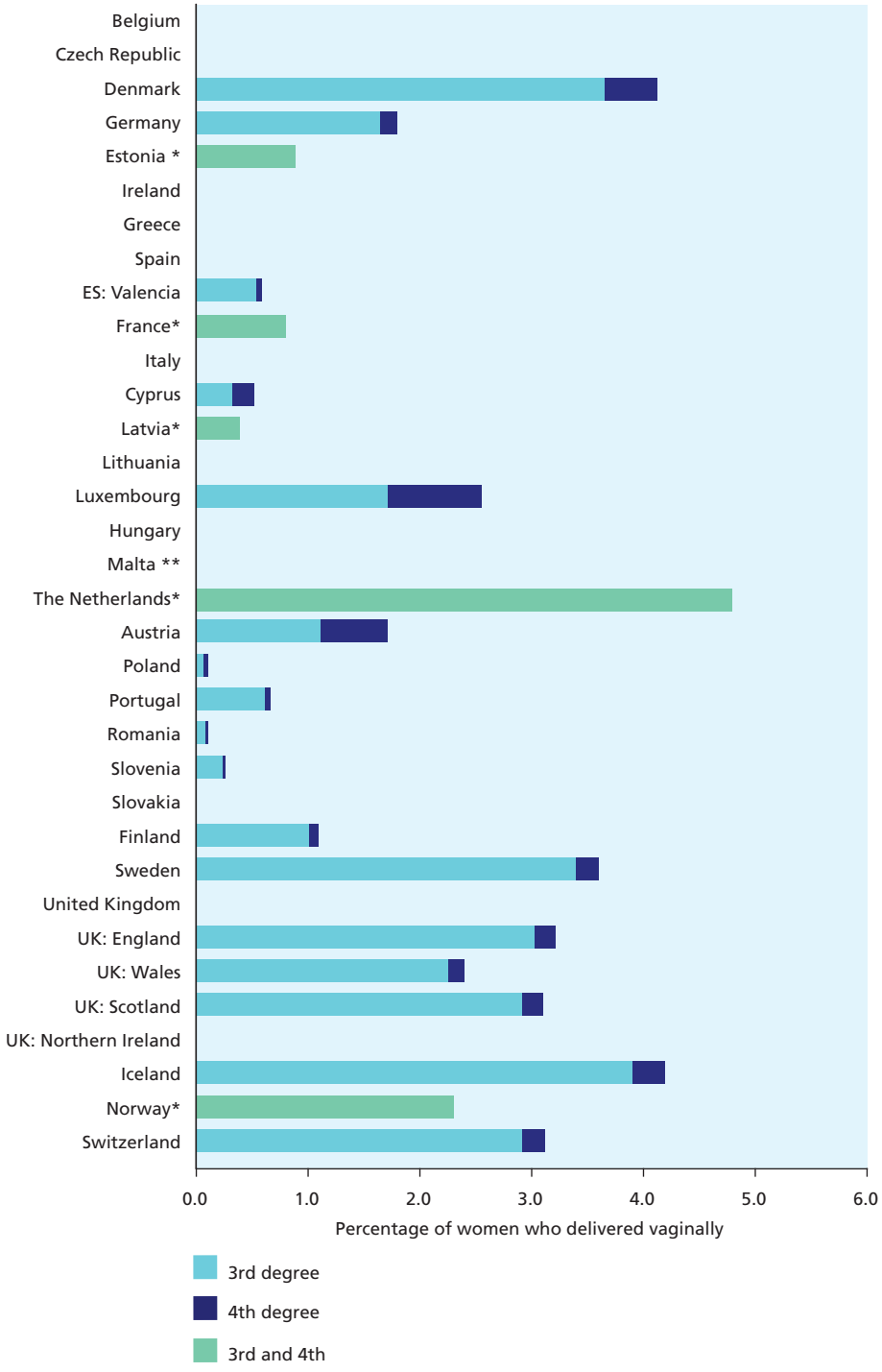
Figure 6.6 Incidence of third- and fourth-degree tears to the perineum in 2010



NOTE: * data for 3rd and 4th degree tears combined; ** only data for all tears

7

BABIES' HEALTH: MORTALITY AND MORBIDITY DURING PREGNANCY AND IN THE FIRST YEAR OF LIFE

7. BABIES' HEALTH: MORTALITY AND MORBIDITY DURING PREGNANCY AND IN THE FIRST YEAR OF LIFE

CORE

Fetal mortality rate by gestational age, birth weight, and plurality (C1)
Neonatal mortality rate by gestational age, birth weight, and plurality (C2)
Infant mortality rate by gestational age, birth weight, and plurality (C3)
Distribution of birth weight by vital status, gestational age, and plurality (C4)
Distribution of gestational age by vital status and plurality (C5)

RECOMMENDED

Prevalence of selected congenital anomalies (reported in Chapter 8) (R1)
Distribution of 5-minute Apgar scores as a percentage of live births (R2)
Fetal and neonatal deaths due to congenital anomalies (R3)
Prevalence of cerebral palsy (reported in Chapter 8) (R4)

Outcomes related to the health of babies in the first year of life, specifically mortality rates, are often used as a measure of the health status of a population or of the quality of the perinatal healthcare system. The main contributory factors to perinatal death include congenital anomalies, very preterm birth, and fetal growth restriction (FGR). Maternal age, parity, multiple pregnancy, maternal conditions such as preeclampsia and diabetes, socioeconomic and migration status, and behaviours such as smoking are well-known risk factors for perinatal mortality and morbidity in high-income countries. The quality of care during pregnancy, delivery, and the neonatal period also influences babies' chances of mortality and morbidity.

The Euro-Peristat indicators of child health include 5 core indicators and 4 recommended indicators. Given the issues related to the comparability of fetal, neonatal, and infant mortality rates across countries (see chapter 3), we requested indicators of mortality by gestational age and birth weight in order to exclude the births and deaths most likely to be influenced by differences in recording and registration criteria. We also collected data on terminations of pregnancy, as screening and termination practices can have a substantial impact on fetal and infant deaths. The 2 recommended indicators on the prevalence of congenital anomalies and cerebral palsy are presented in Chapter 8 by European networks of registries dedicated to these conditions.

C1 FETAL MORTALITY

JUSTIFICATION

Half of all deaths in the perinatal period are fetal deaths, also called stillbirths. While these deaths have declined over past decades, the reductions have slowed or stopped in many high-income countries.[1] The causes of fetal death are multiple and include congenital anomalies, FGR, abruption associated with placental pathologies, preterm birth, and other maternal complications of pregnancy, as well as infections.[2] Between 30 and 50% of fetal deaths remain unexplained, however, and this large proportion impedes the development of prevention;[1] systematic performance of autopsies and histological examinations would reduce this proportion. The principal modifiable risk factors for stillbirth include obesity and overweight, smoking, and older maternal age.[3,4] Women having their first birth face a higher risk of stillbirth as do women

with multifetal pregnancies. Because FGR accounts for a large proportion of fetal deaths, better detection and management of these cases might be an effective preventive strategy.[4]

Countries have different rules about the lower limits for gestational age and birth weight for recording fetal deaths and this complicates international comparisons.[2,5,6] Computing fetal mortality rates by gestational age and birth weight is thus necessary to derive comparable indicators when registration limits differ.[6] Differences in policies and practices related to terminations of pregnancy at or after 22 weeks of gestation also affect fetal mortality rates. In some countries, these terminations should be registered as fetal deaths and are included in the calculation of fetal mortality rates, whereas elsewhere they are notified only separately or not at all.[6,7] Some countries ban any terminations at or after 22 weeks. One of Euro-Peristat's goals is to use its data to propose better methods for comparing fetal mortality between countries.[8]

DEFINITION AND PRESENTATION OF INDICATORS

The fetal mortality rate is defined as the number of fetal deaths at or after 22 completed weeks of gestation in a given year, expressed per 1000 live births and stillbirths that same year. When gestational age is missing, Euro-Peristat requests that fetal deaths be included if they have a birth weight of 500 g or more, but not if both gestational age and birth weight are missing. Fetal mortality rates are presented in Summary Table C1 as the total fetal mortality rate, as the rate for infants with a birth weight of 1000 g or more, and as the rate at or after 28 completed weeks of gestation.

Figure 7.1 presents the overall fetal mortality rate and the fetal mortality rate at or after 28 completed weeks of gestation. The distribution of fetal deaths by gestational-age and birthweight groups are also presented for all countries combined in Figure 7.2. Figure 7.3 compares fetal mortality rates at or after 28 weeks of gestation in 2010 and 2004.

DATA SOURCES AND AVAILABILITY OF INDICATORS IN EUROPEAN COUNTRIES

Most participating countries and regions were able to provide data on fetal deaths according to the Euro-Peristat definition, despite differences in the rules for registering births and deaths. When countries could not provide data on fetal deaths using our definition, they were asked to give data using their own inclusion limits. Chapter 3 provides details on the rules for recording fetal deaths and terminations of pregnancy in participating countries and the inclusion of these deaths in routine reporting systems.

Limit for registration

Germany, Austria, Poland, and Slovenia only recorded fetal deaths with a birthweight limit of 500 g or more. In Hungary and Ireland fetal deaths were registered from of 24+ weeks of gestation or 500+ g of birth weight. In Portugal and the United Kingdom, fetal deaths before 24 weeks of gestation are not legally registered, but there is voluntary notification of late fetal deaths at 22 and 23 weeks, although this was in abeyance in England and Wales in 2010. These notifications are included in the number of fetal deaths. Greece registered fetal deaths from 24+ weeks and their data are from 2009. Spain and the region of Catalonia registered fetal deaths from 180+ days and 26+ weeks, respectively.

Terminations of pregnancy

European countries differ in policies and practices towards screening for congenital anomalies and terminations of pregnancy for fetal anomalies. Terminations can be performed in most

European countries, although the legal gestational-age limit differs; they are not legal in Malta or Ireland. There are very limited circumstances for a lawful termination of pregnancy in Northern Ireland. Polish law bans terminations after the fetus reaches viability, and Estonian statutes allow them only up to up to the end of 21 weeks of gestation. Terminations were not included in fetal mortality statistics by Flanders, Denmark, Ireland, Latvia, Lithuania, Austria, Poland, Portugal, Romania, Finland, Sweden, or Norway. Brussels, Wallonia, the Czech Republic, Denmark, Spain, France, Italy, Cyprus, Luxembourg, Hungary, the Netherlands, England and Wales, Northern Ireland, Scotland, Iceland, Slovenia, and Switzerland included terminations in these data, and 6 of these countries (the Czech Republic, France, Italy, Hungary, Scotland, and Switzerland) were able to distinguish between spontaneous and induced abortions.

Subgroup analysis
Almost all countries were able to provide information on fetal deaths by gestational age, birth weight, and plurality. Greece submitted fetal death data by birth weight but not data on live births by birth weight. France provided data only for a small representative sample of births, as it does not record the gestational age and birth weight of fetal deaths nationally. Data from a French regional stillbirth register were also analysed. Denominators for France were estimated based on a representative sample of total births.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Differences in European legislation governing the lower limit for inclusion of fetal deaths make it difficult to compare rates at lower gestational ages. Computing rates by gestational age and birth weight is therefore necessary to derive valid comparable indicators when registration practices diverge. WHO recommends using a lower limit of 1000 g for international comparisons, but since the guidelines for registration are based primarily on gestational age, a cutoff based on that is used here. Accordingly, the Euro-Peristat project also presents fetal mortality rates per 1000 total births at or after 28 weeks of gestation. As discussed above, some countries include terminations of pregnancy in their registers of fetal deaths, while others only record these in separate systems. The number of terminations at or after 28 weeks of gestation is low in most, although not all, European countries, so comparing fetal mortality rates with this cutoff point partially addresses this problem. Finally, even when the indicator of fetal mortality is constructed to be comparable, its interpretation must also take into consideration the legislation and policies and practices of induced abortions for congenital anomalies that may be registered as fetal deaths. Separating out fetal mortality rates into spontaneous deaths versus terminations would be useful for understanding differences between countries, but this was possible for only 6 of the 15 countries that included terminations as fetal deaths.

RESULTS

Fetal mortality rates at or after 28 weeks of gestation ranged from 1.5 per 1000 live births and stillbirths in the Czech Republic to 4.3 per in France, as Figure 7.1 shows. The highest mortality rates were approximately 3 times higher than the lowest rates, with rates highest in France, Latvia, Brussels, Romania, and the countries of the UK. Overall fetal mortality rates ranged from under 4 per 1000 in 9 countries or regions to over 8 in France and Brussels. In some countries (Romania and Slovakia), the very small difference between overall rates and those at 28 weeks and after suggests that early stillbirths were under-reported.

The information on the proportion of fetal deaths represented by terminations was available for a few countries and showed wide variation. Six percent of all fetal deaths were terminations in Scotland versus 40-50% in France. Terminations accounted for 13% of fetal deaths in Hungary, 15% in Switzerland, and 19% in Italy. Terminations were carried out before 28 weeks of gestation in most countries. In France, however, there is no gestational age limit for medically indicated terminations. In a regional register in France, after terminations are removed, the fetal mortality rate at 28 weeks drops to 2.3 per 1000 total births from 3.8 — a reduction of 41%. This rate is more in line with other European countries. Note, however, that this regional stillbirth register covers 3 districts — Isère, Savoie, and Haute Savoie — with more favourable perinatal outcomes than France as a whole (their neonatal mortality is 1.8 per 1000 live births versus 2.3 nationwide), so this rate is probably lower than the national rate.

While comparisons between countries at currently require a cutoff of 28 weeks or 1000 g because of differences in the recording of early stillbirths, many fetal deaths occur before this limit, as illustrated in Figure 7.2. This figure presents combined data from all countries and shows that one-third of all fetal deaths occurred before 28 weeks of gestation or 1000 g. Given the problem of under-reporting, this percentage is an underestimate.

TRENDS IN FETAL MORTALITY RATES

Figure 7.3 compares fetal mortality rates at or after 28 weeks of gestation in 2004 and 2010 for countries that had comparable indicators in both time periods. Countries are ordered by their fetal mortality rates in 2004. These rates declined in most countries in 2010. Exceptions were Brussels and Slovakia. Decreases (on average 19%; range 0-39%) tended to be more pronounced for western European countries with higher mortality rates in 2004 (Denmark, Italy, and the Netherlands). Some countries with low mortality rates in 2004 achieved significant continued improvements in outcomes; for example the rate in the Czech Republic declined from 2.4 to 1.5 per 1000 births (39% reduction).

KEY POINTS

Comparisons of fetal mortality rates in European countries at and after 28 completed weeks of gestation minimise the effects of differences in registration practices for fetal deaths, but do not completely solve the problems associated with the registration of terminations of pregnancy as fetal deaths. Despite declines in fetal mortality in most European countries, fetal mortality rates at or after 28 weeks of gestation continue to vary highly, with the highest mortality rates almost 3 times higher than lowest.

Although most European countries were able to provide data about births and deaths based on the Euro-Peristat definition of 22 completed weeks of gestation, differences in registration of fetal deaths persisted in 2010. Given the large proportion of deaths that occur before 28 weeks, it is essential to develop European information systems to enable comparative reporting of these deaths.

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Figure 7.1 Fetal mortality rates per 1000 total births in 2010

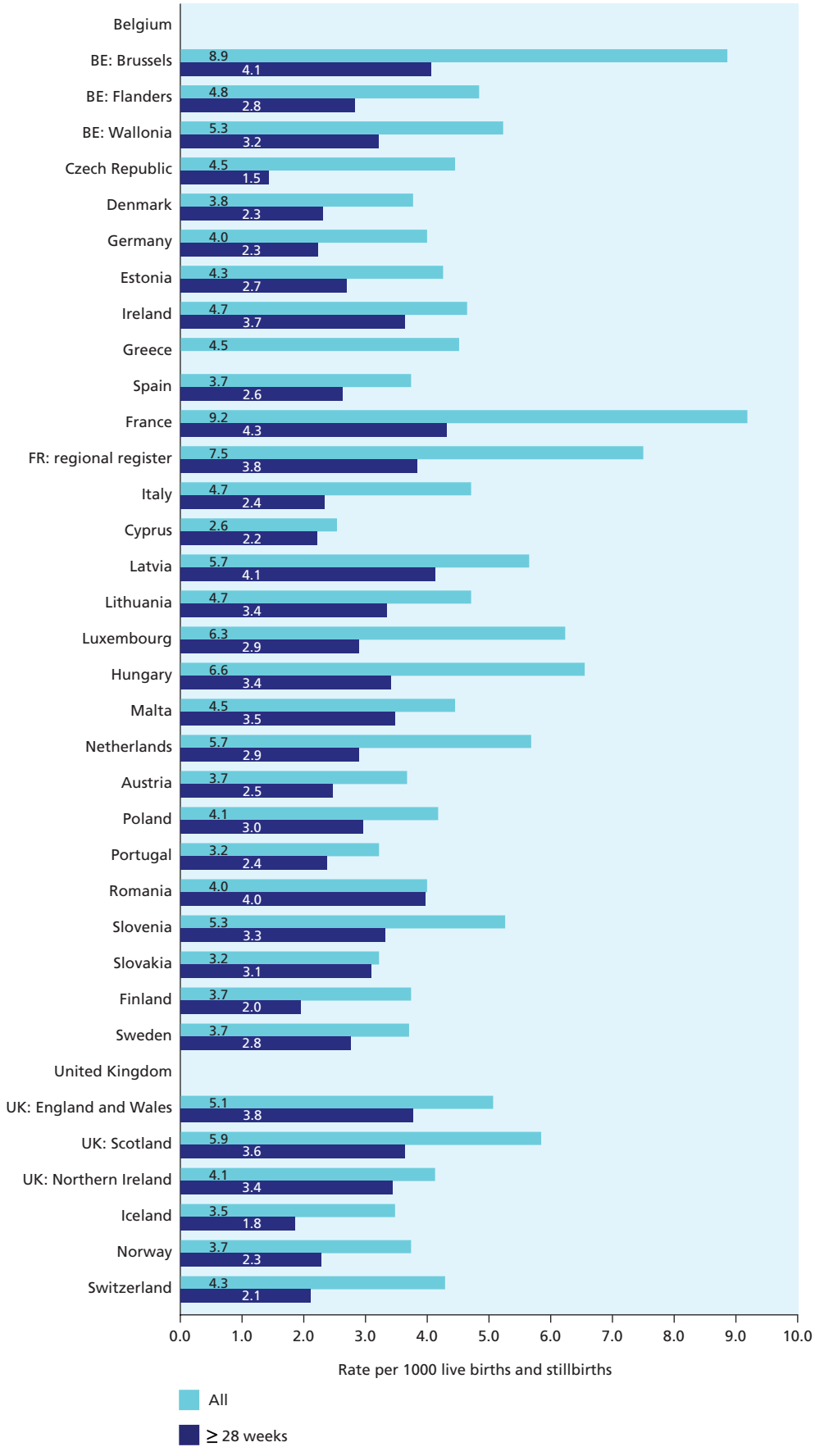


Figure 7.2 Percentage of fetal deaths by gestational-age and birthweight groups from all countries contributing data by these subgroups in 2010

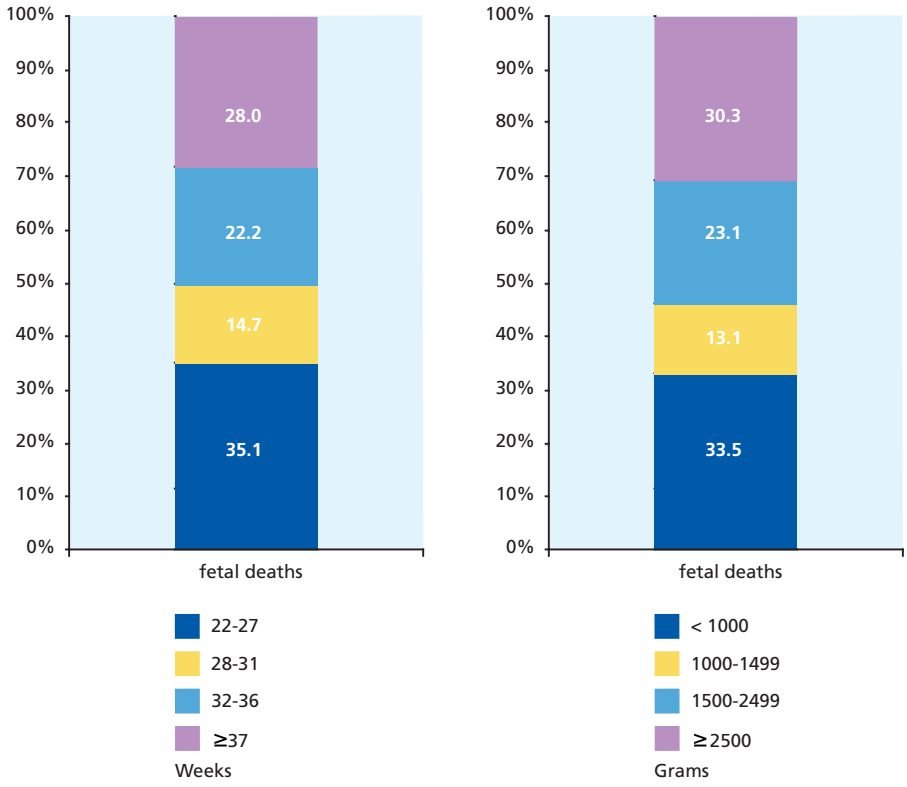
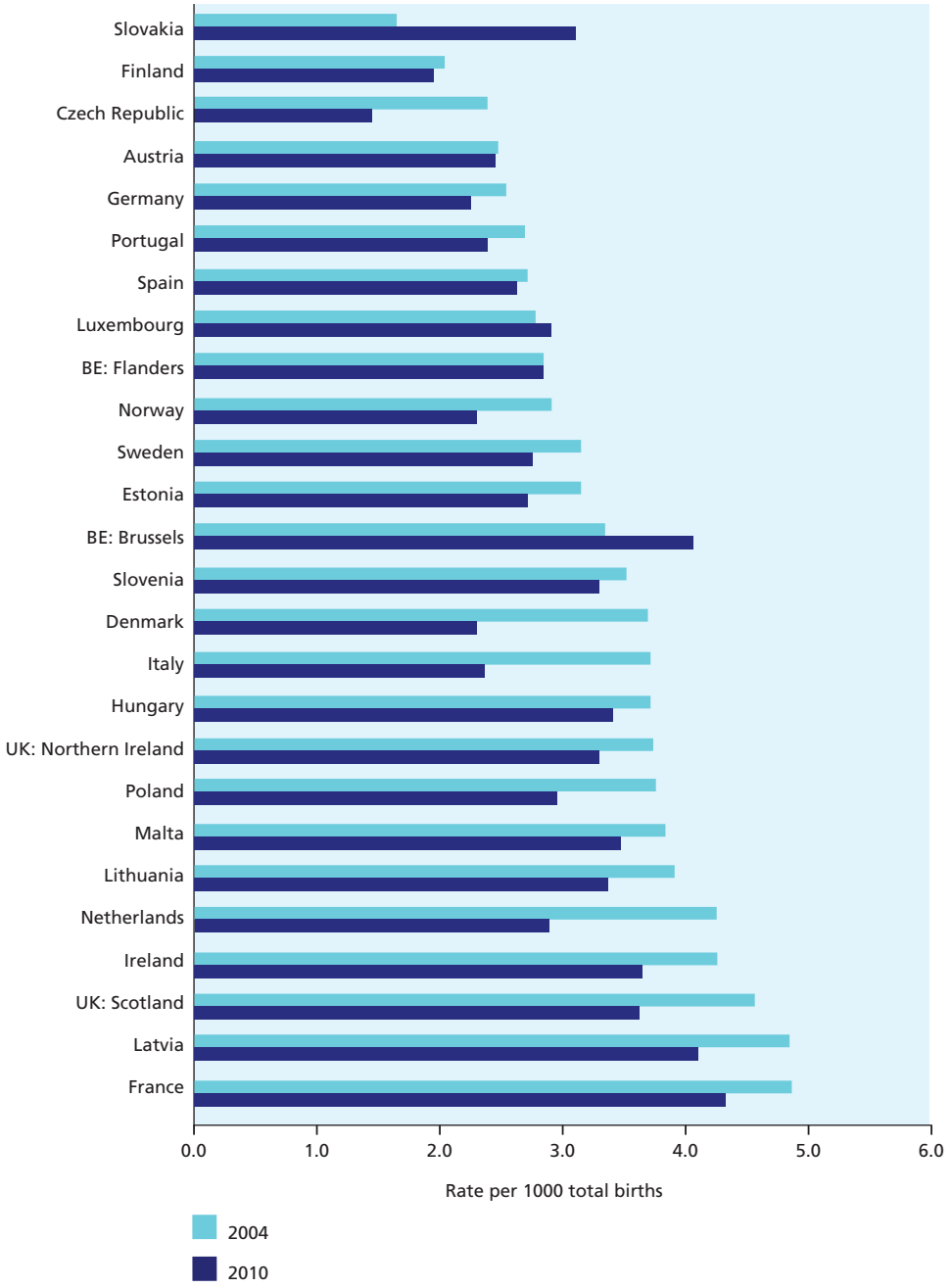


Figure 7.3 Comparison of fetal mortality rates at or after 28 weeks in 2004 and 2010



NOTE: Countries ranked by ascending fetal mortality rate at or after 28 weeks in 2004.

C2 NEONATAL MORTALITY

JUSTIFICATION

The neonatal mortality rate is a key measure of health and care during pregnancy and delivery. Neonatal deaths are subdivided by timing of death into early neonatal deaths (0-6 days after live birth) and late neonatal deaths (7-27 days after live birth). The principal causes of neonatal death in high-income countries are congenital anomalies (see R3) and complications related to very preterm birth (see C5). Babies from multiple pregnancies have neonatal mortality rates 4-6 times higher than singletons.[1] Suboptimal care is also associated with neonatal deaths at term, and these factors contribute to an explanation of the variation in mortality rates between European countries.[2] Healthcare and health-system factors also play a role more generally; for example, for very preterm births, delivery in a maternity unit with on-site neonatal intensive care is associated with lower mortality.[3]

The first *European Perinatal Health Report* showed wide variations in neonatal mortality rates in European countries in 2004.[1,4] In addition, these countries had different patterns of early and late neonatal deaths. New member states of the European Union had high early and high late neonatal mortality rates, while in other countries patterns of either low early with high late or high early and low late rates were observed. In some countries where terminations of pregnancy are not legal, neonatal mortality rates due to congenital anomalies are higher (see R3).[5] The wide variation of gestational age-specific neonatal mortality rates at 22-23 weeks in 2004 suggested that not all births and deaths very early in the neonatal period were systematically included. Even within countries, the reporting of live births at these extremely preterm gestational ages show substantial heterogeneity.[6] Variation in neonatal mortality rates between countries may also reflect differences in policies between European countries related to the resuscitation of babies at the limit of viability.[7]

DEFINITION AND PRESENTATION OF INDICATORS

Data on neonatal deaths are collected for annual and cohort deaths by timing of death, gestational age, birth weight, and plurality. The annual neonatal mortality rate is defined as the number of deaths during the neonatal period (up to 28 completed days after birth) after live birth at or after 22 completed weeks of gestation in 2010, expressed per 1000 live births that year. The cohort neonatal mortality rate is defined as the number of neonatal deaths in 2010 or 2011 at or after 22 completed weeks of gestation occurring to babies born in 2010 expressed per 1000 live births. When gestational-age data were missing, deaths were included if they had a birth weight of at least 500 g. If both gestational age and birth weight were missing, the deaths were not included.

Neonatal mortality rates are presented below as total, early, and late neonatal deaths in Table C2_A. Table C2_B also includes neonatal mortality rates at or after 24 weeks. Figure 7.4 presents neonatal mortality rates by timing of death: early and late neonatal mortality rates. We present annual deaths or, if they are not available, cohort deaths. Figure 7.5 presents overall neonatal mortality rates per 1000 live births and rates at or after 24 completed weeks of gestation in order to take into account differences in registration of extremely preterm live births. The percentage of neonatal deaths by gestational-age groups and birthweight groups are also presented for all countries together in Figure 7.6. Because of the substantial variation in gestational age-specific neonatal mortality rates at 22-23 weeks in 2004, we present trends in neonatal mortality rates (2010 vs. 2004) at or after 24 completed weeks of gestation in Figure 7.7.

DATA SOURCES AND AVAILABILITY OF INDICATORS IN EUROPEAN COUNTRIES

All participating countries were able to provide data on neonatal deaths. Greece provided data on total neonatal deaths from 2009 and Cyprus from 2007. Fifteen countries or regions provided only annual neonatal deaths (Brussels, Flanders, the Czech Republic, Denmark, Germany, Valencia, Catalonia, France, Italy, Cyprus, Hungary, Poland, Romania, Scotland, and Slovakia), 12 provided both annual and cohort neonatal deaths (Flanders, Estonia, Latvia, Lithuania, Luxembourg, Malta, Austria, Portugal, Finland, Northern Ireland, Norway, and Switzerland) and 4 (England and Wales, Ireland, the Netherlands, and Slovenia) submitted only cohort neonatal deaths. There are no data about gestational age in the dataset used routinely in England and Wales to produce annual infant death rates so a 22-week cutoff could not be applied. Cyprus provided no data on neonatal deaths by gestational age, birth weight, or plurality. Italy did not provide data by gestational age or plurality. Data from Ireland were for early neonatal deaths, and Germany and the Czech Republic had data only for early neonatal deaths by gestational age. Hungary provided no data on plurality, and gestational age data were for early neonatal deaths.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATORS

Comparisons of neonatal mortality rates at early gestational ages must be combined with an analysis of fetal mortality rates, since it is possible that early neonatal deaths may be recorded as fetal deaths. Some data recording systems impose a lower limit of 500 g for registration of births, which can create limitations in comparing neonatal mortality rates at low gestational ages (see Summary Table C2_B).

RESULTS

Neonatal mortality rates ranged from 1.2 per 1000 live births in Iceland to 4.5 per 1000 in Malta and 5.5 per 1000 in Romania (Summary Tables C2_A and C2_B). For 10 of the 11 countries where annual and cohort neonatal mortality rates could be compared, differences were minimal (between -0.1 to +0.1 per 1000); the difference was +0.2 per 1000 in Latvia (data not shown in table).

Between 61 and 85% of all neonatal deaths in European countries occurred during the early neonatal period. In Latvia and Romania, rates of late neonatal mortality exceeded 1.0 per 1000 live births. After excluding births and deaths before 24 weeks of gestation, neonatal mortality rates ranged from 0.8 per 1000 live births in Iceland to 4.3 in Romania. The highest mortality rates at gestations of 24 weeks or more were more than 5 times higher than the lowest rates, with Romania, Malta, Latvia, and Poland having the highest rates and Estonia, Iceland, Slovenia, Luxembourg, and Finland the lowest. Countries where terminations of pregnancy are not legal may have higher neonatal mortality rates due to deaths from lethal congenital anomalies, as in Malta.

Babies born before 28 weeks of gestation or under 1000 g accounted for approximately 40% of all neonatal deaths, as shown in Figure 7.6, which combines data from all countries for neonatal deaths at or after 22 weeks of gestation. Slightly over one-quarter of the deaths were of term babies, and 15% of babies born at 22-23 weeks of gestation; 8.5% had a birth weight under 500 g.

TRENDS OVER TIME

Comparison of neonatal mortality rates at or after 24 completed weeks of gestation in 2010 and 2004 was possible for 23 European countries or regions and is presented in Figure 7.7. Countries

are ordered by their neonatal mortality rates in 2004. Ireland was compared for early neonatal mortality at or after 24 weeks. Except for Northern Ireland where the rate in 2010 was 0.5 per 1000 higher, neonatal mortality rates declined in all countries. For smaller countries with low numbers of births (such as Northern Ireland), the differences may be compatible with year-to-year fluctuations.

The largest declines were seen in Estonia, Latvia, and Lithuania. Decreases were most pronounced for countries with higher mortality rates in 2004, but some countries with lower mortality in 2004 achieved significant continued improvements in neonatal outcomes (Slovenia, Finland, and Austria, for example).

KEY POINTS

Wide differences in neonatal mortality rates persisted in European countries in 2010. Compared with 2004, rates declined in most European countries. The largest declines were observed among European countries that were new member states of the European Union in the 2004 data collection, but also among some countries which had lower neonatal mortality rates in 2004.

These data raise questions about the reasons for these disparities in health outcomes. While methodological issues related to registration are less problematic for neonatal than for fetal mortality rates, the inclusion criteria of 500 g or 24 weeks used in some countries may results in lower neonatal mortality rates than in countries where there is no limit for inclusion. Differences in ethical and clinical decisions about babies born very preterm may also contribute to the disparities observed.

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Figure 7.4 Early and late neonatal mortality rates per 1000 live births in 2010

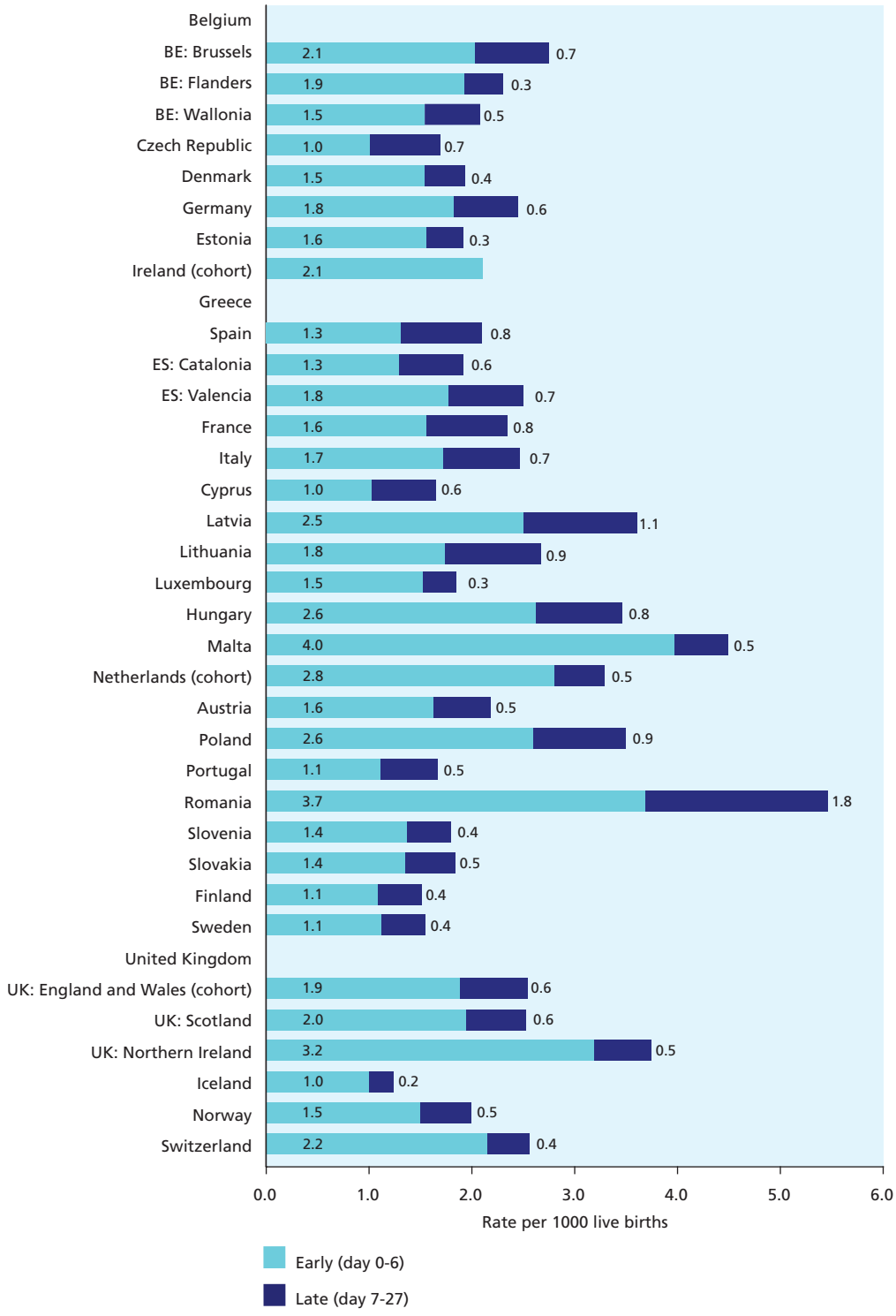
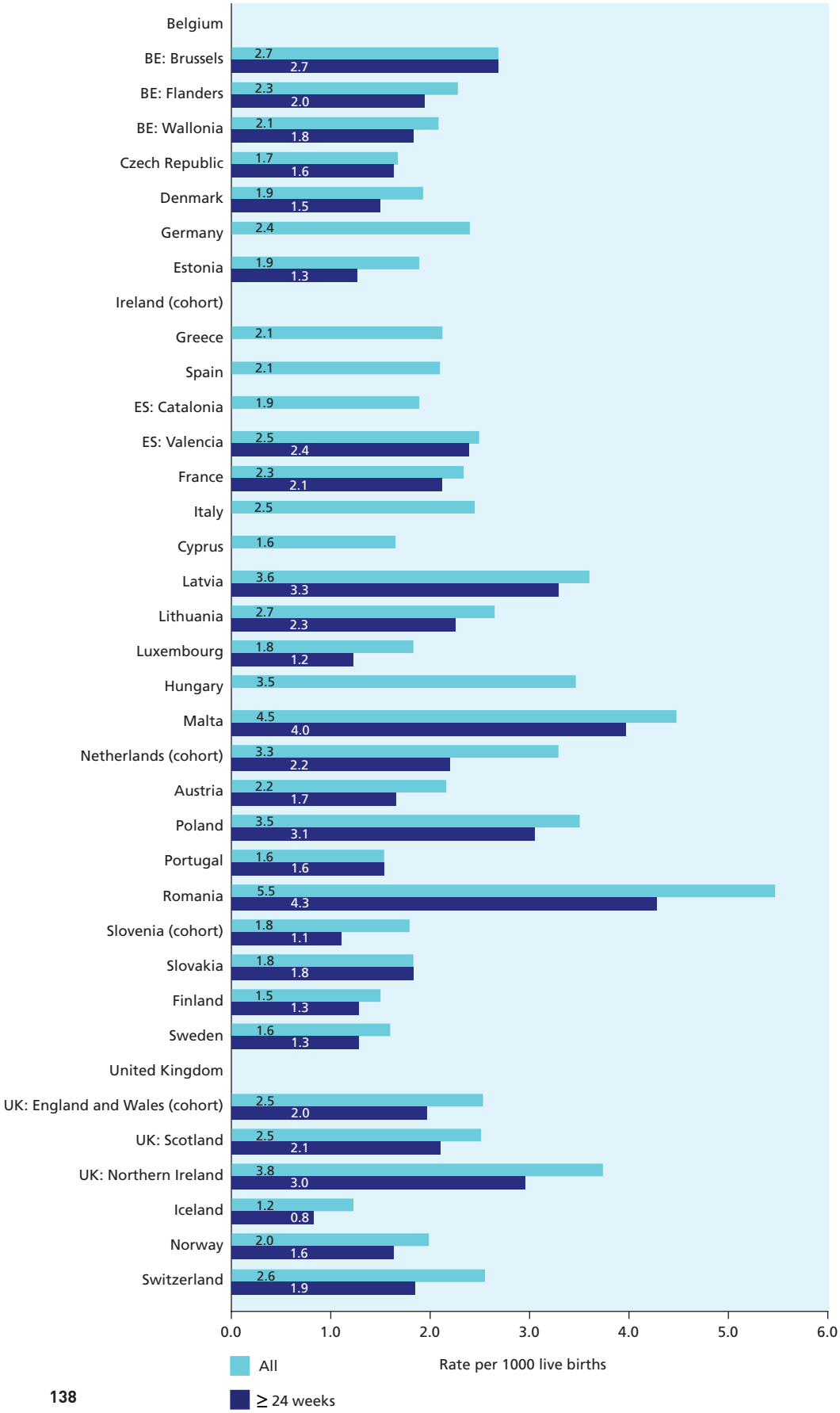


Figure 7.5 Neonatal mortality rates per 1000 live births for all live births and live births at and after 24 weeks of gestation in 2010



NOTE: Rates at ≥24 weeks in France based on estimates (see Summary Table C2B).

Figure 7.6 **Distribution of neonatal deaths by gestational-age and birthweight groups for all live births at or after 22 weeks of gestation in all countries contributing data in 2010**

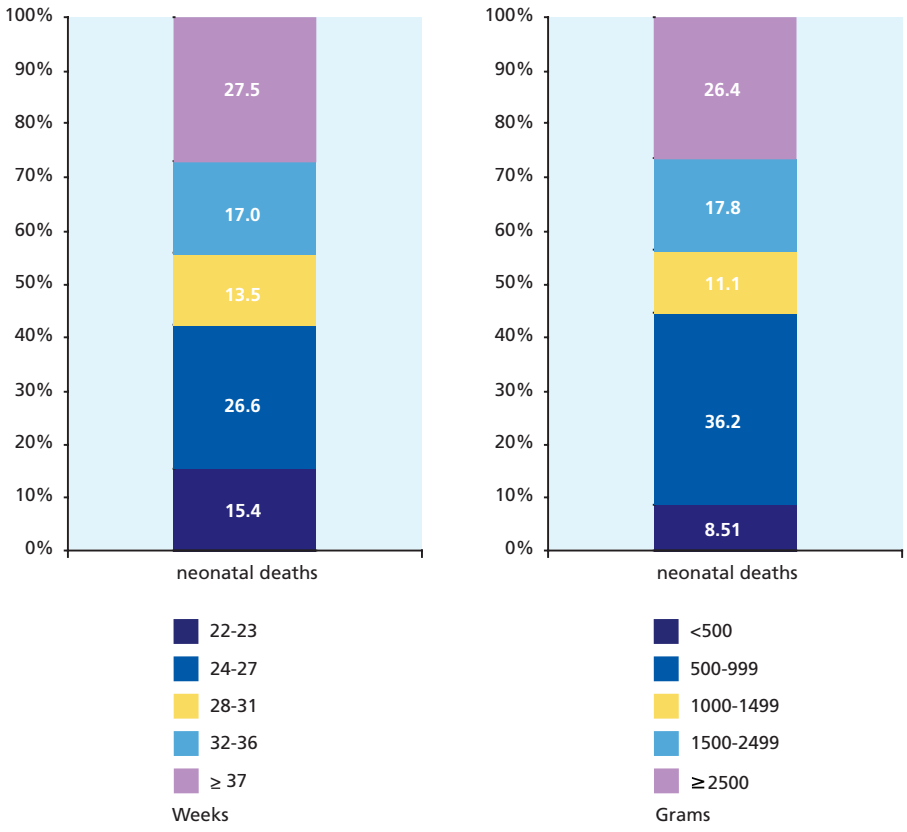
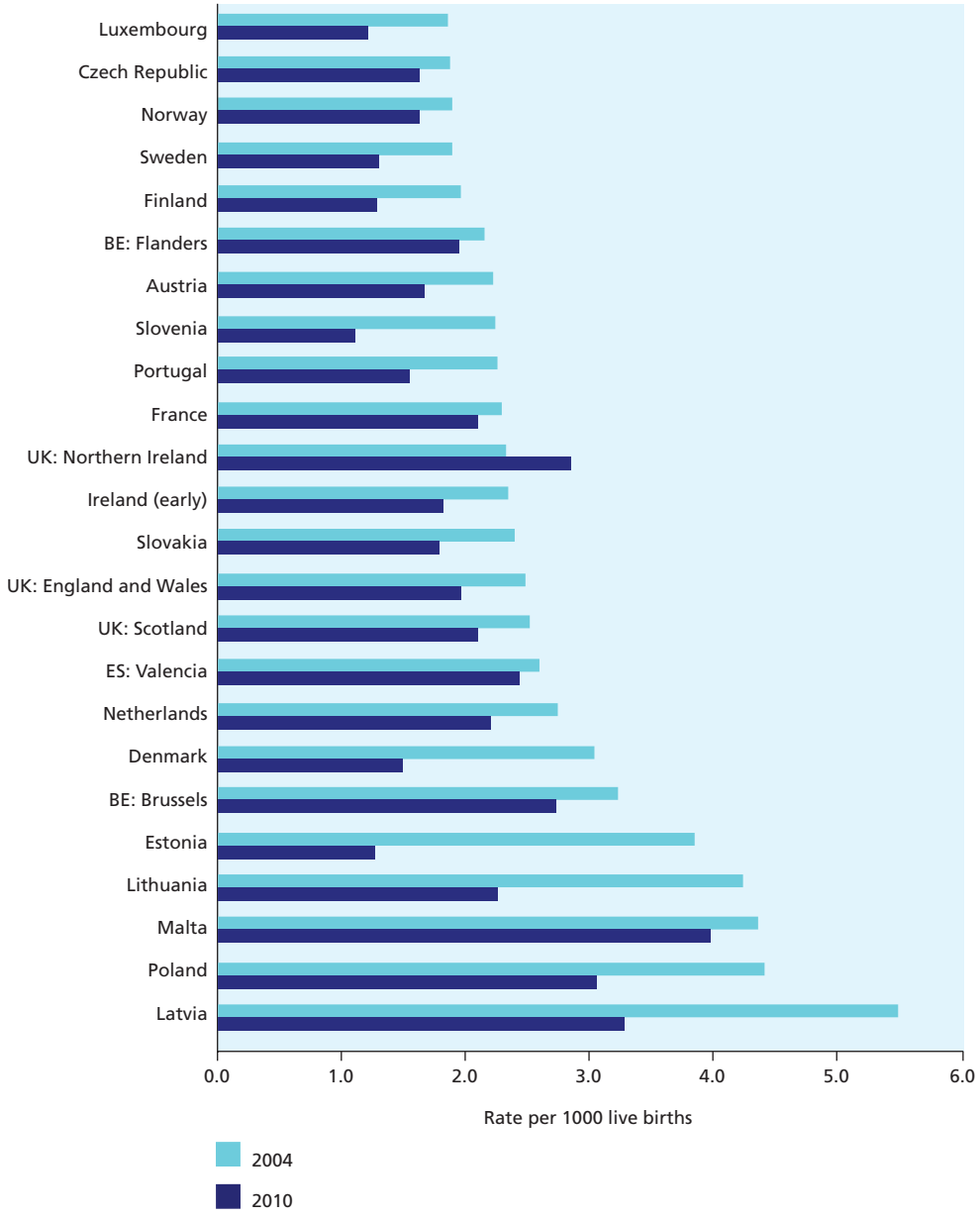


Figure 7.7 Comparison of neonatal mortality rates at or after 24 weeks in 2004 and 2010



NOTE: Countries are ranked according to their mortality rate in 2004.

C3 INFANT MORTALITY

JUSTIFICATION

Even though infant mortality (mortality during the first year of life) extends beyond the perinatal period, it was included as a core indicator by the EURO-PERISTAT group. The infant mortality rate, when presented by gestational age and birth weight, measures the longer-term consequences of perinatal morbidity for high-risk groups, such as very preterm and growth-restricted babies. While most infant deaths due to perinatal causes occur soon after birth, high-risk babies hospitalised in neonatal units after birth can die after the neonatal period. Developments in neonatal care for these high-risk babies are associated with a higher proportion of infant deaths occurring after the neonatal period and this should be taken into consideration in comparisons of mortality over time.[1] The principal causes of death in the post-neonatal period include accidents and infections, which are often preventable, and the post-neonatal mortality rate is more highly correlated with social factors than is the neonatal mortality rate.[2-4] This indicator thus serves as a measure of the quality of medical care and of preventive services.

DEFINITION AND PRESENTATION OF INDICATOR

Data on annual and cohort infant deaths by gestational age, birth weight, and plurality were collected and are presented per 1000 live births in Summary Table C3. The annual infant mortality rate is defined as the number of infant deaths (days 0-364) after live birth at or after 22 completed weeks of gestation in 2010, expressed per 1000 live births in 2010. The cohort infant mortality rate is defined as the number of infant deaths (days 0-364) after live birth at or after 22 completed weeks of gestation occurring to babies born in 2010, expressed per 1000 live births. Infant mortality rates per 1000 live births are presented in Figure 7.8. We present annual deaths or, when they are not available, cohort deaths. Figure 7.9 presents the distribution of infant deaths by gestational-age and birthweight subgroups, and Figure 7.10 trends in infant mortality rates (2010 vs. 2004).

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

Most countries provided data on infant mortality. Compared with 2004, more countries were able to provide data on infant mortality rates by gestational age or birth weight. In many European countries, infant deaths are registered in separate systems and not linked to perinatal data. Countries were able to provide data on infant mortality, however, by linking cause-of-death statistics with medical birth statistics. Greece (for 2009 at 24+ weeks), France, Cyprus (for 2007), Lithuania, and the Netherlands (also 24+ weeks only) submitted numbers of overall infant deaths without tabulations by subgroup. More countries/regions provided data about annual infant deaths than about cohort infant deaths. Flanders, Estonia, Latvia, Lithuania, Luxembourg, Malta, Austria, Slovenia, Finland, Norway, and Switzerland submitted both annual and cohort infant deaths. England and Wales, the Netherlands, and Northern Ireland had numbers of cohort infant deaths only.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Most European countries had no lower limit for registration of live births in 2010, which made it possible to provide data on live births based on the EURO-PERISTAT definition of 22+ weeks of gestation and make valid comparisons at early gestational ages. However, in many European countries, data on infant deaths come from cause-of-death registers, which often do not record information on birth characteristics. Countries had to merge cause-of-death statistics with medical

birth registers to have complete information on infant deaths by gestational age, birth weight, and plurality. In addition, only 12 of 35 countries/regions were able to provide cohort infant deaths, which limits the use of these data for studying outcomes of high-risk groups, since if deaths are not linked to births, information will not be available about birth characteristics, such as multiplicity, gestational age, and birth weight.

RESULTS

Infant mortality rates at or after 22 completed weeks of gestation in 2010 ranged from 2.3 per 1000 live births in Iceland and Finland to 5.5 in Malta, 5.7 in Latvia, and 9.8 in Romania. In total, 18 200 infant deaths and 4 668 395 live births were registered in 2010 (weighted average: 3.2 per 1000 live births). Romania, a relatively new member of the European Union, had a very high infant mortality rate, similar to the infant mortality rates observed among the new member states of the EU in the 2004 data collection. Differences in cohort versus annual infant mortality rates were minimal in most countries where this comparison was possible (ranging from -0.1 to 0.0 per 1000 live births). In countries where terminations of pregnancy are not legal, infant mortality rates are likely to be higher.

Figure 7.9 illustrates the distribution of infant deaths at or after 22 completed weeks of gestation by gestational-age and birthweight subgroups in all countries contributing data. Almost 40% of all infant deaths occurred to babies born near and at term (≥37 weeks of gestation), and babies weighing at least 2500 g at birth accounted for 36% of all infant deaths in European countries in 2010.

TRENDS OVER TIME

Comparison of 2010 and 2004 infant mortality rates at or after 22 completed weeks of gestation was possible for 24 countries or regions and is presented in Figure 7.10. Except for Northern Ireland and Brussels, where rates in 2010 were respectively 1.4 and 0.4 per 1000 live births higher than in 2004, infant mortality rates declined in most countries. The largest differences in infant mortality rates were seen in Latvia (-3.6 per 1000), Estonia (-3.5) and Lithuania (-3.1).

Decreases tended to be more pronounced for countries with higher mortality rates in 2004 (Estonia, Denmark, Latvia, and Lithuania), but some countries with low mortality rates achieved significant continued improvements in outcomes (for example, Finland where the rate declined from 3.4 to 2.3 per 1000 live births). Wide variations in infant mortality rates persisted in 2010, with the highest rate (9.8 per 1000) more than 4 times higher than the lowest (2.3).

KEY POINTS

Infant mortality rates in 2010 declined in most European countries compared with 2004. However, mortality rates still varied substantially between European countries, with rates highest among relatively new member states. More than 60% of the infants who died were born preterm or with a birth weight under 2500 g.

More countries were able to present infant mortality data by gestational age, birth weight, and plurality, which makes it possible to monitor outcomes of high-risk births in the first year of life. However, only one third of participants were able to provide data on cohort infant deaths. Routine linkage of medical birth statistics with cause-of-death statistics is necessary to study outcomes of high-risk infants at the European level.

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Figure 7.8 Infant mortality rates per 1000 live births at or after 22 weeks in 2010

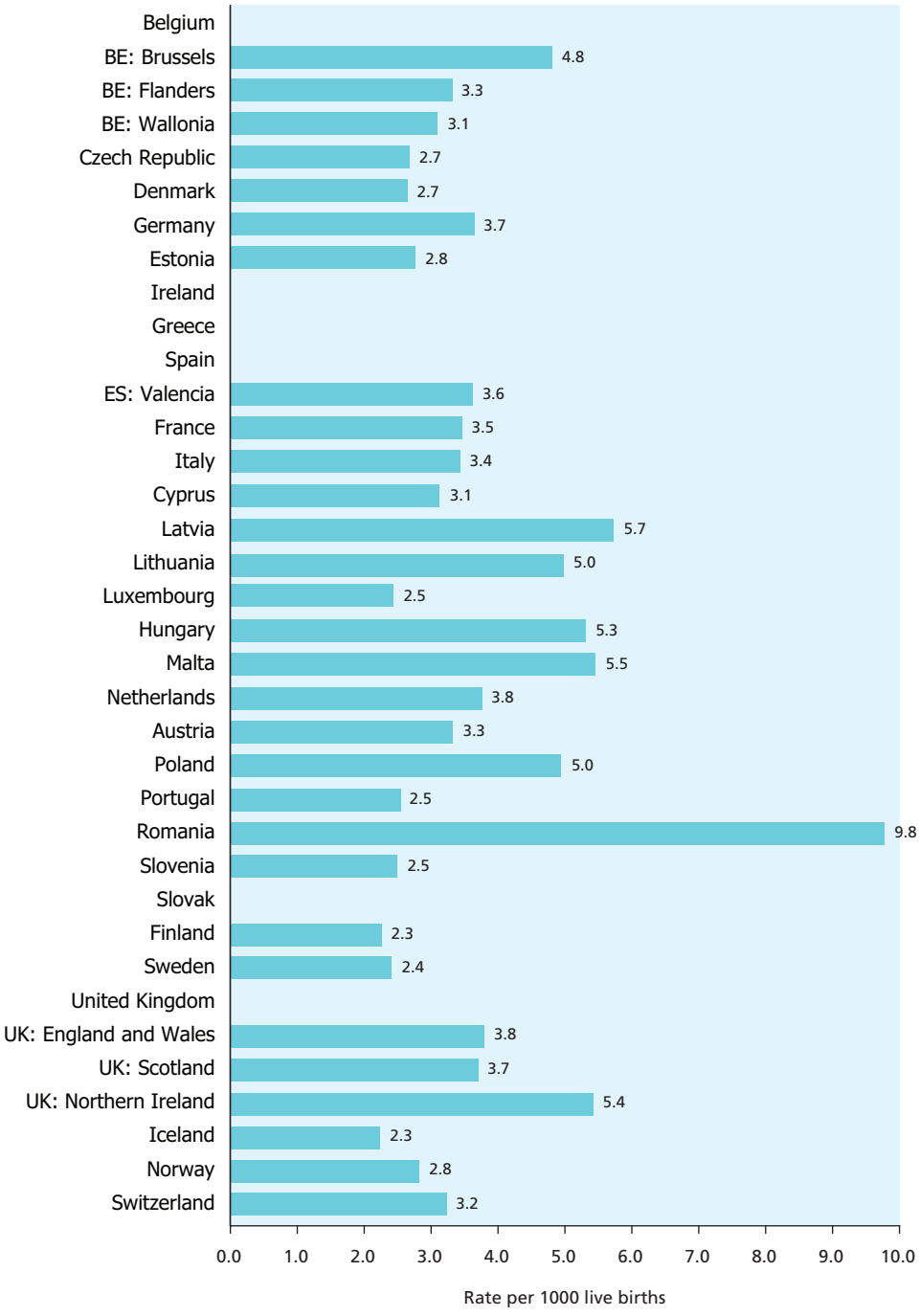


Figure 7.9 Distribution of infant deaths by gestational-age and birthweight subgroups in 2010

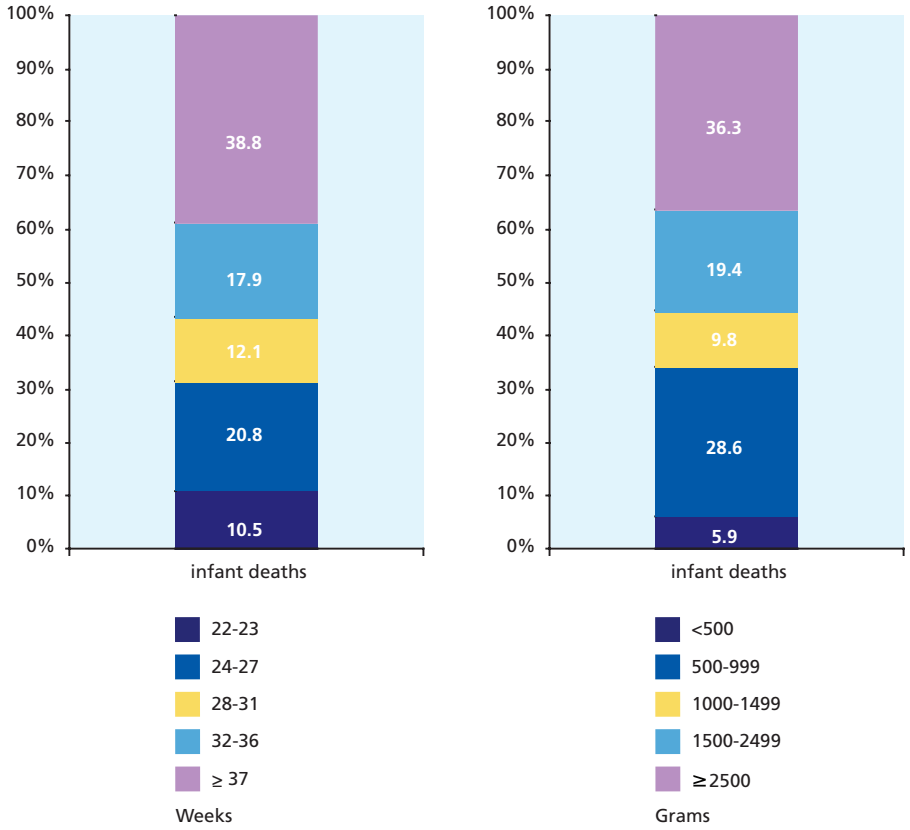
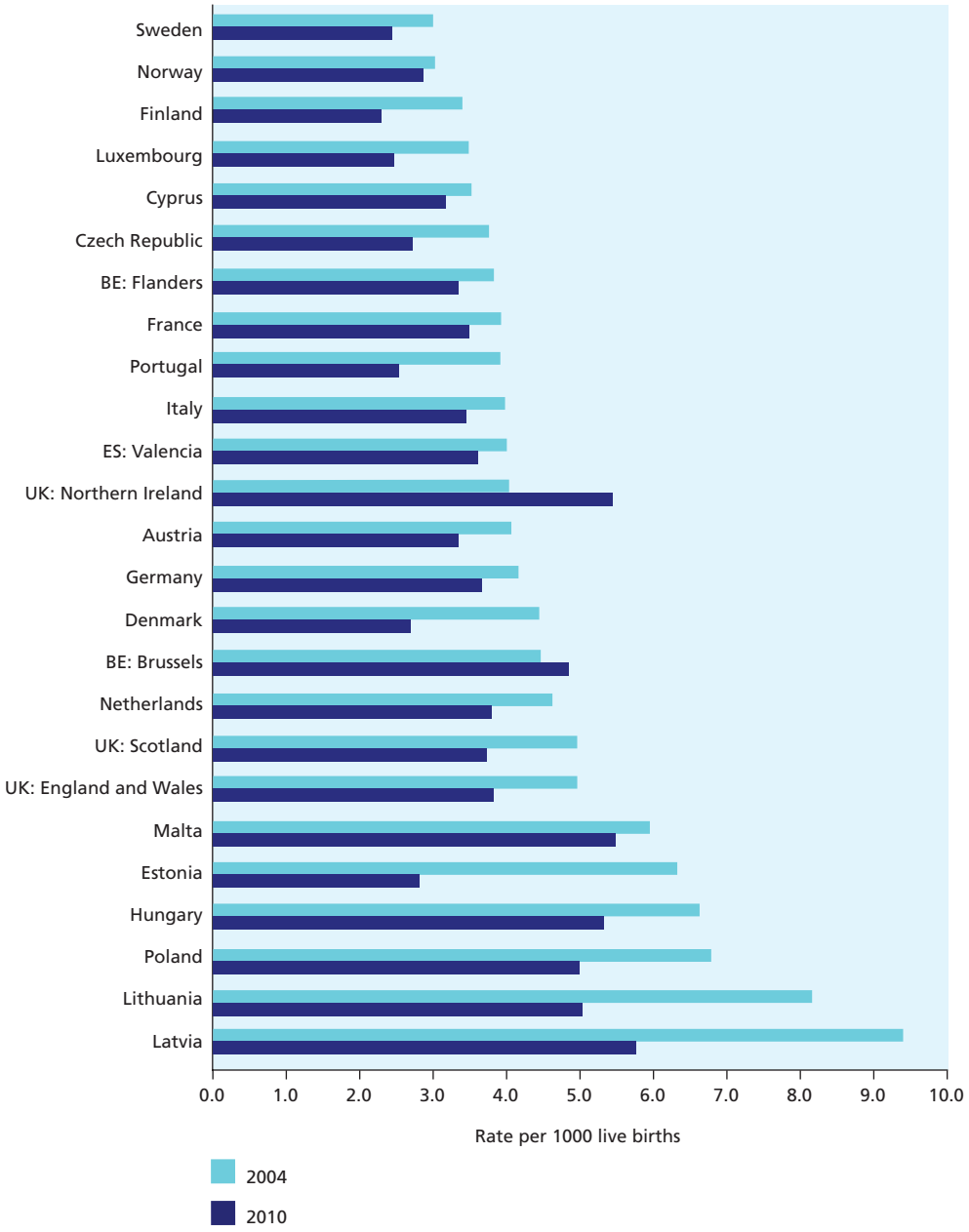


Figure 7.10 Comparison of infant mortality rates at or after 22 weeks (2010 vs. 2004)



NOTES: Some countries could not provide 22-week definition requested by EURO-PERISTAT. Please see Summary Table for indicator C3 in Appendix B. Countries ranked by ascending fetal mortality rates in 2004.

C4 DISTRIBUTION OF BIRTH WEIGHT

JUSTIFICATION

Babies with a low birth weight are at higher risk of poor perinatal outcome and of long-term cognitive and motor impairments.[1-3] The proportion of babies with a birth weight under 2500 g is a widely used indicator for assessing the population at risk, and historical series exist for many countries. Babies with a birth weight under 1500 g are termed very low birthweight (VLBW) babies and are at the highest risk. Twins and triplets have much higher rates of low birth weight than singletons. Babies have a low birth weight because they are born before term (see C5) or because of fetal growth restriction (FGR) or for both these reasons. Some healthy term babies can also have a low birth weight because they are constitutionally small.

FGR is a major complication of pregnancy and is a cause of stillbirth, poor neonatal outcome, and impairments later in life.[1-4] When analysed by gestational age, birthweight distributions provide an indication of growth restriction. FGR is associated with maternal, placental, and fetal conditions, including hypertension and congenital anomalies. Poor fetal growth may also have serious consequences in adult life: it has been associated with a higher prevalence of ischaemic heart disease, other cardiovascular disease, obesity, diabetes, and metabolic syndrome.[4] Management of FGR during pregnancy consists of monitoring the fetus and inducing delivery when there are clinical signs of hypoxia. However, the best time to deliver growth-restricted babies has yet to be determined.[5] Risk factors for FGR include maternal smoking (see R8), low body mass index (see R12), and lower socioeconomic status (R9).

Macrosomia or high birth weight (4500 g and over) is also associated with pregnancy complications.[6] Higher extremes of birth weight may be a consequence of maternal diabetes. Diabetes is associated with older maternal age (see C8) and heavier prepregnancy weight (see R12). More generally, overweight and obese women have a greater risk of macrosomia, a cause of obstetric complications such as shoulder dystocia and other complications which may lead to caesarean delivery.

DEFINITION AND PRESENTATION OF INDICATOR

This indicator is defined as the number of births within each defined birthweight interval, expressed as a proportion of all registered live births and stillbirths. It is computed by vital status at birth, gestational age, and plurality. The indicators selected for inclusion in this summary are live births weighing less than 1500 and 2500 g. This second indicator is habitually presented in international comparisons of births. We focus on live births because registration of live births is more homogenous in Europe than the registration of stillbirths, and this indicator will thus be more comparable (for a discussion of this issue, see indicator C1 on fetal mortality and Chapter 3). The complete distribution of birth weight by vital status is given in Appendix B.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

This indicator was available in almost all countries, although not all countries presented it by multiplicity.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Birth weight is an accurately measured data item, but its interpretation is not always obvious. Low birth weight is associated with 2 distinct complications of pregnancy: preterm birth and FGR. Ideally, growth restriction should be measured with respect to the third or tenth percentile of birth weight at each gestational age. However, agreed-upon norms for birth weight do

not exist. The existence of physiological variation in birth weight in Europe must be taken into consideration when interpreting differences between countries. In other words, some populations may have a lower average normal birth weight than others due to genetic variations in population size. It has been shown that the birth weight associated with the lowest mortality rates differs between European countries.

RESULTS

The percentage of live births with a birth weight under 2500 g ranged from 3.4% to 9.8% of all births in the countries providing data for this indicator. Countries from northern Europe had the lowest percentages of low birth weight (Denmark, Estonia, Ireland, Latvia, Lithuania, Finland, Sweden, Iceland, and Norway). This geographical variation in low birth weight is illustrated in the map in Figure 7.12. Most of the variation in overall rates is due to births between 1500 and 2499 g. The percentage of VLBW babies ranged from 0.3 (Iceland) to 1.4 (region of Brussels and Hungary).

Proportions of low birth weight in 2010 remained similar to those in 2004 for many of the 27 countries or regions for which data are available in both periods. However, some countries experienced declines in their low birth weight rate (France, Scotland, England and Wales, Malta, and Poland) and others increases (Luxembourg, Spain, Brussels region, Czech Republic, Slovakia, and Portugal).

KEY POINTS

About one in 20 babies born in Europe in 2010 weighed less than 2500 g at birth. This proportion varied by a factor of 3 between countries. However, some of this variation may be due to physiological differences in size between populations. A common European approach should be developed to distinguish between constitutionally small babies and those with growth restriction.

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Figure 7.11 Percentage of live births with a birth weight under 2500 grams in 2010

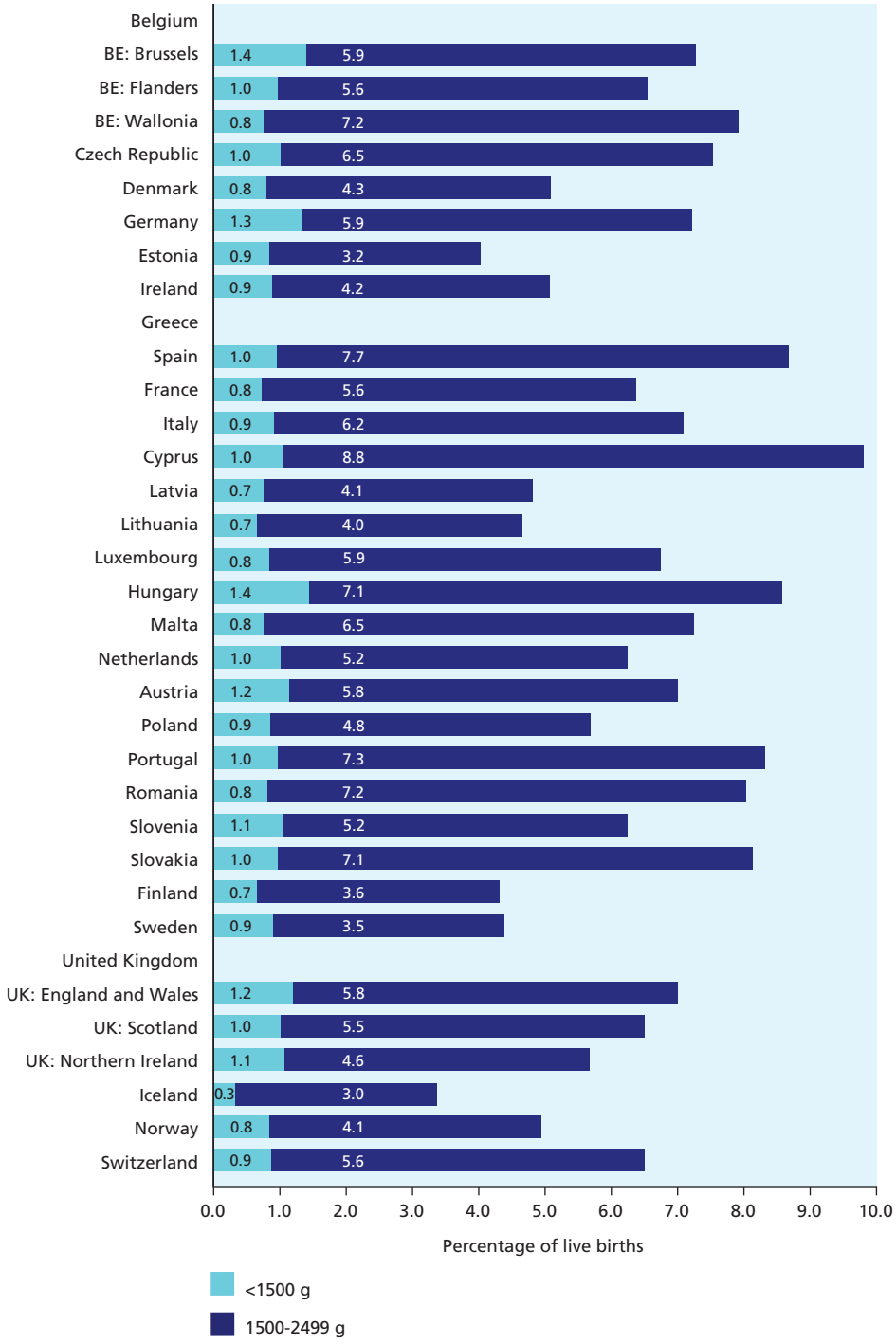
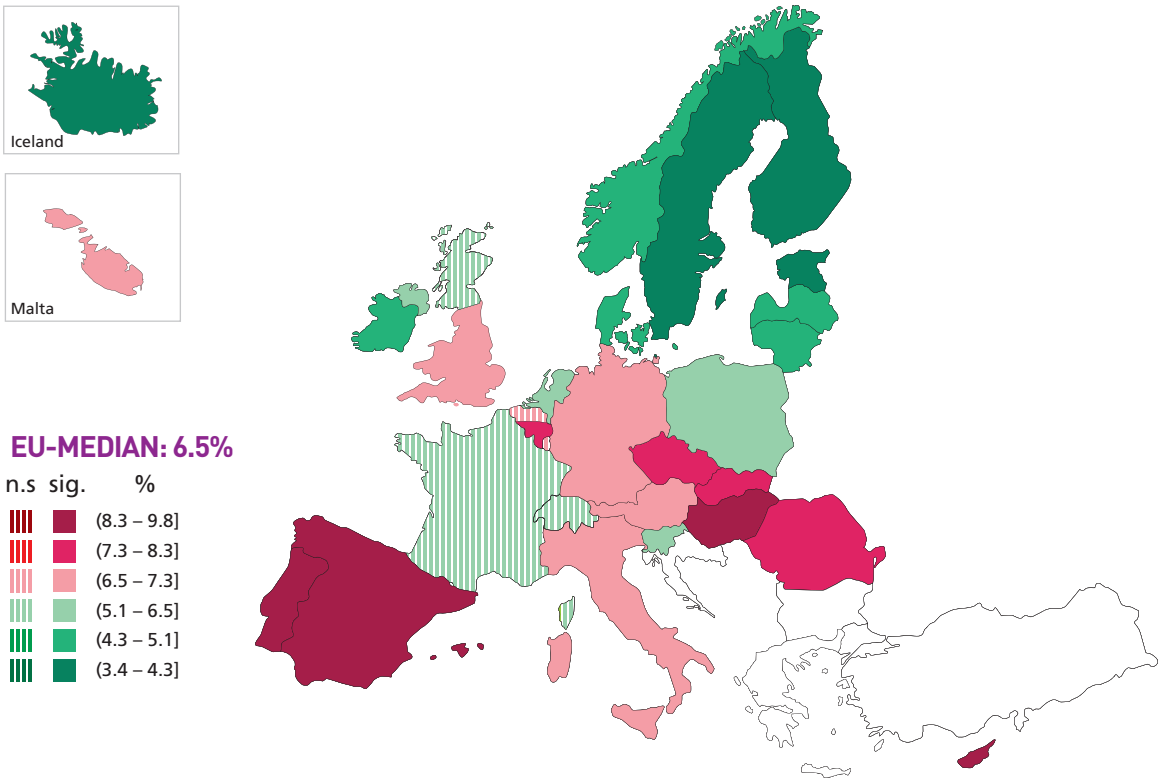
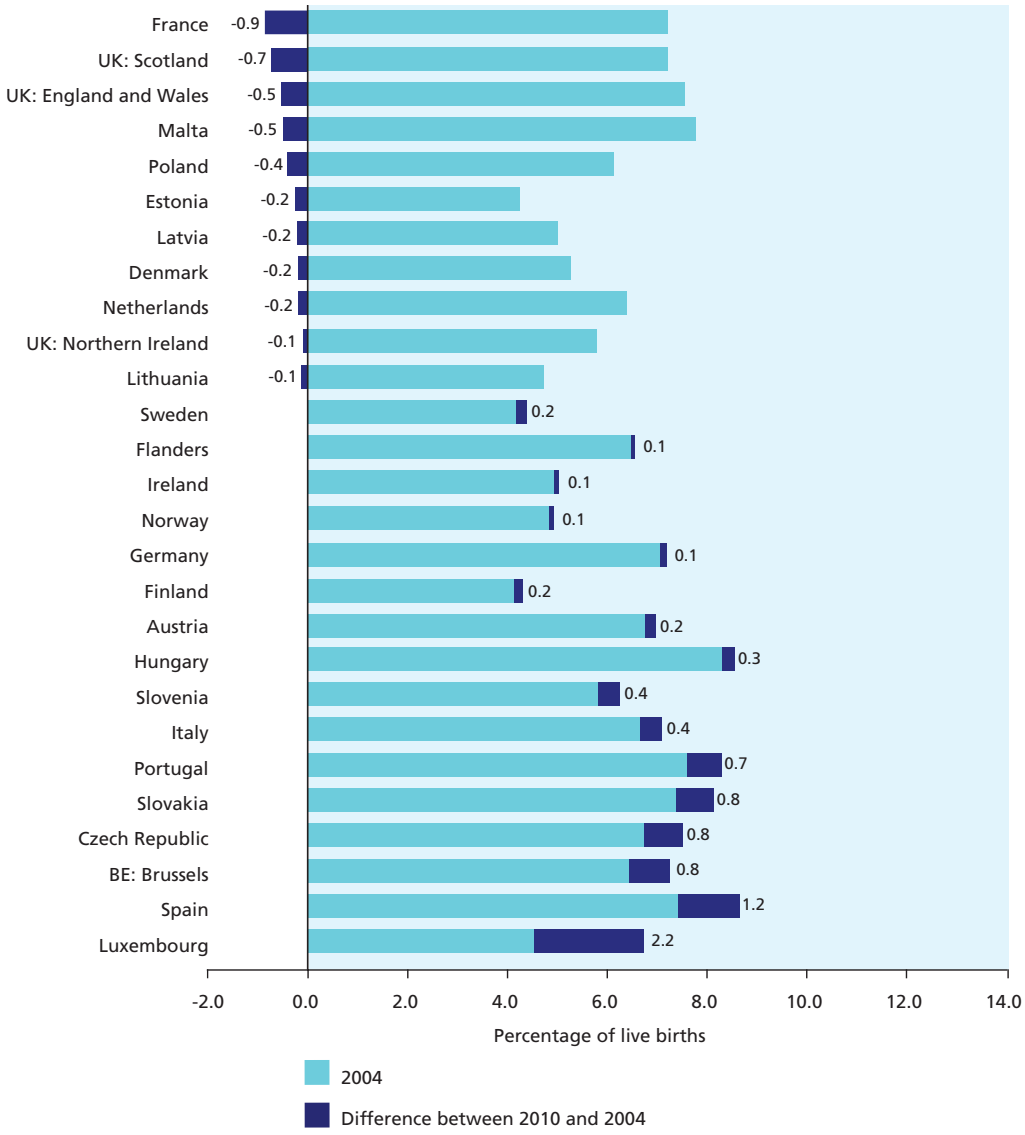


Figure 7.12 Map of distribution of live births with low birth weight (< 2500 grams) in 2010



NOTE: Rates for countries and regions are coloured for groups defined by the 10th, 25th, 50th, 75th, 90th, and 100th percentiles of the indicator. Individual regions are coloured to show sign and significance of difference from the EU median. Regions that fall outside the 99.9 percent Wilson-score control limits of a funnel plot constructed around the EU-median against population size differ significantly (sig) and are shown as solid colours. Regions within the control limits (n.s.) are displayed with vertical hatching.

Figure 7.13 Percentage of live births with birth weight under 2500 grams in 2004 and difference between 2010 and 2004



NOTE: Countries ranked according to increasing difference between 2004 and 2010.

C5 DISTRIBUTION OF GESTATIONAL AGE

JUSTIFICATION

Babies born preterm, defined as before 37 completed weeks of gestation, are at higher risk of mortality, morbidity, and impaired motor and cognitive development in childhood than infants born at term. In high-income countries, between two-thirds to three-quarters of neonatal deaths occur to the 6% to 11% of infants live born before 37 weeks.[1] Babies born before 32 weeks of gestation are at particularly high risk of adverse outcomes, with rates of infant mortality between 10% and 15% and of cerebral palsy between 5% and 10%,[2,3] but moderate preterm birth (32 to 36 weeks of gestation) is also associated with poor outcomes at birth and in childhood.[4,5] Being born preterm predisposes children to higher risks of chronic diseases and mortality later in life.[6]

Many countries have reported increased preterm birth rates over the past 2 decades, and this general trend was recently confirmed by a WHO global survey.[7] Reasons for these increases include rising multiple pregnancy rates, associated with subfertility treatments (see C7 and R13), and changes in population risk factors such as maternal age (C8) and higher maternal BMI (R12). Also, survival of preterm infants has improved markedly over recent decades due to medical advances in neonatal care and this has changed perceptions of risk associated with prematurity versus other pregnancy complications. It has lowered the threshold for indicated (alternatively termed non-spontaneous or provider initiated) preterm births and led to an increase in these births. Finally, progress in the prevention of preterm birth has been limited. However, analysis of data between 1996 and 2008 in the Euro-Peristat group found that trends were more heterogeneous in Europe, especially for singleton preterm births, and that preterm birth rates have decreased in some countries.[8]

Post-term births are also associated with poor outcomes, and wide variations in rates in Europe illustrate differences in approaches to the management of prolonged pregnancies.[9]

DEFINITION AND PRESENTATION OF INDICATOR

This indicator is defined as the number of live births and fetal deaths at each completed week of gestation (starting from 22 weeks), expressed as a proportion of all live births and stillbirths. This distribution is presented as follows: 22-36 weeks of gestation (preterm births); 37-41 weeks (term births); 42 or more weeks (post-term). Preterm births can be subdivided as 22-27 weeks (extremely preterm), 28-31 weeks (very preterm), and 32-36 weeks (moderately preterm). This indicator is computed by vital status at birth and plurality.

The summary indicators presented below are computed for live births. We focus on live births because registration of live births is more homogenous in Europe than the registration of stillbirths, and this indicator will thus be more comparable (for a discussion of this issue, see the indicator on fetal mortality in this chapter and Chapter 3). The complete distribution of gestational age for total births is provided in the Summary Tables in Appendix B.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

This indicator is available in most European countries.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

EURO-PERISTAT requests data on gestational age based on the *best obstetrical estimate*, which combines clinical and ultrasound data. However, we do not know how this best estimate is derived, and it may vary by country as well as between health providers within countries. Ultrasound is widely used for dating pregnancies in Europe, however, and most women receive care in the first trimester of pregnancy (see R14). The method of determining gestational age can influence the reported gestational age distribution; use of ultrasound estimates tends to shift the distribution to the left and increase the reported preterm birth rate,[10] although not all studies have found this to be the case.[11] Research about the methods used within Europe for determining gestational age and their impact on the gestational age distribution should be undertaken to better elucidate the comparability of this indicator.

RESULTS

The preterm birth rate for live births varied from about 5% to 10% in Europe. We observed relatively lower preterm birth rates (below 6.5%) in Iceland, Lithuania, Finland, Estonia, Ireland, Latvia, Sweden, Norway, and Denmark, and higher rates (above 8.5%) in Cyprus (10.4%) and Hungary (8.9%). Rates were around 8% in Austria, Germany, Romania, the Czech Republic, Luxembourg, Portugal, the Netherlands, and all regions of Belgium.

Similar relations between preterm birth rates are observed for both singleton and multiple births, with the exception of Romania where a relatively high proportion of singleton preterm births is accompanied by a relatively low proportion of multiple preterm births. The percentage of preterm births ranged from 4.1 to 7.6% among singletons and from 39.6 to 66.9% among multiples (See Summary Tables C5_B). Very preterm births, that is, births before 32 weeks of gestational age, accounted for about 1% of live births (range: 0.7 to 1.4%).

Proportions of preterm live births were similar to those in 2004 for many of the countries for which data were available. However, rates increased over this period in Luxembourg, Brussels, the Czech Republic, Portugal, Northern Ireland, and Italy. On the other hand, Norway, Scotland, Germany, England and Wales, Denmark, and Sweden experienced declines. Rates in Austria in 2004 and 2010 were not compared because their definitions of gestational age changed.

KEY POINTS

Gestational age is an essential indicator of perinatal health but is still not currently included in international data sets, although the data are available almost everywhere and should be routinely reported. The most vulnerable babies, those born before 32 weeks of gestation, account for about 1% of all births.

There are wide differences in the prevalence of preterm birth between European countries, and these data confirm heterogeneity in trends observed in more detailed analyses of data from 1996 to 2008.[8] The fact that rates are stable or declining in many countries goes against widely held beliefs that preterm birth rates are rising and raises questions about policies and practices associated with these divergent trends between countries.

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Figure 7.14 Percentage of live births with a gestational age <32 weeks and between 32-36 weeks in 2010

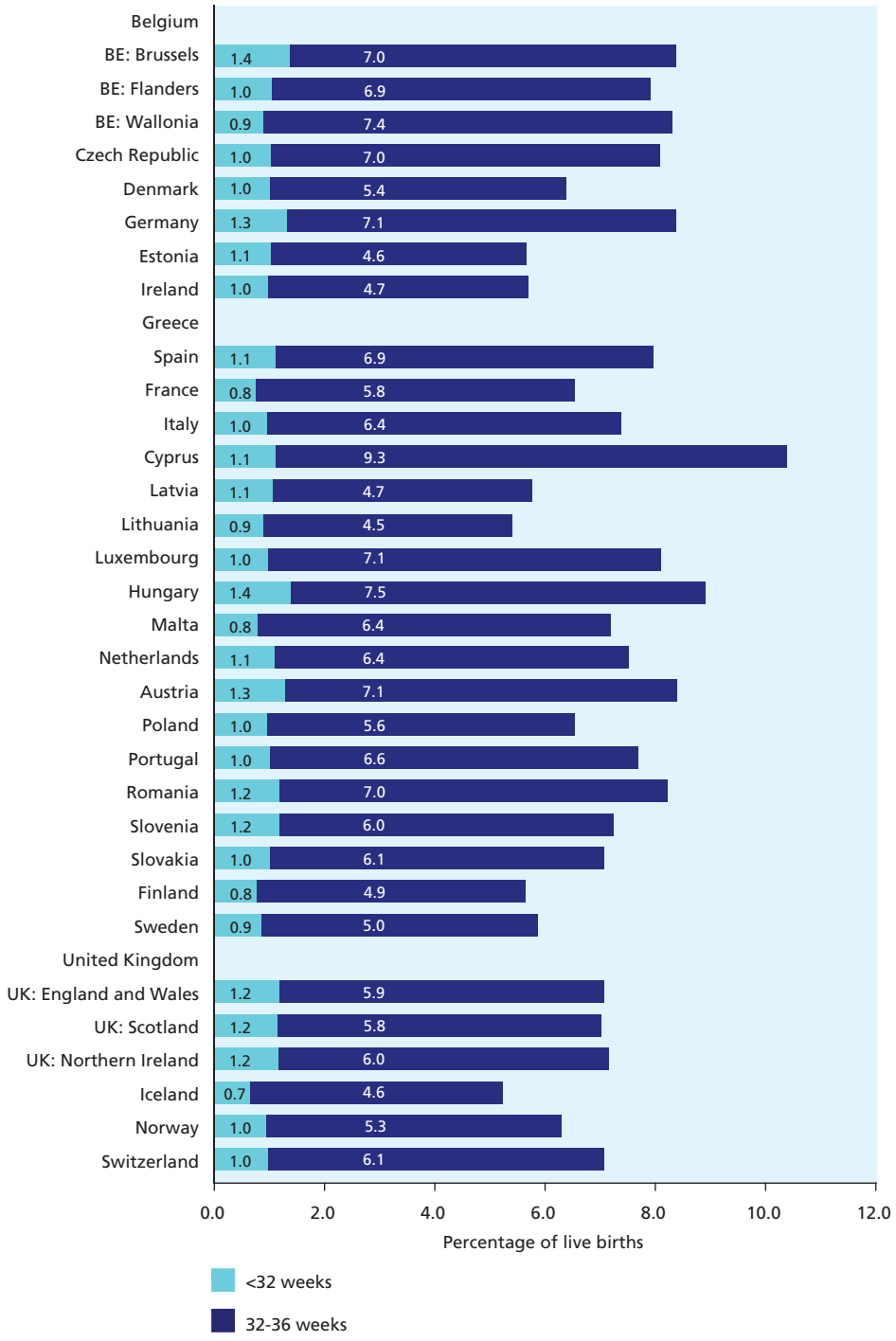
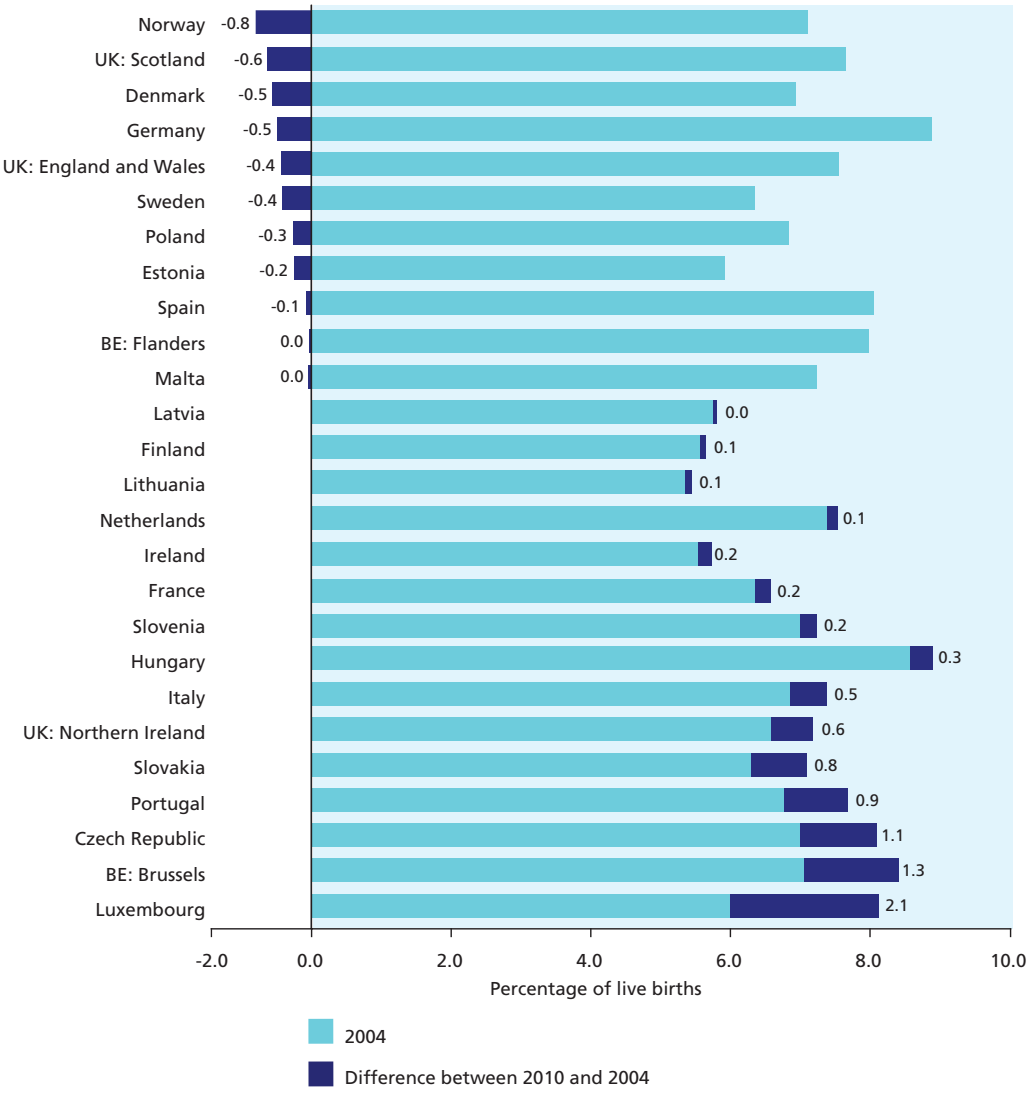


Figure 7.15 Percentage of preterm live births in 2004 and difference between 2010 and 2004



NOTES: Countries ranked according to increasing difference between 2004 and 2010. Data for England and Wales were for 2005 not 2004.

R2 DISTRIBUTION OF 5-MINUTE APGAR SCORES AMONG LIVE BIRTHS

JUSTIFICATION

The Apgar score was defined by Dr Virginia Apgar in 1952.[1] It is a standardised assessment of newborns that comprises 5 items: heart rate, respiratory effort, muscle tone, reflex irritability, and colour. Each item is scored 0, 1, or 2, and thus the total score ranges from 0 to 10. It is usually assessed at 1 minute, at 5 minutes, and at 10 minutes after birth in most facilities in most countries. Both term and preterm babies with an Apgar score of 0 to 3 have a higher risk of early neonatal death. At 1 minute, the Apgar score can be used to determine which children need resuscitation and, at 10 minutes, which children still require resuscitation.

The value of the Apgar score at 5 minutes is highly correlated with neonatal mortality and provides the best predictive value for subsequent mortality. A low Apgar score was retained recently as one of the elements that suggest intrapartum asphyxia insult as the cause of cerebral palsy.[2] The Apgar score provides good information about the infant's activity and responsiveness, but should not be used alone to predict survival without brain injury or disability, especially in preterm babies.[3,4]

DEFINITION AND PRESENTATION OF INDICATORS

This indicator is collected as the distribution of the Apgar score for all live births at or after 22 completed weeks of gestation. The 2 cutoff points at which the indicator is presented here — less than 4 and less than 7 — are those most often encountered in the literature.

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

Twenty-three countries or regions provided data on this indicator. The proportion of missing values was 1% or less in most countries, excluding Finland (15.2%) where 5-minute Apgar scores are not routinely given and/or recorded if the scores at 1 minute are high. In Wales, missing observations were also higher (8.6%).

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

Although the Apgar score is supposed to be a standardised measure, there can be some subjectivity and differences between countries in the value recorded for each element of the Apgar score. Percentages are calculated from valid values (excluding those not stated). Another difficulty is due to the counting of missing values: missing values should not be coded as 0 and then classified in the group of values of 0-3.

RESULTS

Overall, under 2% of children had low 5-minute Apgar scores, with the exception of Iceland (2.0%) and Finland (2.4%); Finland had a high proportion of missing cases, as noted above, and is not comparable with the other countries. The highest proportions of Apgar scores below 4 at 5 minutes were observed in Scotland and Estonia (0.5-0.7%); these countries also had high proportions of 5-minute Apgar scores below 7. This proportion seems rather low in some countries but this could arise from under-reporting. Variations in the data collection process may partially explain these differences between countries.

KEY POINTS

One to two percent of children born alive have difficulties at birth that require resuscitation.

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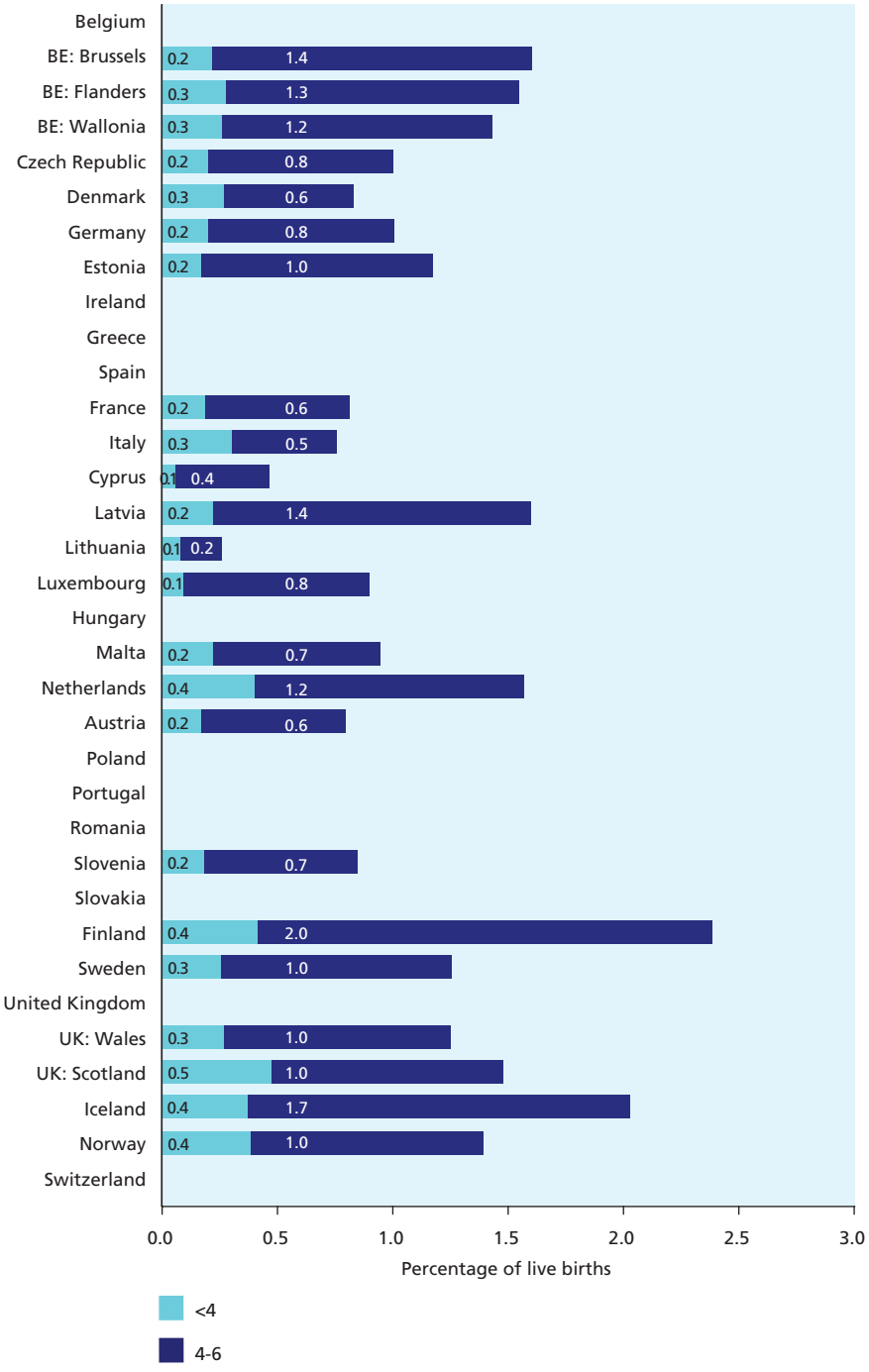
Figure 7.16 Percentage of live births with a 5-minute Apgar score less than 4 and less than 7 in 2010



R3 FETAL AND NEONATAL DEATHS DUE TO CONGENITAL ANOMALIES

JUSTIFICATION

Congenital anomalies are a leading cause of fetal and neonatal deaths. There are wide international variations in antenatal screening policies, regulations regarding the termination of pregnancies and its timing, and medical attitudes towards children born alive with a severe anomaly.[1-3] Differences in these policies and clinical practices affect fetal and neonatal mortality rates as well as the proportion of deaths due to congenital anomalies.[4-7] The countries in Europe use different classifications for reporting cause of death, and up to now there has been no consensus about the best way to report these deaths. However, all classifications include a category for congenital anomalies. Thus, while waiting for a common European cause-of-death classification, the EURO-PERISTAT project focused on fetal and neonatal deaths due to congenital anomalies.

DEFINITION AND PRESENTATION OF INDICATORS

For this indicator, we present data on the percentage of fetal deaths and early neonatal deaths attributed to congenital anomalies (that is, for which congenital anomalies were the underlying cause). We chose not to present mortality rates, because the number of deaths is small in some cases. In the calculation of the percentages, cases with unknown causes are included in the denominators; for stillbirths, this can represent a high proportion of all cases (see discussion in C1).

DATA SOURCES AND AVAILABILITY OF INDICATOR IN EUROPEAN COUNTRIES

These data were provided by 27 countries or regions for neonatal deaths, although 3 could only provide information for early neonatal deaths (the Czech Republic, Germany, and Ireland) and by 25 for fetal deaths. In France, national data on fetal deaths were not available for 2010, so data come from a regional register of stillbirths in 3 French districts. Data on the causes of neonatal deaths were only available for 2008 in France. In Germany, the presence of congenital anomalies for fetal deaths is not routinely recorded and these data should be interpreted with caution. In Finland, data on the main cause of death are not linked to the Medical Birth Register, and the data provided refer to stillbirths and neonatal deaths with at least one confirmed major congenital anomaly in the Register of Congenital Malformations.

METHODOLOGICAL ISSUES IN THE COMPUTATION, REPORTING, AND INTERPRETATION OF THE INDICATOR

The main problem is verifying that the cause of death has been attributed in the same way in all cases and that a congenital anomaly is not only present but is the underlying cause of death. Another factor that can influence the detection of an anomaly is whether an autopsy was conducted after death. In general, more deaths are attributed to this category when autopsies are performed. We did not compare these data with the earlier data collection, given the wide variation in percentages arising from the small numbers.

RESULTS

The percentage of fetal deaths attributed to congenital anomalies varied widely, ranging from below 5% to 38% (Figure 7.14). In general, about 15-20% of fetal deaths were attributed to congenital anomalies. For neonatal mortality, reported in Figure 7.15, the range is wider, but about one-quarter of early neonatal deaths are attributed to congenital anomalies in most countries. In Finland, the high rate of 53% is related to the definition, as explained above. Some

of the variation between countries may be due to differences in policies for antenatal screening and terminations for congenital anomalies. If anomalies are detected and terminated before 22 weeks of pregnancy, this should reduce the number of fetal and neonatal deaths attributed to congenital anomalies. In countries that allow terminations after 22 weeks of gestation, this policy may increase the percentage of fetal deaths due to congenital anomalies. In Malta and Ireland, for example, where terminations of pregnancy are illegal, higher rates of fetal and neonatal deaths attributed to congenital anomalies were observed.

KEY POINTS

These statistics are essential for interpreting mortality rates and especially neonatal mortality rates of babies born at term, because congenital anomalies account for a substantial proportion of these deaths. Further collaborative work is planned between Euro-Peristat and EUROCAT (see chapter 8) to assess the role of congenital anomalies in perinatal mortality through the use of both birth data reporting systems and congenital anomaly registers.

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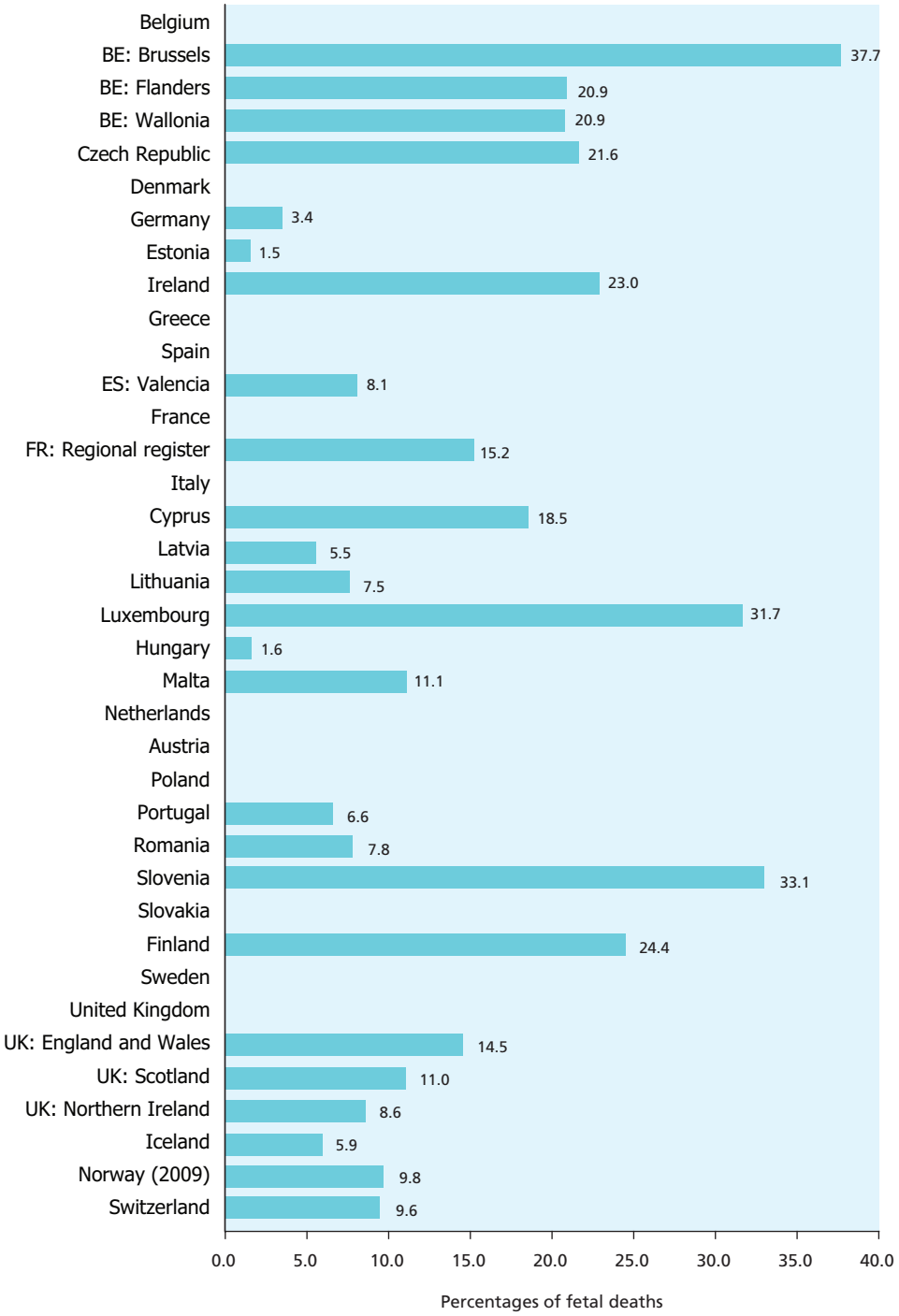
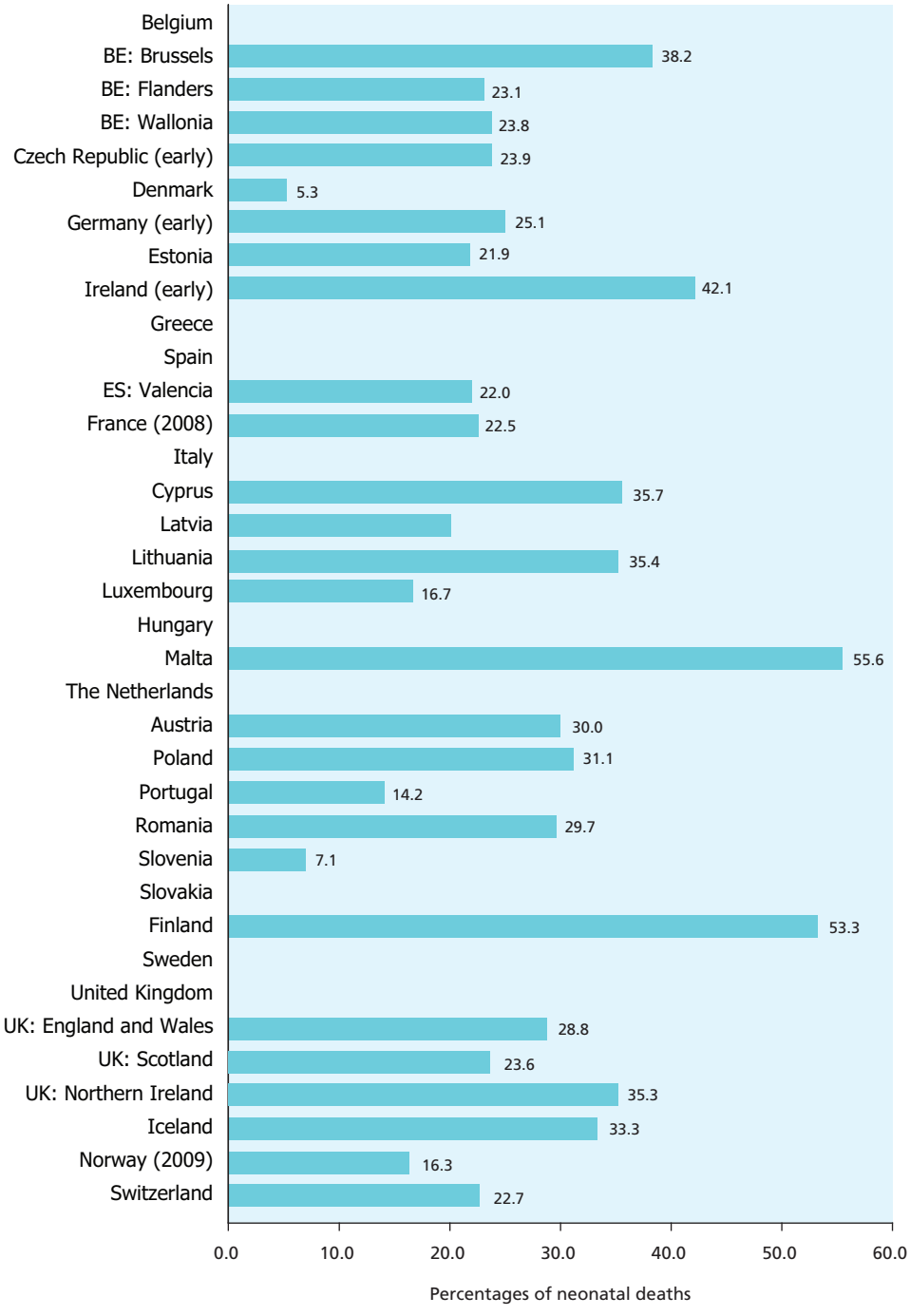
Figure 7.17 Percentage of fetal deaths due to congenital anomalies in 2010



NOTE: In Finland, data refer to at least one confirmed major congenital anomaly.

Figure 7.18 Percentage of neonatal deaths due to congenital anomalies in 2010



NOTE: Data from Germany, Ireland, and the Czech Republic relate only to early neonatal deaths

8

INDICATORS FROM OTHER EUROPEAN NETWORKS

8. INDICATORS FROM OTHER EUROPEAN NETWORKS

8.1 EUROCAT: PREVALENCE OF CONGENITAL ANOMALIES (R1)

1. INTRODUCTION

Collectively, congenital anomalies have an important public health impact in terms of their effect on the quality of life of affected children and adults and their families, their contribution to fetal and infant mortality (both in terms of loss of potential years of life and emotional costs to the family), the provision, quality, and financial cost of medical, social, and educational services to improve the participation and quality of life of affected individuals and their families, and the provision, quality, and financial cost of prenatal screening in the population, as well as its psychological cost to pregnant women.

Congenital anomalies can be caused by genetic or environmental factors or an interaction of both. The precise cause of congenital anomalies is not known for the majority. In EUROCAT data, 1.85% of congenital anomaly cases are recorded as monogenic syndromes, 13% as chromosomal anomalies, and 0.65% as teratogenic syndromes caused by maternal infections, drugs, or alcohol. Although genetic factors play an important role, it is by changing environmental exposures that we can prevent congenital anomalies.[1]

Congenital anomalies straddle different public health agendas — perinatal and child health, rare diseases,[1] environmental health, drug safety surveillance, and major health determinants. Many major "lifestyle" determinants of ill health in the population, such as alcohol, recreational drugs, smoking, and obesity, are also risk factors for congenital anomalies. Any strategy to tackle these health determinants should pay special attention to women of childbearing age, remembering that the harm is often done in very early pregnancy before the pregnancy is recognised and that the fetus may have special susceptibility. Policies aimed at ensuring "healthy pregnancy" or good perinatal outcomes include congenital anomalies as part of a range of outcomes, including fetal and infant mortality, birth weight, and neurodevelopmental outcomes. However, a system of preconceptional and periconceptional care is needed for congenital anomalies. Much greater investment is needed in postmarketing surveillance of medicinal drugs and assisted reproduction technologies (ART), and in environmental health surveillance, particularly of sources of environmental pollution that may have the potential to harm the fetus.

2. EPIDEMIOLOGIC SURVEILLANCE OF CONGENITAL ANOMALIES

Congenital ("present from birth") anomalies, which involve structural malformations diagnosed prenatally, at birth, or within the first year of life, are the focus of epidemiologic surveillance through congenital anomaly registries. EUROCAT (European Surveillance of Congenital Anomalies) is the principal source of information on the epidemiology of congenital anomalies in Europe. EUROCAT is a network comprising almost all of the population-based congenital anomaly registries in Europe. It currently surveys more than 1.7 million births per year in Europe, covered by 37 registries in 21 countries. Using multiple sources of information to collect high quality data (both in terms of case ascertainment and diagnostic detail), registries record cases of all major structural congenital and chromosomal anomalies (standard EUROCAT congenital anomaly subgroups).[2] EUROCAT registries cover affected live births, fetal deaths from 20 weeks of gestation (including stillbirths), and terminations of pregnancy for a fetal anomaly (TOPFA) following prenatal diagnosis (whether before or after 20 weeks of gestation). Registries may cover only diagnoses made prenatally and in infancy, or extend registration to new diagnoses

made during childhood. Using common software, each member registry transmits a standard dataset to a central database at the EUROCAT Central Registry, where further quality validation is performed. By October, 2012, the EUROCAT database contained 431 048 anonymised cases. The EUROCAT system and process are described in EUROCAT report 9.[3-9]

The main issues for surveillance by EUROCAT are (i) the identification of environmental risk factors and high risk groups, which leads to opportunities for prevention;[10-16] (ii) the evaluation of preventive strategies (such as periconceptional folic acid supplementation)[17-19] (iii) the estimation of the numbers of children and families requiring specialist health or other services;[20-22] and (iv) evaluation of the impact of prenatal screening and diagnostic services.[23, 24]

Within Europe, there are geographic and socioeconomic inequalities in the prevalence of congenital anomalies. These are now of 2 main types — variation in the prevalence of risk factors affecting total prevalence and additional variation in prenatal detection and TOPFA rates affecting prevalence among live births.

3. POPULATION COVERAGE BY EUROCAT

EUROCAT started in 1979. In 2010 there were 39 (full and associate) EUROCAT member registries in 21 countries covering 29.6% of births across the 27 EU member states (Table 8.1), in addition to coverage in 4 non-member states — Norway, Switzerland, Croatia, and Ukraine (Table 8.1). Moldova and Slovenia are affiliate member registries and Slovakia is working towards full membership in 2014.

Maintaining high quality data usually requires a limit to the total size of the population to be covered by a register. Thus, there is a preference in larger nations for regional rather than national registries, networked nationally, and networked at a European level by EUROCAT. The proportion of national births covered by registries in each country is shown in Table 8.1, ranging among those countries participating from 3% (Germany) to 100% (Czech Republic, Norway, Poland, Sweden, Finland, Malta, and Hungary). Although complete coverage of the European population may be an ideal, it should not replace deeper investment of resources in areas already covered — excellent data from one quarter of Europe will give us more meaningful information than poor data from all of Europe.

4. PREVALENCE OF CONGENITAL ANOMALIES IN EUROPE

EUROCAT recorded a total prevalence of major congenital anomalies of 25.5 per 1000 births for 2006-2010 (Table 8.2). Extrapolating to the entire EU-27 in 2010, this represents approximately 140 000 cases. Total prevalence includes live births, fetal deaths after 20 weeks of gestation (including stillbirths), and TOPFA following prenatal diagnosis. Major congenital anomalies are those associated with high mortality or other serious medical or functional consequences, as defined by EUROCAT guidelines.[2] The prevalence of major congenital anomalies among live births recorded by EUROCAT was 20.9 per 1000 births for 2006-2010 (Table 8.2). Extrapolating to the entire EU-27, this represents approximately 112 000 affected live births.

Congenital heart defects are the most common subgroup, with total prevalence of 8.1 per 1000 births including ventricular septal defects (3.4 per 1000), followed by limb defects (4.1), chromosomal defects (3.6), and defects of the urinary system (3.3) and nervous system (2.5). The total prevalence of chromosomal anomalies was 3.6 per 1000 births (Table 8.2).

The EURO-PERISTAT indicators include 3 congenital anomaly subgroups: cleft lip (with or without palate), spina bifida, and Down syndrome. Total prevalence for these anomalies by country is shown in Figure 1. Further data (including confidence intervals) about these conditions can be found on EUROCAT's website tables, reported by pregnancy outcome and year of birth.

Anonymous aggregate prevalence data (updated biannually) can be interrogated, by registry, year, and congenital anomaly of interest, via the interactive EUROCAT website prevalence tables (available at http://www.eurocat-network.eu/accessprevalencedata/prevalencetables). In April 2013, the website data was updated to birth year 2011. The prevalence of selected monogenic syndromes in Europe can also be accessed via the same link.

The latest EUROCAT perinatal mortality data can be viewed on the Key Public Health Indicator section of the EUROCAT website (available at: http://www.eurocat-network.eu/accessprevalencedata/keypublichealthindicators).

Prenatal detection rates for the latest 5-year period, created from surveillance data collected by EUROCAT member registries, can be viewed at any time (available at: http://www.eurocat-network.eu/prenatalscreeninganddiagnosis/prenataldetection(pd)rates).

5. TERMINATION OF PREGNANCY FOR FETAL ANOMALIES

Some congenital anomalies in Europe are very commonly prenatally diagnosed. For example EUROCAT data for 2006-2010 show the proportion of total cases prenatally diagnosed was 96% for anencephalus, 82% for spina bifida, 70% hypoplastic left heart, 91% gastroschisis, 88% bilateral renal agenesis (including Potter syndrome), and 63% Down syndrome (Table 8.3).

For some anomalies, including various forms of congenital heart defects, gastroschisis, and diaphragmatic hernia, prenatal diagnosis leads to better preparation of families and health services for an affected baby and can improve treatment success.[23, 24]

For other anomalies, particularly neural tube defects and chromosomal anomalies, including Down syndrome, prenatal diagnosis is commonly followed by TOPFA.

The reported TOPFA rate varies from 0 (Ireland and Malta, where TOPFA is illegal) to 10.5 (Paris, France) per 1000 births (Table 8.4). Differing prenatal screening policies and practices, differences in uptake of prenatal screening due to cultural and organisational factors, and differences in TOPFA laws and practices all influence the rate of TOPFA in the population.[23, 24] Some countries allow TOPFA at any gestational age. Others have an upper gestational age limit, and yet others have an upper gestational age limit but allow TOPFA for lethal anomalies beyond this limit.[23]

Of all TOPFA in 2006-2010 (all EUROCAT full member registries combined), 16% were for neural tube defects (7% anencephaly and 7% spina bifida) and 26% for Down syndrome (Table 8.2). Table 8.4 shows TOPFA before and after 20 weeks of gestation. The highest TOPFA rate for both periods is recorded in Paris (France) (6.29 and 4.24 per 1000 births respectively) (Table 4). Comparison between countries is complicated by different laws and practices regarding the recording of late terminations. Late TOPFA, where legal, may be recorded as stillbirths or as live births with neonatal death in some countries.

Differences between countries in the proportion of cases prenatally diagnosed leading to TOPFA lead to wide variations in live birth rates of certain congenital anomalies. The live birth rate of spina bifida (2006-2010) varies from 0.04 per 1000 births in Denmark to 0.93 in Malta. The livebirth rate of Down syndrome, which is in addition influenced by the maternal age profile of the population, varies from 0.38 per 1000 births in Portugal to 2.3 in Ireland.

6. FETAL AND NEONATAL MORTALITY ASSOCIATED WITH CONGENITAL ANOMALIES

Congenital anomalies are an important contributor to perinatal mortality. In EUROCAT the overall recorded rate of late fetal deaths/stillbirths with congenital anomalies is 0.44 per 1000 births for the period 2006-2010, and the rate of deaths in the first week is 0.36 per 1000 births, resulting in a total perinatal mortality rate of 0.81 per 1000 births associated with congenital anomalies (Table 8.5). The main congenital anomaly subgroups contributing to perinatal mortality in 2006-2010 were chromosomal anomalies (27% of perinatal deaths had a chromosomal anomaly), congenital heart defects (24%), and nervous system anomalies (16%) (Table 8.6). Chromosomal anomalies contribute more to stillbirths than to deaths during the first week, while congenital heart defects contribute more to deaths during the first week than to stillbirths. Anomalies of the nervous system contribute slightly more to deaths during the first week than to stillbirths (Table 8.5).

Perinatal mortality associated with congenital anomalies varies by country (Table 8.6). The rates vary from 0.27 per 1000 births in Portugal to 1.11 in Switzerland.

In most countries, TOPFA far outnumber stillbirths and neonatal deaths with congenital anomalies (Table 8.4). Up to 1.1% (France) of fetuses result in a TOPFA, stillbirth, or early neonatal death associated with a congenital anomaly, and 5 countries record rates above 0.5% for an overall rate of 6.3 per 1000 (Table 8.4). The differences in total mortality (TOPFA + perinatal death) between countries probably mainly reflects the frequency with which TOPFA is carried out for non-lethal anomalies, but is also influenced by differences between countries in the prevalence of anomalies such as neural tube defects and Down syndrome and in the completeness of ascertainment of stillbirths, neonatal deaths, and TOPFA.

Despite the important mortality consequences of congenital anomalies, the vast majority of cases of congenital anomalies across Europe are liveborn children who survive infancy, but who may have important medical, social, or educational needs.

7. STATISTICAL MONITORING FOR TRENDS AND CLUSTERS

EUROCAT annually performs statistical monitoring for the rates of congenital anomalies over time, to enable the detection of signals of new or increasing teratogenic exposures that require public health action.

EUROCAT's Annual Statistical Monitoring Reports can be accessed online via the EUROCAT website homepage (www.eurocat-network.eu).

The EUROCAT Statistical Monitoring Report for 2010 describes statistical monitoring of both clusters and trends in Europe for the 10-year period 2001-2010 (http://www.eurocat-network.eu/clustersandtrends/statisticalmonitoring/statisticalmonitoring-2010).

Key findings from the pan-Europe (all EUROCAT registries combined) analyses in 2010 were:

- Rates of neural tube defects (NTDs) declined on average by 1.7% per year, with rates for spina bifida declining on average by 2.1% per year.
- There was a decreasing trend detected over time for the subgroup of congenital heart defects (CHD). However, increasing trends were detected in 2 of the more severe types of CHD: tetralogy of Fallot increased on average by 2.3% per year, and single ventricles increased on average by 5.9% per year.
- Increasing trends were found for the following digestive anomalies: oesophageal atresia with or without trachea-oesophageal fistula, duodenal atresia and stenosis, and atresia and stenosis of other parts of the small intestine. In contrast, atresia of bile ducts decreased by an average of 9% per year.
- The prevalence of the abdominal wall defect gastroschisis increased on average by 1.6% per year. Four out of the 5 registries with the highest prevalence rates were located in the UK.
- Prevalence of the 3 chromosomal autosomal trisomies increased on average by 1.0% to 2.4% per year (Down syndrome, 1%; Edward syndrome, 2.3%; Patau syndrome, 2.4%). This increase in prevalence is explained by the increase in the proportion of older mothers giving birth.
- Investigation of clusters in the last 2 years (for 2009-2010) identified no clusters of immediate public health concern. The Taskforce for the Evaluation of Clusters (TEC) continues to be available for consultation on clusters identified by statistical monitoring.
- The report also published the findings of a survey on local dissemination of the Annual Statistical Monitoring report. Two thirds (68%) of registries reported submitting the report findings to the relevant person within their public health system.

8. CONGENITAL ANOMALIES IN MULTIPLE BIRTHS

EUROCAT has recently analysed the prevalence and relative risk of congenital anomalies in multiple births for the period 1984-2007.[10] In the European population studied, the multiple birth rate rose by approximately 50%. Of the 5.4 million births covered, 3.0% of babies were from multiple births. Of the total number of major congenital anomaly cases (148 359), 3.83% were from multiple births. The prevalence of congenital anomalies from multiple births increased from 0.6 (1984-1987) to 1.1 (2004-2007) per 1000 births. The risk of congenital anomalies was 27% higher in multiple than singleton births, with this risk increasing over time, potentially related to ART rather than multiple birth status. Multiple births with congenital anomalies were more than twice as likely to be stillbirths compared to singleton births (4.6% compared to 1.8%) and more than twice as likely to be early neonatal deaths (5.45% compared to 2.51%). However, cases from multiple pregnancies were less likely to be TOPFA. The co-occurrence of multiple births and congenital anomalies among liveborn infants places particular demands on parents and health services. This may be even more relevant for the 1 in 9 affected twin pairs where both babies have a congenital anomaly. The increase in multiple birth rates may be explained by changes in maternal age and increased use of ART. More research needs to be done to determine the contribution of ART to the risk of congenital anomalies in multiple births.

9. TRENDS IN CHROMOSOMAL ANOMALIES RELATING TO INCREASES IN MATERNAL AGE

EUROCAT has recently analysed trends in the prevalence of Down syndrome and other trisomies for the period 1990 to 2009.[13] The proportion of births to mothers aged 35 years and older in Europe increased from 13% in 1990 to 19% in 2009, and this has led to an increase in rates of Down syndrome, Edward syndrome, and Patau syndrome (3 chromosomal anomalies). Data showed that, in Europe, women over 40 have a risk of having a Down syndrome baby 17 times

higher than do women aged 25-29 years. Edward and Patau syndromes are much rarer (both combined will occur in 1 in every 1400 pregnancies), are severe, and have high perinatal mortality. They have a similar increased risk for older mothers. Across Europe, over half the babies with Down syndrome have mothers older than 34 years of age. While the total rates for these 3 syndromes have increased steadily since 1990, the number of cases resulting in a live birth has remained stable over time in Europe. This is largely due to the increased rate of prenatal diagnosis and subsequent TOPFA. Approximately 50% of cases with Down syndrome, 70% of cases with Edward syndrome, and 70% of Patau syndrome cases resulted in a TOPFA, although this varied widely by country. The live birth rates of Down syndrome also varied; they were lowest in Spain and Switzerland and highest in Ireland and Malta, where termination of pregnancy is illegal. From a public health perspective, this is important for assessing the impact of delayed childbearing and prenatal screening programmes as well as for planning health care for mothers and for children with Down syndrome.

10. EUROmediCAT

In 2007-2009 EUROCAT performed case-control studies using EUROCAT data to address and evaluate hypotheses (or signals) generated from the literature about the teratogenicity of antiepileptic drugs (AEDs), of both the newer generation (lamotrigine[25]) and the older generation (valproic acid[16] and carbamazepine[15]). An AED database was created for this, covering 3.9 million total births (19 registries, 1995-2005), including 98 075 with congenital anomalies (live births, stillbirths, and TOPFA).

The lamotrigine study responded to a signal from the North American AED cohort that indicated a more than 10-fold risk of orofacial clefts with lamotrigine. The study did not support the original signal. Valproic acid was known to be teratogenic, but with which birth defects it is specifically associated was unknown — 7 of 14 birth defects were confirmed as significantly associated with valproic acid exposure, with risk increases up to 13-fold. This was the first study to identify specific types of birth defects caused, and its implications go beyond clinical practice, to the elucidation of teratogenic mechanisms of action. The carbamazepine study proceeded as for valproic acid, but in contrast confirmed only one significantly associated birth defect — spina bifida, with much less risk than for valproic acid.

Following on from these studies, EUROCAT's daughter project EUROmediCAT, which commenced in 2011 (http://euromedicat.eu/), has begun to contribute to the development of a pharmacovigilance system in Europe. EUROCAT is also further analysing the EUROCAT data in relation to antidepressant safety, and EUROmediCAT is looking further at newer generation AEDs, insulin analogs, and antiasthmatic drugs.

11. THE FUTURE

The last few decades have not seen any real progress in primary prevention of congenital anomalies, as evidenced by the lack of decline in prevalence. Implementation of current knowledge with effective policies and research into causes of congenital anomalies, if combined with political will, have the potential to change this situation. Primary prevention is a main goal of the EUROCAT Joint Action (2011-2013), cofunded by the EC, under the framework of the EU Health Programme 2008-2013, Grant Agreement 2010 22 04 (Executive Agency for Health & Consumers). EUROCAT is collecting data on current policies in the EU member states for primary prevention of congenital anomalies and proactively liaising with the European Project for Rare Diseases National Plans Development (EUROPLAN) to indicate the areas that member states might target in their strategies for primary prevention of congenital anomalies.[19]

Clusters of congenital anomalies and their potential relations to environmental pollution or to newly marketed drugs are the most prominent public health concern about congenital anomalies, whether detected by the community or by surveillance. They require epidemiologic preparedness (see EUROCAT's Taskforce for the Evaluation of Clusters, http://www.eurocat-network.eu/clustersandtrends/clusteradvisoryservice/introduction) and further investment and co-operation between countries in cluster response, with effective dialogue with communities. However, primary prevention of congenital anomalies needs to be proactive as well as reactive.

EUROCAT's daughter project EUROmediCAT is contributing to the development of a pharmacovigilance system in Europe.

Prenatal screening and diagnosis have seen rapid development. The near future will bring less invasive technologies for the detection of chromosomal anomalies, and greater sensitivity and specificity of diagnosis of anomalies. Variations in the quality of screening services within Europe need examination. Another challenge for European countries is to reduce the number of women who may need to consider termination of pregnancy as an option by achieving effective primary prevention and improving the outcome of affected children and their families in terms of health, quality of life, and participation. It is vital to invest in the epidemiologic surveillance of congenital anomalies across Europe in order to direct and track our progress in these areas.

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Table 8.1 Coverage of the European population, birth year 2010, by EUROCAT full or associate member registries

Country	EUROCAT Registry	Year started EUROCAT data transmission	Annual Births 2010, Registry	Annual Births 2010, Country[1]	% Country Covered
EU (Present EU member states)			1 588 051	5 361 874	29.6
Belgium	Antwerp	1990	21 445		
	Hainaut	1980	12 403		
	Total		33 848	126 827	26.7
Bulgaria				75 637	0.0
Czech Republic	Czech Republic[2, 3]	2000	117 153	117 153	100.0
Denmark	Odense	1980	5059	63 096	8.0
Germany	Mainz	1990	3168		
	Saxony-Anhalt	1987	17 363		
	Total		20 531	678 959	3.0
Estonia				15 813	0.0
Ireland	Cork & Kerry	1996	10 248*		
	Dublin	1980	27 815*		
	South East	1997	7969*		
	Total		46 032	73 720	62.4
Greece				114 182	0.0
Spain	Barcelona	1992	14 862*		
	Basque Country	1990	21 246		
	Spain Hospital Network[2]	1980	87 086		
	Valencia Region	2007	51 739		
	Total		174 933	482 885	36.2

Table 8.1 (Continued)

Country	EUROCAT Registry	Year started EUROCAT data transmission	Annual Births 2010, Registry	Annual Births 2010, Country[1]	% Country Covered
France	French West Indies	2009	10 456		
	Isle de la Reunion	2002	14 543*		
	Paris	1981	27 400		
	Rhone-Alpes[2]	2006	60 083		
	Strasbourg	1982	13 239*		
	Total		125 721	834 559	15.1
Italy	Emilia Romagna	1981	42 154		
	Tuscany	1980	30 836		
	Total		72 990	561 165	13.0
Cyprus				9959	0.0
Latvia				19 336	0.0
Lithuania				35 954	0.0
Luxembourg				5824	0.0
Hungary	Hungary[3]	1998	90 722	90 722	100.0
Malta	Malta[3]	1986	4036	4036	100.0
Netherlands	Northern	1981	17 569	183 982	9.5
Austria	Styria	1985	10 442	78 728	13.3
Poland	Wielkopolska	1999	40 396		
	Rest of Poland[2, 3]	1999	371 811		
	Total		412 207	412 207	100.0
Portugal	South	1990	21 202	101 058	21.0
Romania				212 476	0.0
Slovenia				22 312	0.0
Slovakia				60 217	0.0
Finland	Finland[2, 3]	1993	61 161	61 161	100.0
Sweden	Sweden[2, 3]	2001	114 480	114 890	99.6
UK	E Mid & S York	1998	75 698		
	Northern England	2000	34 461		
	South West England	2005	51 328		
	Thames Valley	1991	31 321		
	Wales	1998	36 142		
	Wessex	1994	31 135		
	Total		260 085	806 351	32.3
Non EU					
Croatia	Zagreb	1983	6870*	43 372	15.8
Norway	Norway[3]	1980	62 770	62 770	100.0
Switzerland	Vaud	1989	8169	80 194	10.2
Ukraine	Ukraine[4]	2005	31 094	494 408	6.3

1 Source: EUROSTAT crude birth rate (accessed 06-03-2012)
http://epp.eurostat.ec.europa.eu/portal/page/portal/population/data/main_tables
2 Associate EUROCAT Registries (transmit aggregate data only)
3 Source of annual births in country provided by registry rather than EUROSTAT
4 http://www.ukrstat.gov.ua/operativ/operativ2010/ds/kn/kn_e/kn1210_e.html (accessed 12-03-2012)
*Provisional estimated figures provided by the registry

Table 8.2 Prevalence rates (per 1000 births) of EUROCAT congenital anomaly subgroups (2006-2010), for all EUROCAT full member registries combined*

Anomaly	LB Rate (per 1000 births)	LB+FD+TOPFA
Rate^ (per 1000 births)	20.89	25.51
Nervous system	1.23	2.47
Neural tube defects	0.25	0.95
Anencephalus and similar	0.03	0.35
Encephalocele	0.03	0.12
Spina bifida	0.19	0.48
Hydrocephalus	0.33	0.59
Microcephaly	0.23	0.26
Arhinencephaly/holoprosencephaly	0.03	0.13
Eye	0.38	0.41
Anophthalmos/microphthalmos	0.09	0.10
Anophthalmos	0.02	0.02
Congenital cataract	0.12	0.12
Congenital glaucoma	0.04	0.04
Ear, face, and neck	0.17	0.20
Anotia	0.03	0.03
Congenital heart defects	7.31	8.05
Severe CHD§	1.64	2.04
Common arterial truncus	0.05	0.07
Transposition of great vessels	0.31	0.35
Single ventricle	0.05	0.08
Ventricular septal defect	3.21	3.41
Atrial septal defect	2.27	2.31
Atrioventricular septal defect	0.28	0.39
Tetralogy of Fallot	0.28	0.32
Tricuspid atresia and stenosis	0.04	0.06
Ebstein anomaly	0.04	0.05
Pulmonary valve stenosis	0.39	0.40
Pulmonary valve atresia	0.08	0.10
Aortic valve atresia/stenosis§	0.11	0.12
Hypoplastic left heart	0.15	0.27
Hypoplastic right heart§	0.03	0.05
Coarctation of aorta	0.34	0.37
Total anomalous pulmonary venous return	0.06	0.06
PDA as only CHD in term infants (>=37 weeks)	0.38	0.38
Respiratory	0.47	0.63
Choanal atresia	0.08	0.08
Cystic adenomatous malformation of lung§	0.07	0.08

Table 8.2 (Continued)

Anomaly	LB Rate (per 1000 births)	LB+FD+TOPFA
Oro-facial clefts	1.32	1.47
Cleft lip with or without palate	0.79	0.89
Cleft palate	0.54	0.58
Digestive system	1.53	1.77
Oesophageal atresia with or without tracheo-oesophageal fistula	0.22	0.25
Duodenal atresia or stenosis	0.12	0.13
Atresia or stenosis of other parts of small intestine	0.09	0.09
Ano-rectal atresia and stenosis	0.25	0.31
Hirschsprung's disease	0.12	0.12
Atresia of bile ducts	0.03	0.03
Annular pancreas	0.02	0.02
Diaphragmatic hernia	0.21	0.28
Abdominal wall defects	0.37	0.64
Gastroschisis	0.24	0.29
Omphalocele	0.12	0.29
Urinary	2.85	3.34
Bilateral renal agenesis including Potter syndrome	0.03	0.12
Renal dysplasia	0.31	0.41
Congenital hydronephrosis	0.95	1.01
Bladder exstrophy and/or epispadia	0.05	0.07
Posterior urethral valve and/or prune belly	0.07	0.09
Genital	2.15	2.22
Hypospadias	1.79	1.81
Indeterminate sex	0.05	0.07
Limb	3.69	4.12
Limb reduction	0.36	0.52
Upper limb reduction	0.25	0.36
Lower limb reduction	0.12	0.20
Complete absence of a limb	0.00	0.02
Club foot - talipes equinovarus	0.94	1.07
Hip dislocation and/or dysplasia	0.78	0.78
Polydactyly	0.83	0.89
Syndactyly	0.48	0.51
Skeletal dysplasias[§]	0.09	0.18
Craniosynostosis	0.20	0.21
Congenital constriction bands/amniotic band	0.03	0.05
Situs inversus	0.05	0.06

Table 8.2 (Continued)

Anomaly	LB Rate (per 1000 births)	LB+FD+TOPFA
Conjoined twins	0.00	0.02
Congenital skin disorders	0.15	0.16
Teratogenic syndromes with malformations§	0.10	0.13
Fetal alcohol syndrome§	0.05	0.05
Valproate syndrome§	0.01	0.01
Maternal infections resulting in malformations	0.04	0.06
Genetic syndromes + microdeletions	0.38	0.47
Sequences	0.14	0.23
Chromosomal	1.48	3.64
Down syndrome	0.97	2.12
Patau syndrome/trisomy 13	0.04	0.20
Edwards syndrome/trisomy 18	0.08	0.49
Turner syndrome	0.06	0.22
Klinefelter syndrome	0.04	0.08

LB = Live Births
FD = Fetal Deaths/stillbirths from 20 weeks of gestation
TOPFA = Termination of pregnancy for a fetal anomaly following prenatal diagnosis
- = Data not available
§ = Incomplete or missing specification of ICD 9 codes
^ = Perinatal mortality rates associated with congenital anomalies as reported in EUROCAT database. Data not available

*cases and prevalence (per 1000 births) for the following registries (as of December 2012): Styria (Austria), Antwerp (Belgium), Hainaut (Belgium), Zagreb (Croatia), Odense (Denmark), French West Indies (France), Isle de la Reunion (France), Paris (France), Strasbourg (France), Mainz (Germany), Saxony-Anhalt (Germany), Hungary, Cork and Kerry (Ireland), Dublin (Ireland), SE Ireland, Emilia Romagna (Italy), Tuscany (Italy), Malta, N Netherlands (NL), Norway, Wielkopolska (Poland), S Portugal, Basque Country (Spain), Valencia Region (Spain), Vaud (Switzerland), East Midlands & South Yorkshire (UK), Northern England (UK), South West England (UK), Thames Valley (UK), Wales (UK), Wessex (UK), Ukraine, from 2006 - 2010

Table 8.3 Prenatal diagnosis of 18 selected congenital anomaly subgroups (2006-2010)

Malformation	Total Cases	Cases Prenatally Diagnosed (% of Total Cases)
Non-chromosomal		
All anomalies (excluding chomosomals)	75 751	22 573 (30%)
Anencephalus and similar (excluding chromosomals)	1232	1185 (96%)
Spina bifida (excluding chromosomals)	1577	1288 (82%)
Hydrocephalus (excluding chromosomals)	1914	1403 (73%)
Transposition of great vessels (excluding chromosomals)	1188	454 (38%)
Hypoplastic left heart (excluding chromosomals)	888	624 (70%)
Cleft lip with or without palate (excluding chromosomals)	2857	1379 (48%)
Diaphragmatic hernia (excluding chromosomals)	893	509 (57%)
Gastroschisis (excluding chromosomals)	993	904 (91%)
Omphalocele (excluding chromosomals)	730	596 (82%)
Bilateral renal agenesis including Potter syndrome (excluding chromosomals)	392	343 (88%)
Posterior urethral valve and/or prune belly (excluding chromosomals)	291	234 (80%)
Limb reduction (excluding chromosomals)	1626	811 (50%)
Club foot - talipes equinovarus (excluding chromosomals)	3678	1398 (38%)
Chromosomal		
Chromosomal	12 479	8765 (70%)
Down syndrome	7233	4538 (63%)
Patau syndrome/trisomy 13	685	625 (91%)
Edwards syndrome/trisomy 18	1709	1537 (90%)

Table 8.4 Rate of TOPFA and rates of perinatal deaths (per 1000 births) by country (2006-2010), for 13 EUROCAT full member registries

Centre	Prevalence TOPFA <20 Weeks per 1000 births	Prevalence TOPFA 20+ Weeks per 1000 births	Total Prevalence TOPFA per 1000 births	Perinatal Mortality per 1000 births	^Perinatal Mortality + TOPFA per 1000 births
Denmark (Odense)	4.44	2.00	6.44	0.72	7.16
France (Paris)	6.29	4.24	10.54	0.87	11.41
Italy (Tuscany)	2.70	1.39	4.42	0.30	4.71
Netherlands (North)	1.75	1.87	3.71	1.05	4.76
Switzerland (Vaud)	6.00	2.06	8.06	1.11	9.17
Portugal (South)	0.39	0.20	0.64	0.27	0.91
Spain (Basque Country, Valencia Region)	3.27	2.01	5.35	0.53	5.88
Germany (Saxony Anhalt)	2.07	1.23	3.35	0.96	4.31
Austria (Styria)	3.04	0.85	3.97	0.90	4.87
UK (Thames Valley, SW England, Wessex)	3.56	2.22	5.87	1.10	6.97
EUROCAT total	**3.33**	**2.02**	**5.44**	**0.81**	**6.25**

^Perinatal mortality+TOPFA is sum of previous 2 columns. All figures rounded to 2 decimal places.

Table 8.5 Gestational age and prevalence rate (per 1000 births) of TOPFA for all anomalies, by EUROCAT registry in 2010

Description	Breakdown by anomaly subgroup (as a % of all FDs)	Breakdown by anomaly subgroup (as a % of all LBs with death in 1st week)	Prevalence of FD per 1000 births	Prevalence of 1st week deaths per 1000 births	*Perinatal Mortality per 1000 births
All Anomalies	100.0	100.0	0.44	0.36	0.81
All Anomalies Excluding Chromosomal Anomalies	64.7	83.8	0.29	0.30	0.59
Nervous system	14.2	17.5	0.06	0.06	0.13
Neural Tube Defects	4.8	6.5	0.02	0.02	0.04
Congenital heart defects	17.7	31.0	0.08	0.11	0.19
Severe CHD §	8.8	19.7	0.04	0.07	0.11
Ventricular septal defect	3.5	5.8	0.02	0.02	0.04
Hypoplastic left heart	2.6	8.5	0.01	0.03	0.04
Respiratory	6.7	13.4	0.03	0.05	0.08
Digestive system	5.7	18.2	0.03	0.07	0.09
Diaphragmatic hernia	0.7	8.7	0.00	0.03	0.03
Urinary	10.1	18.4	0.04	0.07	0.11
Limb	12.3	11.0	0.05	0.04	0.09
Chromosomal	35.3	16.2	0.16	0.06	0.22
Down Syndrome	13.8	2.7	0.06	0.01	0.07
Edward syndrome/trisomy 18	7.9	5.8	0.04	0.02	0.06

*Perinatal mortality is sum of previous 2 columns. All figures rounded to 2 decimal places.
^ Odense, Paris, Tuscany, N Netherlands, Vaud, S Portugal, Basque Country, Valencia Region, Saxony Anhalt, Styria, Thames Valley, Wessex, SW England

Table 8.6 Perinatal mortality associated with congenital anomalies in 13 EUROCAT full member registries (2006-2010), by type of anomaly

Centre	Prevalence of FD per 1000 births	Prevalence of Early Neonatal Deaths per 1000 births	*Perinatal Mortality per 1000 births
Denmark (Odense)	0.49	0.23	0.72
France (Paris)	0.40	0.47	0.87
Italy (Tuscany)	0.17	0.13	0.30
Netherlands (North)	0.55	0.50	1.05
Switzerland (Vaud)	0.62	0.49	1.11
Portugal (South)	0.07	0.20	0.27
Spain (Basque Country, Valencia Region)	0.17	0.36	0.53
Germany (Saxony Anhalt)	0.66	0.30	0.96
Austria (Styria)	0.54	0.37	0.90
UK (Thames Valley, SW England, Wessex)	0.69	0.41	1.10
EUROCAT total	**0.44**	**0.36**	**0.81**

*Perinatal mortality is sum of previous 2 columns. All figures rounded to 2 decimal places.

Figure 8.1 Total prevalence rates per 1000 births (including live births, fetal deaths, and TOPFAs) for spina bifida, cleft lip (with or without palate), and Down syndrome (2006-2010)

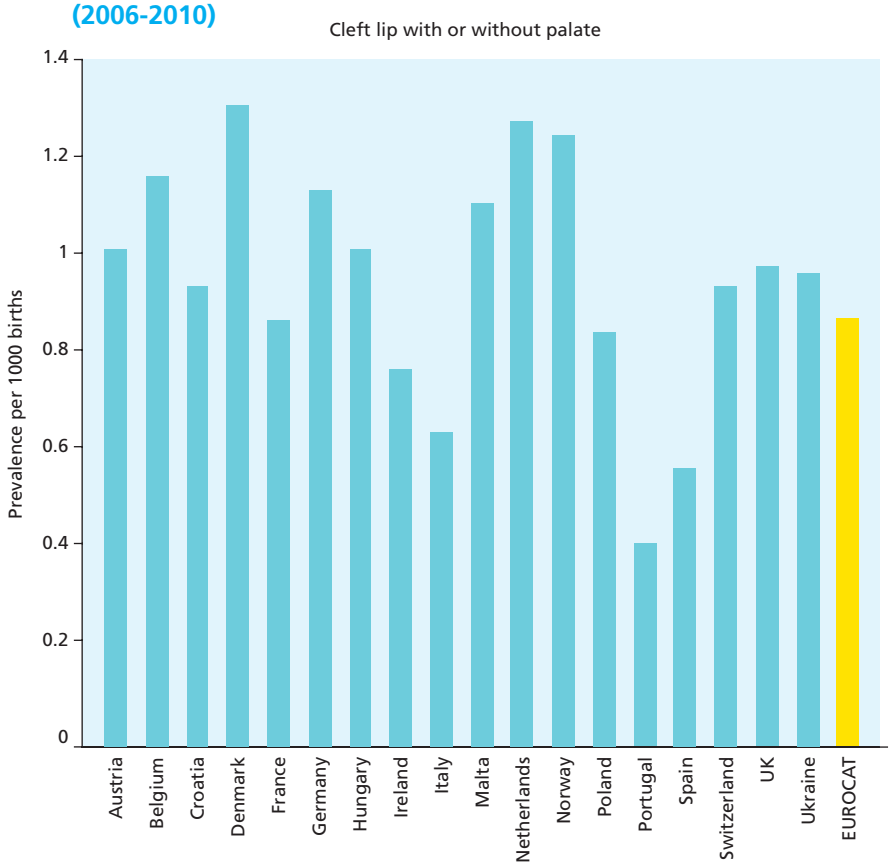
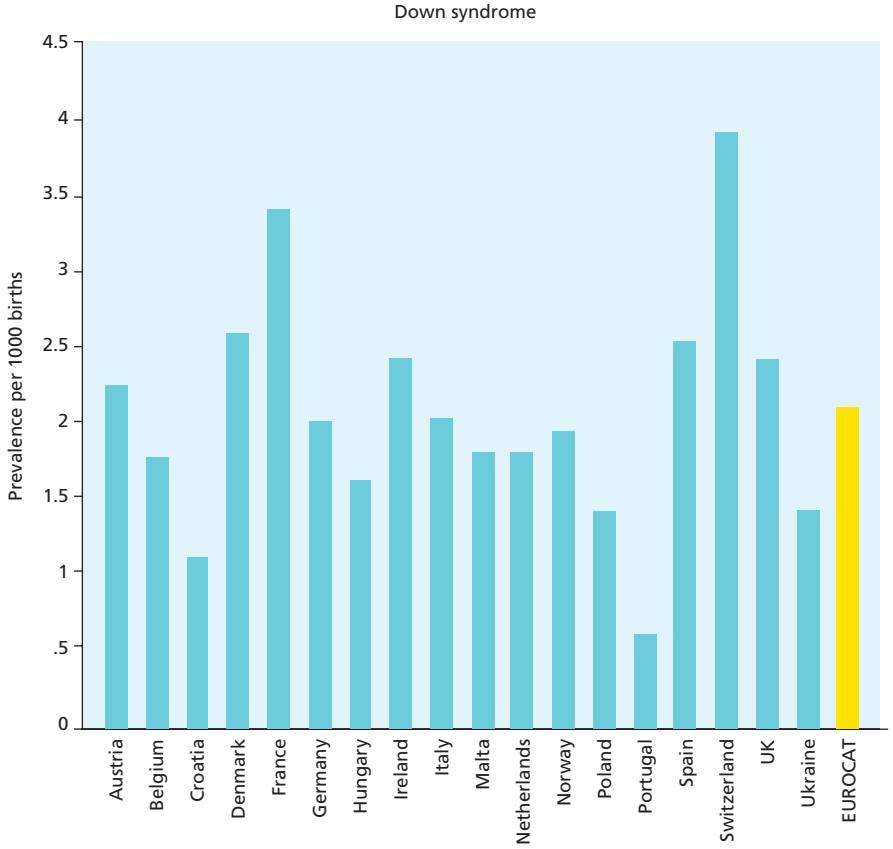
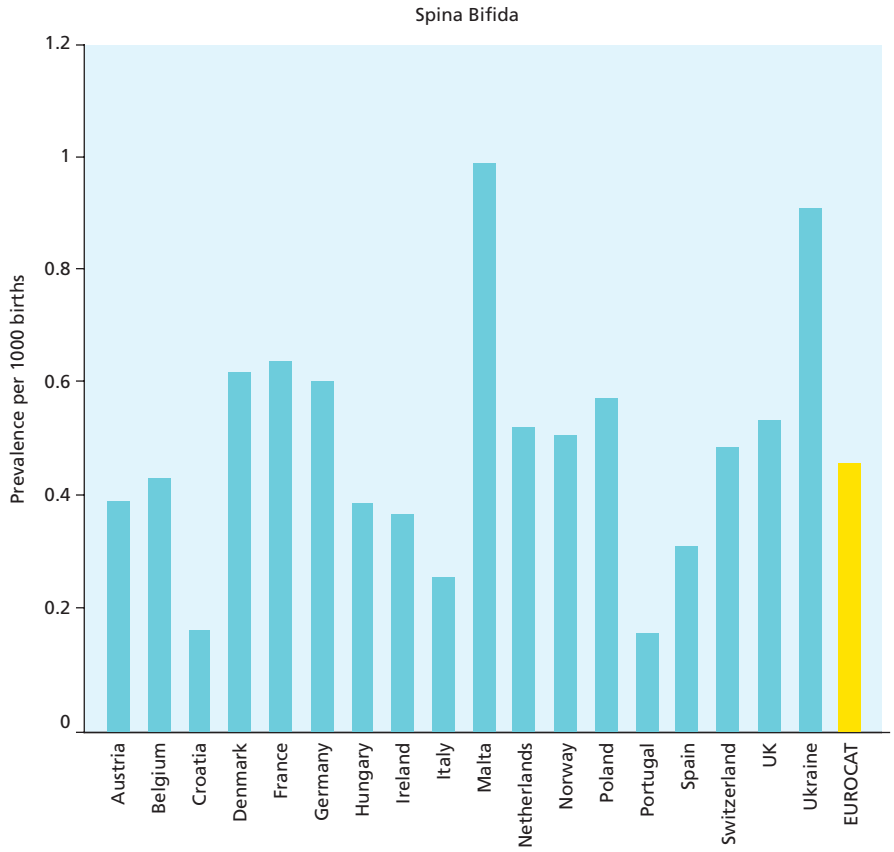


Figure 8.1 (continued)





8.2 SCPE: PREVALENCE OF CEREBRAL PALSY (R4)

Cerebral palsy (CP) has been a recommended PERISTAT indicator for long-term child health outcomes (R4) since 2007, especially as mortality rates can no longer reflect standards in perinatal care accurately in view of the improved survival rates.

CP is the most common motor impairment in childhood. Affecting one child in 500, it is responsible for permanent lifelong activity limitations and participation restrictions. It is often considered to be a group of disorders or clinical descriptions rather than a diagnosis in itself. Since its founding in 1998, the main aim of the Surveillance of Cerebral Palsy (SCPE) network has been to develop a central database of children with CP to monitor trends in birth weight-specific groups,1 to provide data for service planning, and to provide a framework for collaborative research (eg, the SCPE-NET project).

1 HOW DOES SCPE WORK?

1.1 CP DESCRIPTION AND DATA COLLECTION

Criteria for cerebral palsies

Before 1998, the criteria for the different CP subtypes varied through Europe, between countries and between registers. Assessment of the severity of CP in terms of motor and associated impairments also varied. The SCPE network's first important achievement was to establish a consensus on standards, definitions, and classification systems for children with CP. The inclusion criteria and classification of subtypes are available on the SCPE website (www.scpenetwork.eu/) as decision and classification trees. An important follow-up was the development of the Reference and Training Manual (RTM), initially a CD with interactive video illustrations of typical cases, now accessible on the SCPE website. These SCPE standards and criteria have been implemented in a number of European countries, and even on other continents. They have been widely accepted by clinicians as well as scientists and are referenced in a number of recent studies.

Data collection on children with cerebral palsies

The registries acquire their data from different sources, partly due to differences in healthcare organisation. Whereas some registries use questionnaires and forms to be completed by paediatric departments or rehabilitation registries, others have direct access to the patients' health records. SCPE registries put a great effort into ascertainment of cases, using various sources such as summary data from national public health sources, hospital statistics, and health insurance data. Such sources also vary between countries.

CP surveillance requires that the motor deficiency for each child be described in a consistent manner, with specific scales to record motor impairment and associated deficiencies, eg, measurement of the intelligence quotient. The SCPE network has developed a specific data collection form for children with CP.

Data collection of denominators

Finally, the SCPE has worked intensively to acquire accurate background information (ie, denominators). For many countries, these data come from national birth data systems. Routinely collected data on child health present many difficulties, however. One of the most important challenges is that systems usually are not standardised. Data stored for each child in each health

system vary, not only by type, but also in quality. A comparison of cases of CP identified by the Northern Ireland Cerebral Palsy Register with those on the Child Health Computing System found that only 50% of cases were recorded in both systems. Assessment of health at the age of 2 years, for example, is likely to underestimate the prevalence of disability in the population, regardless of whether it uses data from follow-up studies or routinely collected data.

1.2 DATA QUALITY CONTROLS

Feedback to registries

Several measures were established to improve data quality. Firstly, we described all existing tools devoted to data quality. Secondly we requested reports based on information from each 'old' register as well as the new ones. The report contained comprehensive information about the functioning of the register and the data collected. Thirdly, we decided to set up a system of feedback to the registries after each data submission wave. The aim of the feedback is to provide to each registry a summary of the data it submitted, compared with the data submitted by the other registries. During the 2011 annual meeting, we proposed data quality indicators for all registers. These quality indicators were percentages of missing values for 5 core variables (CP type, gross and fine motor function, intellectual impairment, and neuroimaging) and the number of missing values for all the variables in the database. Thanks to this feedback, each registry is more aware now about its own data quality and is able to compare it with the other registries.

Reliability of the SCPE inclusion and classification process[2]

The registration of children with CP is a process that begins with paediatricians examining the child and ends with data managers from the registries. Consequently, we conducted 2 different evaluations. The first focused on agreement between clinicians, based on primary observations, and the second on agreement based on data abstracted from medical records. Overall agreement was rather good for classifying children with CP in different subtypes. Another important finding was that non-physicians knew their limitations and quite often felt that they were not able to decide about inclusion or classification.

Our results indicate that CP is best diagnosed on clinical grounds — a clinician should see the child to assess the neurological signs and assign them to a CP subtype. The use of classification systems, such as that presented in the SCPE Reference and Training Manual, provides a systematic approach to the clinical description of children with CP. Reliability was higher than in previous studies, probably because of the training of professionals in the use of the SCPE classification system. Reliability tended to be higher for clinicians seeing videos. It also appeared that it was sometimes difficult to differentiate between bilateral spastic CP and dyskinetic CP, especially when extracting data from medical records. Ideally, therefore, the clinician seeing and examining the child should: (1) make the decision about CP classification, and then (2) write it clearly in the medical records and, in particular, specify the predominant type for a child with a mixed form of CP. To improve written communication with families and for those abstracting data for CP registers, clinicians should avoid ambiguous or unreliable clinical descriptions.

2 WHAT DATA AND ANALYSIS DOES SCPE PRODUCE?

2.1 NEW DATA

The SCPE common database added more than 3500 children with CP born in 1999-2003. A total of 17 registries submitted data for at least one birth-year cohort. There were 5 new registries

(Iceland, Austria, Latvia, Hungary, and Croatia). Two of them also submitted data on children with CP born in 1990-1998 (Austria and Iceland).

During the second and third waves, the 17 registries submitted data on denominators for birth years 2001-2003, through an Excel file containing 14 sheets. Many also updated denominator data for previous birth years.

Table 8.7 21 European registries submitting data to the SCPE Common Database for 1990-1998 and 1999-2003 periods – Number of children with CP

"Registry	Registry name	Previous data: 1990-1998 birth-year cohorts	New data submitted for 1999-2003 birth-year cohorts	'n' of these new data	Comments
AU-CCPT	Children with Cerebral Palsy in Tyrol	83	1999-2003	47	
DK - DCPR	Danish cerebral palsy register	649	1999-2003	661	extended nationwide
FR - RHE31	Childhood disabilities register of the Haute-Garonne	158	1999-2003	124	
FR - RHEOP	Register for childhood disabilities and perinatal survey	230	1999-2003	197	extended to 2 other counties
HR-CCPR	Croatian Cerebral Palsy Register		2003	19	
HU-HCPS	Pecs Cerebral Palsy Register		1999-2003	96	
IE - EICPR	Eastern Area CP Study	333	1999-2003	211	
IE - SICPR	Southern Ireland CP register	128	no data provided	no data provided	nationwide register planned
IE - WICPR	Western Ireland CP register	98			
IS-ICPR	Iceland CP register	86	1999-2003	46	
IT - CICPR	Central Italy CP register	55	no data provided	no data provided	
IT - CPSNI	Cerebral Palsy Survey of North Italy	61			
LV-RC	Mes esam lidzas rehabilitation center		2000-2003	46	
NO – CPRN	The Cerebral Palsy Register of Norway	201	1999-2002	378	extended nationwide
PT-LCPS	Programa Vigilância Nacional da Paralisia Cerebral aos 5 anos	115 (1996-1997)	2001-2003	492	extended nationwide
SE - GCPR	CP register of western Sweden	377	1999-2003	219	
SL-SCPS	Slovenian Register for CP		1999-2003	195	
SP - DIMAS	Madrid Cerebral Palsy Register	80 (1991-1998)	1999	13	
UK - 4Child	Four Counties database of CPO, vision loss and hearing loss in children	543	1999-2003	201	register closed in 2011
UK - NECCPS	North of England Collaborative Cerebral Palsy Survey	731	1999-2003	305	
UK - NICPR	Northern Ireland Cerebral Palsy Register	490	1999-2003	255	

2.2 NEW ITEMS

New items were added to the common database, providing

i) more information when multiple congenital anomalies co-exist,

ii) age at onset for epilepsy as a proxy for severity, and

iii) neuroimaging classification with 6 different groups for MRI and neonatal ultrasound results.

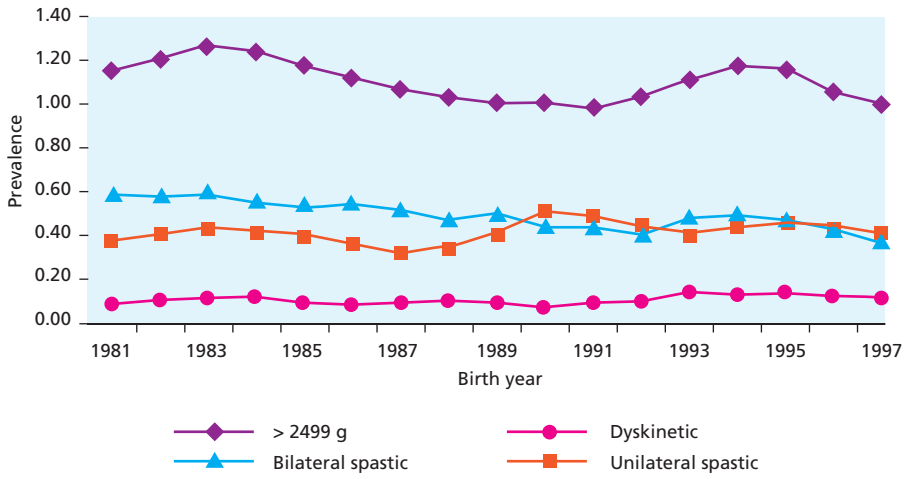
Availability of data and ease of its collection for these items will be checked in the years to come. Further candidates are a communication scale (speech performance) and classification of the mothers' education level.

2.3 TRENDS OVER TIME IN PREVALENCE OF CEREBRAL PALSY

Analysis of the trends in CP prevalence in children with a birth weight ≥ 2500 g or at term[3]

The prevalence of CP did not change much between 1980 and 1998. For every 1000 children born with a birth weight in the typical range, one was likely to have CP. However, the rate of children with a bilateral spastic form decreased from 0.58 in 1980 to 0.33 per 1000 live births in 1998. The rate of children with a unilateral spastic form increased from 0.37 to 0.46 per 1000 live births. During the same period, mortality, ie, the rate of deaths of children with a birth weight in the typical range, decreased by nearly half (from 1.7 to 0.9 per 1000 live births), and the rate of children with a moderate (children either unable to walk or with an intellectual quotient below 50) or severe form of CP (children unable to walk and with an intellectual quotient below 50) decreased slightly.

Figure 8.2 Prevalence of cerebral palsy (3-year moving average), in children of normal birth weight from 15 European registers, 1980-1998.*



* Sellier et al. 2010, Eur J Epidemiol[3]

What does this tell us?
This work tells us that the CP rate was stable among children with a birth weight in the typical range between 1980 and 1998. This may seem disappointing at first glance. Nonetheless, mortality (the number of children who died) decreased quite substantially among children with a birth weight in the typical range, a reflection of progress in neonatal care. Although it is difficult to determine why the rate of bilateral spastic CP decreased and the rate of unilateral spastic CP increased, one plausible hypothesis is that progress in neonatal care led to a reduction in the number of more severe cases.

Further work
We need to follow the trends in CP rates in this population, including by CP subtype (ie, bilateral spastic predominant, unilateral spastic predominant, dyskinetic predominant, or ataxic). Another study showed a decrease in the number of children with CP with very low birth weights.[4] This finding reflects some progress in neonatal care, but especially progress in preventing CP in children with very low birth weights. We also need to improve our understanding of the reasons for the changes in prevalence by CP subtype.

Analysis of the trends in prevalence of children with cerebral palsy with a birth weight between 1500 and 2499 g or a gestational age between 32 and 36 weeks[5]
We used the SCPE database to obtain data on 1164 children with CP born at 32-36 weeks of gestation and on 2159 children with CP and a birth weight from 1500 to 2500 g. These data come from 19 CP registers in Europe and concern children born between 1980 and 1998.

What were the findings?
We found that the proportion of children born between gestational weeks 32-36 who developed CP decreased by approximately 3 per 100 in each year of the study period. This decrease was mainly found among children with the bilateral spastic CP subtype (the subtype considered the form of CP most typically associated with preterm birth). However, we did not find a corresponding decrease in occurrence among children with a birth weight between 1500-2499 g, although fewer children were diagnosed with the most severe CP subtypes.

What does this tell us?
The results show that the observed improvement in survival in these high-risk groups of children during the last 2 decades of the last century has not resulted in an increase in the occurrence of CP. In fact, our results suggest that it may have led to a slight, but significant, reduction in the prevalence of children with CP among those born moderately preterm.

Analysis of trends in children with cerebral palsies of post-neonatal origin[6]
We also sought to analyse trends over time in the prevalence of CP of post-neonatal origin, to investigate the changes in prevalence and severity and to describe the disability profile by aetiology.

What were the findings?
Over the 1976-1998 study period, 404 children were identified with CP of post-neonatal origin (5.5% of the total children registered). The mean prevalence was 1.20 per 10 000 live births, with a significant downward trend ($p=0.001$) and an accentuated decrease in the 1990s. The prevalence of severe cases, which account for around one third of all cases, also decreased significantly over time ($p<0.001$). The prevalence of infectious causes has also decreased significantly since 1989, but no significant decrease occurred for cases due to a vascular episode or of traumatic origin.

What does this tell us?
These results emphasise the need for large population-based surveillance systems for reliable monitoring of trends in prevalence in rare subgroups of children, such as those with acquired CP. The decrease in the overall prevalence as well as in the rate of the most severe cases may be due in part to public health actions targeted specifically at preventing these events.

3 SCPE-NET: COLLABORATION WITH CLINICAL NETWORKS

3.1 AIMS AND OBJECTIVES

The SCPE-NET project (2009-2012), funded by the EU Second Health Programme (DG SANCO), aimed to improve the health and wellbeing of children and young people with cerebral palsies in 2 primary ways: by developing guidance on best practices for the care of children and young people with CP for use by both health professionals and lay carers (eg, parents) and by improving the collection, recording, description, and use of clinical and epidemiological data.
In addition, the project explored the feasibility of applying across Europe the knowledge and experience gained from this work to other childhood impairments and chronic conditions, such as intellectual impairment.

Specific objectives of SCPE-NET project were:
- to disseminate information and best practices for children and young people with CP to parents and professionals;
- to document variations in healthcare provision and access and in outcomes in children and young people with CP;
- to make recommendations for monitoring CP and intellectual impairment at regional or national levels.

3.2 ACHIEVEMENTS

The newly developed classification (neuroimaging findings) and scale (speech performance) add to the already available SCPE tools used worldwide. They facilitate communication between professionals and families. Persons with CP and their families, carers, and professionals may benefit from using the common language elements developed in the project for the purpose of describing children and young people with CP.

The project produced quantitative evidence about variations in a series of clinical interventions and outcomes across Europe (relations between hip luxation rates and preventive programmes, use of intrathecal baclofen, rate and age at gastrostomy tube feeding,[7] and assessment of nutritional status[7]). The demonstration studies included analyses by socioeconomic status, based on the limited data available. A protocol for obtaining good-quality and comparable socioeconomic status data in the EU CP registers is under consideration.

The project succeeded in increasing the SCPE common database by adding 3500 children with CP. Five new registers provided cases and denominators. New items were included in protocols for the registration and data quality assurance procedures, which were further developed and enhanced. Innovative data analysis methods have been incorporated, and new epidemiologic data published. The experience obtained in monitoring CP was applied in drafting recommendations for monitoring severe intellectual disabilities in children and young people.

The SCPE open-access and multilingual website developed by SCPE-NET is an effective platform for disseminating epidemiological information on CP and innovative medical education materials, such as the SCPE Reference and Training Manual. The website includes lay summaries of most reports produced by the project. It contributes to the sustainability of the network by providing access to SCPE publications and reports to all persons and groups interested in children and young people with the cerebral palsies.

3.3 WEBSITE: WWW.SCPENETWORK.EU/

A literature review and 2 online surveys have confirmed that the number of individuals and professionals seeking health-related information on the internet is growing in Europe, although large differences exist between countries. The review identified clear recommendations for providing accessible, up-to-date, and accurate information that is understandable and readable. Surveys in which individuals with CP, their parents, and professionals participated tested these recommendations and identified further information needs. A set of priorities was established to enable the website to become a reference platform for information on the epidemiology of CP: inclusion of lay summaries and graphs; information by type and severity of CP; participation of a user group in the development of the material; and delivery in languages relevant to the target users.

The Reference and Training Manual is the main SCPE tool for disseminating good practices in the CP field. During the past 4 years, existing content has been updated by the authors and new content added. Video sequences and images are available for all types of neurological and neuroimaging findings. This main SCPE information repository is already available online in 3 languages (English, German, and Portuguese) and more will be available soon (Swedish, Latvian, French, Slovenian, Italian, and Spanish).

4 CONCLUSION

The recent SCPE-NET collaborative project took advantage of a unique surveillance network of population-based registers and surveys of **children and young people with the cerebral palsies.**[8] The work plan of the project required close collaboration between registries and their clinical networks, which provided a unique, productive platform for work of high quality and quantity. This collaboration **is in line with the Health Programme's priorities**, including the facilitation of access to medical expertise and information, the validation of best practices in as many member states as possible, and the prevention and reduction of complications of chronic diseases and impairments.

The cerebral palsies are rare conditions. A European network of CP registries permits the study of trends over time in subgroups of children and young people that represent very small numbers in individual registers; these studies would not be feasible otherwise.

The public health interest of registers as useful tools for monitoring chronic conditions has been proved in several domains. However, **running a register requires continued effort and funding.** The participation of registries in a European network represents a great opportunity for enhancing data quality and for taking part in public health and research studies; this participation may also affect their own funding.

The sustainability of the network requires that funding of the registers be reinforced at the level of regions or member states and that the collaborative work — the common database and website — be supported at the EU level. The SCPE network is now in position to intensify its collaboration with international teams in this field.

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APPENDIX B:

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CORE INDICATORS

C1: Fetal mortality rate by gestational age and birth weight in 2010

			Number of total births			Number of total deaths			Fetal mortality rate per 1000 total births		
Country/ coverage	Source	Inclusion criteria for fetal deaths	All	≥1000 g	≥ 28 weeks	All	≥1000 g	≥ 28 weeks	All	≥1000 grams	≥ 28 weeks
Belgium											
BE: Brussels	1	22+ weeks or 500+ g	25 098	24 764	24 805	223	106	101	8.9	4.3	4.1
BE: Flanders	3	22+ weeks	69 976	69 585	69 613	339	178	198	4.8	2.6	2.8
BE: Wallonia	1	22+ weeks or 500+ g	38 430	38 124	38 163	202	106	123	5.3	2.8	3.2
Czech Republic	1	22+ weeks	116 920	116 167	116 239	521	149	169	4.5	1.3	1.5
Denmark	1	22+ weeks	63 513	62 994	63 223	240	97	146	3.8	1.5	2.3
Germany	5	500+ g	638 126	633 399	634 042	2565	1337	1429	4.0	2.1	2.3
Estonia	1	22+ weeks	15 884	15 792	15 790	68	40	43	4.3	2.5	2.7
Ireland	1	500+ g or 24+ weeks	75 595	75 229	75 266	352	250	275	4.7	3.3	3.7
Greece (2009)	1	24+ weeks	111 741	NA	NA	505	358	NA	4.5	NA	NA
Spain	1	180 days	400 415	461 518	398 316	1501	982	1052	3.7	2.1	2.6
France	1	22+ weeks or 500 + g	14 898	14 741	14 753	137	57	64	9.2	3.9	4.3
FR: regional register	1	22+ weeks	30 964	30 664	30 679	233	92	118	7.5	3.0	3.8
Italy	5	22+ weeks	547 569	543 084	539 749	2578	1130	1276	4.7	2.1	2.4
Cyprus (2007)	1	22+ weeks perinatal register; 28+ weeks death register	8602	8481	8512	22	14	19	2.6	1.7	2.2
Latvia	3	22+ weeks	19 248	19 175	19 164	109	80	79	5.7	4.2	4.1
Lithuania	1	22+ weeks	30 977	30 862	30 849	146	104	104	4.7	3.4	3.4
Luxembourg	1	22+ weeks	6560	6501	6517	41	18	19	6.3	2.8	2.9
Hungary	1	24+weeks or 500+ g or 30+ cm; fetal deaths and TOP at 22-23 weeks included	90 920	90 041	90 155	598	283	309	6.6	3.1	3.4
Malta	1	22+ weeks, if missing 500+ g	4036	4021	4020	18	13	14	4.5	3.2	3.5
Netherlands	1	22+ weeks or 500+ grams, if gestational age is missing	178 838	177 320	176 261	1021	443	509	5.7	2.5	2.9
Austria	1	500+ g	78 989	78 482	78 539	291	136	194	3.7	1.7	2.5
Poland	1	500+ g	415 015	412 951	413 150	1720	1150	1226	4.1	2.8	3.0
Portugal	1	24+ weeks, voluntary data at 22-23 weeks	101 790	101 297	101 278	327	223	242	3.2	2.2	2.4
Romania	2	22+ weeks	213 055	212 532	212 691	856	823	848	4.0	3.9	4.0
Slovenia	1	500+ g; in case of multiples, all babies are included if any fulfills criteria	22 416	22 266	22 282	118	73	74	5.3	3.3	3.3
Slovakia	1	22+ weeks	55 825	55 645	55 665	180	171	173	3.2	3.1	3.1

			Number of total births			Number of total deaths			Fetal mortality rate per 1000 total births		
Country/ coverage	Source	Inclusion criteria for fetal deaths	All	≥1000 g	≥ 28 weeks	All	≥1000 g	≥ 28 weeks	All	≥1000 grams	≥ 28 weeks
Finland	1	22+ weeks or 500+ g, if gestational age is missing	61 421	61 141	61 123	230	114	120	3.7	1.9	2.0
Sweden	1	22+ weeks	115 135	114 447	114 649	429	278	316	3.7	2.4	2.8
United Kingdom											
UK: England and Wales	5	24+ weeks	721 925	711 456	711 217	3659	2441	2684	5.1	3.4	3.8
UK: Scotland	11	22+ weeks; not complete at 22-23 weeks	57 488	57 103	57 133	337	189	208	5.9	3.3	3.6
UK: Northern Ireland	16	24+ weeks	25 692	25 502	25 259	106	50	87	4.1	2.0	3.4
Iceland	1	22+ weeks or 500+ g, if gestational age is missing	4889	4885	4866	17	7	9	3.5	1.4	1.8
Norway	1	22+ weeks	62 612	62 291	61 783	234	120	142	3.7	1.9	2.3
Switzerland	1	22+ weeks or 500+ g, if gestational age is missing	80 276	79 764	79 790	345	149	170	4.3	1.9	2.1

NA: not available.
NOTES: Fetal mortality rate per 1000 total births = ((number of fetal deaths)/(number of total births))*1000
EURO-PERSISTAT requested data for all births at 22 completed weeks of gestation or with a birth weight of 500 g if gestational age was missing.
Data from Cyprus are from 2007, and data from Greece from 2009.

C2_A: Neonatal mortality rate by timing of death, births ≥22 weeks of gestation in 2010

			Number of neonatal deaths			Neonatal mortality rate per 1000 live births		
Country/coverage	Source	Number of live births	All (day 0-27)	Early (day 0-6)	Late (day 7-27)	All (day 0-27)	Early (day 0-6)	Late (day 7-27)
Belgium								
BE: Brussels	1	24 875	68	51	17	2.7	2.1	0.7
BE: Flanders	3	69 637	159	135	24	2.3	1.9	0.3
BE: Wallonia	1	38 228	80	59	21	2.1	1.5	0.5
Czech Republic	1	116 399	196	119	77	1.7	1.0	0.7
Denmark	1	63 273	122	98	24	1.9	1.5	0.4
Germany	2	635 561	1541	1175	366	2.4	1.8	0.6
Estonia	3	15 816	30	25	5	1.9	1.6	0.3
Ireland (cohort)	1	75 243	NA	159	NA	NA	2.1	NA
Greece (2009)	1	111 741	238	NA	NA	2.1	NA	NA
Spain	1	486,575	1,025	654	371	2.1	1.3	0.8
ES: Catalonia	1	84 071	158	105	53	1.9	1.3	0.6
ES: Valencia	2	50 444	126	91	35	2.5	1.8	0.7
France	2	802 224	1881	1269	612	2.3	1.6	0.8
Italy	3	544 991	1349	945	404	2.5	1.7	0.7
Cyprus (2007)	2	8575	14	9	5	1.6	1.0	0.6
Latvia	3	19 139	69	48	21	3.6	2.5	1.1
Lithuania	1	30 831	82	54	28	2.7	1.8	0.9
Luxembourg	2	6519	12	10	2	1.8	1.5	0.3
Hungary	1	90 322	313	239	74	3.5	2.6	0.8
Malta	3	4018	18	16	2	4.5	4.0	0.5
Netherlands (cohort)	1	177 817	587	502	85	3.3	2.8	0.5
Austria	3	78 698	170	129	41	2.2	1.6	0.5
Poland	1	413 295	1448	1081	367	3.5	2.6	0.9
Portugal	1	101 463	167	115	52	1.6	1.1	0.5
Romania	2	212 199	1160	787	373	5.5	3.7	1.8
Slovenia (cohort)	1	22 298	40	31	9	1.8	1.4	0.4
Slovakia	1	55 645	102	76	26	1.8	1.4	0.5
Finland	2	61 191	92	67	25	1.5	1.1	0.4
Sweden	1	114 706	180	132	48	1.5	1.1	0.4
United Kingdom								
UK: England and Wales (cohort)	5	718 266	1822	1366	456	2.5	1.9	0.6
UK: Scotland	11	57 151	144	112	32	2.5	2.0	0.6
UK: Northern Ireland	15	25 586	96	82	14	3.8	3.2	0.5
Iceland	1	4886	6	5	1	1.2	1.0	0.2
Norway	1	62 378	124	94	30	2.0	1.5	0.5
Switzerland	1	79 931	204	174	30	2.6	2.2	0.4

NA: not available.
NOTES: Neonatal mortality rate per 1000 live births = ((number of neonatal deaths)/(number of live births))*1000
Early neonatal mortality rate per 1000 live births = ((number of early neonatal deaths)/(number of early live births))*1000
Late neonatal mortality rate per 1000 live births = ((number of late neonatal deaths)/(number of late live births))*1000
Inclusion criteria were based on gestational age 22+ weeks; if gestational age was missing, births were included if birth weight was at least 500 g.
Data from Cyprus are from 2007, and data from Greece from 2009.

C2_B: Neonatal mortality rate for all births and births at ≥24 weeks of gestation in 2010

			Number of live births		Number of neonatal deaths		Neonatal mortality rate	
Country/coverage	Source	Inclusion criteria for live births	All	≥24 weeks	All	≥24 weeks	All	≥24 weeks
Belgium								
BE: Brussels	1	22+ weeks or 500+ g	24 875	24 803	68	67	2.7	2.7
BE: Flanders	3	22+ weeks	69 637	69 614	159	136	2.3	2.0
BE: Wallonia	1	22+ weeks or 500+ g	38 228	38 137	80	70	2.1	1.8
Czech Republic	1	22+ weeks	116 399	116 376	196	190	1.7	1.6
Denmark	1	22+ weeks	63 273	63 243	122	95	1.9	1.5
Germany	2	22+ weeks	635 561	635 097	1541	NA	2.4	NA
Estonia	3	22+ weeks	15 816	15 802	30	20	1.9	1.3
Ireland (early cohort)								
Greece (2009)	1	24+ weeks	111 741	NA	238	NA	2.1	NA
Spain	1	22+ weeks	486,575	NA	1025	NA	2.1	NA
ES: Catalonia	1	22+ weeks	84 071	NA	158	NA	1.9	NA
ES: Valencia	2	22+ weeks	50 444	NA	126	119	2.5	2.4
France	2	22+ weeks or 500+ g	802 224	798 213	1881	1693	2.3	2.1
Italy	3	22+ weeks	544 991	539 959	1349	NA	2.5	NA
Cyprus (2007)	2	22+ weeks	8 575	8 517	14	NA	1.6	NA
Latvia	3	22+ weeks	19 139	19 136	69	63	3.6	3.3
Lithuania	1	22+ weeks	30 831	30 815	82	70	2.7	2.3
Luxembourg	2	22+ weeks	6 519	6 517	12	8	1.8	1.2
Hungary	1	22+ weeks	90 322	90 259	313	NA	3.5	NA
Malta	3	22+ weeks or 500+ g	4 018	4 016	18	16	4.5	4.0
Netherlands (cohort)	1	22+ weeks or 500+ g if GA missing	177 817	176 249	587	390	3.3	2.2
Austria	3	500+ grams	78 698	78 644	170	131	2.2	1.7
Poland	1	22+ weeks	413 295	413 070	1448	1267	3.5	3.1
Portugal	1	22+ weeks (not complete at 22-23 weeks)	101 463	101 269	167	157	1.6	1.6
Romania	2	22+ weeks	212 199	212 182	1160	911	5.5	4.3
Slovenia (cohort)	1	22+ weeks	22 298	22 278	40	25	1.8	1.1
Slovakia	1	22+ weeks	55 645	55 637	102	98	1.8	1.8
Finland	2	22+ weeks	61 191	61 126	92	79	1.5	1.3
Sweden	1	22+ weeks	114 706	114 648	180	146	1.6	1.3
United Kingdom								
UK: England and Wales (cohort)	5	22+ weeks	718 266	710 862	1822	1397	2.5	2.0
UK: Scotland	11	22+ weeks	57 151	57 102	144	120	2.5	2.1
UK: Northern Ireland	15	22+ weeks	25 586	25 252	96	75	3.8	3.0
Iceland	1	22+ weeks	4 886	4 870	6	4	1.2	0.8
Norway	1	22+ weeks	62 378	61 786	124	101	2.0	1.6
Switzerland	1	22+ weeks or 500+ g if GA missing	79 931	79 834	204	148	2.6	1.9

GA: gestational age.
NOTES: Neonatal mortality rate per 1000 live births = ((number of neonatal deaths)/(number of live births))*1000
Inclusion criteria were based on gestational age 22+ weeks; if gestational age was missing, births were included if birth weight was at least 500 g.
Rates could not be computed for Ireland (data on early neonatal deaths) and for Germany and Hungary at 24+ weeks (data on early neonatal deaths by gestational age)
Distribution refers to annual neonatal deaths except for the Netherlands, Slovenia, and England and Wales (cohort deaths).
For France, the number of neonatal deaths at 24+ weeks and more is estimated from a register with 90% of deaths recorded, corrected for missing values.
Denominators are estimated based on a nationally representative survey.
Data from Cyprus are from 2007 and data from Greece from 2009.

C3: Infant mortality rate, births ≥22 weeks of gestation in 2010

Country/coverage	Source	Inclusion criteria for live births	Live births	Infant deaths	Infant mortality rate
Belgium					
BE: Brussels	1	22+ weeks or 500+ g	24 875	120	4.8
BE: Flanders	3	22+ weeks	69 637	231	3.3
BE: Wallonia	1	22+ weeks or 500+ g	38 228	119	3.1
Czech Republic	2	22+ weeks	116 399	313	2.7
Denmark	1	22+ weeks	63 273	168	2.7
Germany	2	22+ weeks	635 561	2322	3.7
Estonia	3	22+ weeks	15 816	44	2.8
Ireland					
Greece					
Spain					
ES: Valencia	2	22+ weeks	50 927	185	3.6
France	2	22+ weeks or 500+ g	802 224	2785	3.5
Italy	3	22+ weeks	544 991	1877	3.4
Cyprus (2007)	2	22+ weeks	8575	27	3.1
Latvia	3	22+ weeks	19 139	110	5.7
Lithuania	3,1	22+ weeks	30 831	154	5.0
Luxembourg	2	22+ weeks	6519	16	2.5
Hungary	1	22+ weeks	90 322	481	5.3
Malta	3	22+ weeks or 500+ g	4018	22	5.5
Netherlands	2	24+ weeks	184 397	695	3.8
Austria	3	500+ grams	78 698	263	3.3
Poland	1	22+ weeks	413 295	2051	5.0
Portugal	1	22+ weeks (not complete at 22-23 weeks)	101 463	258	2.5
Romania	2	22+ weeks	212 199	2078	9.8
Slovenia	2	22+ weeks	22 298	56	2.5
Slovakia					
Finland	2	22+ weeks	61 191	139	2.3
Sweden	1	22+ weeks	114 706	278	2.4
United Kingdom					
UK: England and Wales	5	22+ weeks	718 266	2735	3.8
UK: Scotland	11	22+ weeks	57 151	212	3.7
UK: Northern Ireland	15	22+ weeks	25 586	139	5.4
Iceland	1	22+ weeks	4886	11	2.3
Norway	1	22+ weeks	62 378	177	2.8
Switzerland	1	22+ weeks or 500+ g if GA is missing	79 931	259	3.2

GA: gestational age.
NOTES: For Lithuania, the total number of live births are from source number 1 in 2004 and 2010.
Data from Cyprus are from 2007.

C4_A: Distribution of birth weight for total births in 2010

		Number of live births		Percentage of total births by birth weight (g)				
Country/coverage	Source	All stated	Not stated	<500	500-1499	1500-2499	2500-4499	≥4500
Belgium								
BE: Brussels	1	24 990	108	0.1	1.8	6.0	91.2	0.9
BE: Flanders	3	69 980	0	0.1	1.2	5.6	92.1	1.1
BE: Wallonia	1	38 321	109	0.1	1.0	7.2	91.1	0.5
Czech Republic	1	116 912	0	0.2	1.2	6.5	91.2	0.9
Denmark	1	63 266	247	0.1	0.9	4.3	91.8	3.0
Germany	2	637 642	22	0.1	1.4	6.0	91.4	1.2
Estonia	3	15 877	7	0.1	1.0	3.2	92.5	3.2
Ireland	1	75 587	8	0.0	1.1	4.3	92.0	2.7
Greece								
Spain	2	463 123	24 953	0.0	1.1	7.7	90.6	0.6
France	1	14 844	54	0.1	1.2	5.7	92.2	0.7
Italy	5	545 282	2286	0.0	1.0	6.2	92.3	0.5
Cyprus (2007)	1	8524	74	0.0	1.2	8.8	89.6	0.4
Latvia	3	19 248	0	0.0	1.0	4.1	92.3	2.5
Lithuania	1	30 977	0	0.0	0.8	4.1	93.0	2.1
Luxembourg	1	6544	16	0.1	1.2	5.9	92.3	0.6
Hungary	1	90 695	225	0.1	1.6	7.2	91.1	2.3
Malta	3	4035	1	0.0	1.0	6.6	92.0	0.4
Netherlands	1	178 571	267	0.2	1.2	5.3	91.0	2.4
Austria	1	78 989	0	0.2	1.2	5.9	91.8	0.9
Poland	1	415 014	1	0.0	1.0	4.9	92.5	1.5
Portugal	1	101 694	96	0.0	1.1	7.4	91.1	0.4
Romania	1	213 052	3	0.0	0.9	7.3	91.1	0.7
Slovenia	1	22 409	7	0.1	1.2	5.3	92.2	1.1
Slovakia	1	55 825	0	0.0	1.0	7.3	90.9	0.8
Finland	1	61 362	59	0.1	0.8	3.7	93.0	2.5
Sweden	1	114 894	241	0.1	0.8	3.5	92.0	3.6
United Kingdom								
UK: England and Wales	5	716 424	5501	0.2	1.2	5.9	91.0	1.7
UK: Scotland	12	57 458	30	0.1	1.2	5.5	91.0	2.1
UK: Northern Ireland	17	25 677	15	0.2	1.1	4.6	91.7	2.4
Iceland	1	4895	8	0.1	0.5	3.0	91.5	4.9
Norway	1	62 576	32	0.1	0.9	4.2	91.7	3.2
Switzerland	1	80 258	18	0.2	1.0	5.7	92.3	0.8

NOTES: Hungary provided data only for all births 2500 g and over.
Data from Cyprus are from 2007.

C4_B: Distribution of birth weight by plurality for live births in 2010

		Number of live births			% of live singleton births			% of live multiple births	
		Birth weight (g)			Birth weight (g)			Birth weight (g)	
Country/ coverage	Source	All stated	<1500	1500-2499	All stated	<1500	1500-2499	All stated	<1500	1500-2499
Belgium										
BE: Brussels	1	24 776	1.4	5.9	23 635	1.0	4.0	1126	10.5	44.7
BE: Flanders	3	69 637	1.0	5.6	67 029	0.6	4.0	2608	9.9	45.6
BE: Wallonia	1	38 122	0.8	7.2	36 866	0.6	5.6	1256	6.9	54.3
Czech Republic	1	116 399	1.0	6.5	111 616	0.7	4.7	4783	9.2	48.2
Denmark	1	63 096	0.8	4.3	60 506	0.6	2.9	2590	6.8	36.8
Germany	3	635 539	1.3	5.9	611 843	0.9	4.3	23 696	11.3	47.4
Estonia	1	15 810	0.9	3.2	15 351	0.7	2.3	459	4.8	31.8
Ireland	1	75 237	0.9	4.2	72 701	0.6	2.9	2536	8.3	39.3
Greece										
Spain	1	461 870	1.0	7.7	443 091	0.7	5.7	18 779	8.2	54.1
France	1	14 716	0.8	5.6	14 285	0.6	4.5	431	7.2	42.7
Italy	4	543 899	0.9	6.2	526 954	0.7	4.7	16 945	8.8	52.9
Cyprus (2007)	1	8504	1.0	8.8	8039	0.7	6.0	465	7.7	56.8
Latvia	1	19 139	0.7	4.1	18 662	0.6	3.3	477	4.8	35.0
Lithuania	1	30 831	0.7	4.0	30 035	0.5	2.9	796	5.2	44.5
Luxembourg	1	6505	0.8	5.9	6275	0.6	4.3	230	7.4	50.4
Hungary	1	90 308	1.4	7.1						
Malta	1	4017	0.8	6.5	3855	0.6	4.6	162	4.9	50.0
Netherlands	1	177 598	1.0	5.2	171 568	0.7	3.9	6030	8.6	43.0
Austria	1	78 698	1.2	5.8	75 950	0.8	4.2	2748	11.4	52.2
Poland	1	413 294	0.9	4.8	402 170	0.7	3.7	11 124	7.7	46.1
Portugal	1	101 378	1.0	7.3	98 303	0.7	5.7	3075	10.4	58.6
Romania	3	212 199	0.8	7.2	208 325	0.7	6.4	3874	7.6	50.3
Slovenia	1	22 292	1.1	5.2	21 476	0.7	3.6	816	11.3	47.9
Slovakia	1	55 645	1.0	7.1	54 041	0.7	5.9	1604	9.3	49.7
Finland	1	61 182	0.7	3.6	59 309	0.5	2.6	1873	6.4	37.7
Sweden	1	114 498	0.9	3.5	111 039	0.5	2.5	3227	8.2	33.7
United Kingdom										
UK: England and Wales	5	712 938	1.2	5.8	691 181	0.9	4.6	21 757	9.5	45.7
UK: Scotland	12	57 133	1.0	5.5	55 351	0.7	4.3	1782	10.0	43.4
UK: Northern Ireland	17	25 571	1.1	4.6	24 791	0.8	3.5	780	9.5	40.3
Iceland	1	4878	0.3	3.0	4748	0.2	2.0	130	4.6	40.0
Norway	1	62 373	0.8	4.1	60 318	0.6	3.0	2055	7.1	38.2
Switzerland	1	79 915	0.9	5.6	77 003	0.6	4.0	2912	8.9	48.5

NOTE: Data from Cyprus are from 2007.

C5_A: Distribution of gestational age for total births in 2010

				Percentage of total births Gestational age in completed weeks				
Country/coverage	Source	All stated	Not stated	<28	28-31	32-36	37-41	≥42
Belgium								
BE: Brussels	1	25 029	69	0.9	1.1	7.1	90.4	0.5
BE: Flanders	3	69 976	0	0.5	0.8	6.9	91.3	0.4
BE: Wallonia	1	38 346	84	0.5	0.7	7.5	91.1	0.2
Czech Republic	1	116 920	0	0.6	0.8	7.1	89.9	1.7
Denmark	1	63 513	0	0.5	0.7	5.4	87.7	5.6
Germany	1	638 126	0	0.6	0.9	7.1	90.5	0.8
Estonia	1	15 881	3	0.6	0.7	4.7	91.9	2.2
Ireland	1	75 586	9	0.4	0.7	4.9	90.8	3.2
Greece								
Spain	1	400 161	262	0.3	0.9	6.9	89.1	2.8
France	1	14 850	48	0.7	0.8	5.9	92.3	0.3
Italy	4	542 737	4832	0.6	0.7	6.4	90.9	1.3
Cyprus (2007)	1	8539	42	0.5	0.7	9.3	89.4	0.1
Latvia	1	19 248	0	0.4	0.9	4.8	93.2	0.7
Lithuania	1	30 977	0	0.4	0.7	4.6	93.9	0.4
Luxembourg	1	6560	0	0.7	0.7	7.1	91.3	0.2
Hungary	1	90 893	27	0.8	1.0	7.6	90.3	0.3
Malta	1	4036	0	0.4	0.6	6.5	92.3	0.1
Netherlands	1	177 449	1389	0.7	0.8	6.4	90.1	2.0
Austria	1	78 989	0	0.6	0.9	7.2	90.7	0.7
Poland	1	415 015	0	0.4	0.7	5.7	90.6	2.5
Portugal	1	101 604	186	0.3	0.9	6.7	91.6	0.5
Romania	3	213 055	0	0.2	1.1	7.1	90.6	1.0
Slovenia	1	22 416	0	0.6	0.9	6.1	90.4	2.0
Slovakia	1	55 825	0	0.3	0.8	6.2	91.9	0.8
Finland	1	61 371	50	0.4	0.6	4.9	89.4	4.7
Sweden	1	115 135	0	0.4	0.6	5.1	87.3	6.6
United Kingdom								
UK: England and Wales	5	714 916	7009	0.5	0.9	6.0	88.4	4.2
UK: Scotland	12	57 464	24	0.6	0.9	5.9	90.0	2.6
UK: Northern Ireland	17	25 381	311	0.5	0.9	6.1	88.3	4.3
Iceland	1	4889	14	0.5	0.4	4.6	91.8	2.8
Norway	1	62 335	577	0.4	0.7	5.4	87.1	6.4
Switzerland	1	80 235	41	0.6	0.7	6.1	92.1	0.5

NOTES: Gestational age= best obstetric estimate in completed weeks;
Data from Cyprus are from 2007.

C5_B: Distribution of gestational age by plurality for live births in 2010

		Number of live births			% of live singleton births			% of live multiple births		
			Gestational age in weeks			Gestational age in weeks			Gestational age in weeks	
Country/ coverage	Source	All stated	<32	32-36	All stated	<32	32-36	All stated	<32	32-36
Belgium										
BE: Brussels	1	24 806	1.4	7.0	23 662	1.0	5.2	1129	9.6	45.4
BE: Flanders	3	69 637	1.0	6.9	67 029	0.7	5.3	2608	10.5	46.7
BE: Wallonia	1	38 145	0.9	7.4	36 882	0.7	5.8	1263	8.6	53.1
Czech Republic	1	116 399	1.0	7.0	111 616	0.7	5.4	4783	8.7	45.0
Denmark	1	63 273	1.0	5.4	60 667	0.7	4.1	2606	7.5	34.1
Germany	1	635 561	1.3	7.1	611 864	0.9	5.5	23 697	11.0	46.8
Estonia	1	15 813	1.1	4.6	15 354	0.9	3.7	459	7.6	35.1
Ireland	1	75 235	1.0	4.7	72 699	0.7	3.5	2536	8.6	39.9
Greece										
Spain	1	398 914	1.1	6.9	382 136	0.8	5.2	16 778	8.3	45.5
France	1	14 714	0.8	5.8	14 279	0.6	4.9	435	7.1	34.9
Italy	4	540 175	1.0	6.4	523 153	0.7	5.0	17 022	8.9	49.7
Cyprus (2007)	1	8517	1.1	9.3	8067	0.8	6.4	450	6.7	60.2
Latvia	1	19 139	1.1	4.7	18 662	1.0	4.0	477	5.9	33.8
Lithuania	1	30 831	0.9	4.5	30 035	0.7	3.6	796	8.2	39.7
Luxembourg	1	6519	1.0	7.1	6285	0.6	5.6	234	10.3	47.4
Hungary	1	90 295	1.4	7.5	NA	NA	NA	NA	NA	NA
Malta	1	4018	0.8	6.4	3856	0.6	4.8	162	5.6	43.8
Netherlands	1	176 437	1.1	6.4	170 404	0.8	5.0	6033	9.6	44.7
Austria	1	78 698	1.3	7.1	75 950	0.9	5.5	2748	12.4	53.6
Poland	1	413 295	1.0	5.6	402 171	0.8	4.5	11 124	8.1	44.5
Portugal	1	101 284	1.0	6.6	98 207	0.7	5.2	3077	10.1	53.1
Romania	3	212 199	1.2	7.0	208 325	1.1	6.5	3874	7.2	35.5
Slovenia	1	22 298	1.2	6.0	21 482	0.8	4.7	816	12.4	40.6
Slovakia	1	55 645	1.0	6.1	54 041	0.8	5.0	1604	9.2	42.6
Finland	1	61 146	0.8	4.9	59 273	0.5	3.8	1873	8.2	38.6
Sweden	1	114 706	0.9	5.0	111 474	0.6	4.1	3232	8.5	37.0
United Kingdom										
UK: England and Wales	5	711 365	1.2	5.9	689 420	0.9	4.7	21 945	10.1	43.3
UK: Scotland	12	57 127	1.2	5.8	55 343	0.9	4.6	1784	10.6	43.0
UK: Northern Ireland	17	25 275	1.2	6.0	24 504	0.9	4.7	771	11.9	46.3
Iceland	1	4872	0.7	4.6	4739	0.4	3.7	133	9.8	34.6
Norway	1	62 112	1.0	5.3	60 131	0.7	4.2	1981	8.8	39.9
Switzerland	1	79 890	1.0	6.1	76 975	0.7	4.6	2915	8.9	46.3

NOTES: Gestational age = best obstetric estimate in completed weeks
Data from Cyprus are from 2007.

C6_A: Maternal mortality ratio from routine statistical systems in 2006-2010

				Maternal mortality ratio per 100 000 live births			
Country/coverage	Source	Live births 2006-2010	Maternal deaths 2006-2010	2006-2010	95%	CI	2003-2004
Belgium							
BE: Brussels	1	118 310	8	6.8	2.9	13.3	6.2
BE: Flanders	3	339 534	11	3.2	1.6	5.8	4.2
BE: Wallonia	2	188 220	17	9.0	5.3	14.5	NA
Czech Republic	1	591 913	22	3.7	2.3	5.6	9.9
Denmark (2005-2009)	3	323 159	10	3.1	1.5	5.7	9.3
Germany	1	2 741 631	108	3.9	3.2	4.8	5.3
Estonia	3	77 859	2	2.6	0.3	9.3	29.6
Ireland							
Greece							1.9
Spain	1	2 476 835	88	3.6	2.9	4.4	NA
ES: Catalonia	7	425 927	16	3.8	2.2	6.1	4.6
France	3	4 090 069	345	8.4	7.6	9.4	7.0
Italy (2006-2009)	3	2 253 048	56	2.5	1.9	3.2	3.2
Cyprus	2	45 920	3	6.5	1.4	19.6	NA
Latvia	2	110 365	27	24.5	16.1	35.6	12.1
Lithuania	2	170 984	7	4.1	1.7	8.4	9.8
Luxembourg	2	30 288	3	9.9	2.0	29.0	7.3
Hungary	1	483 410	65	13.4	10.4	17.1	7.4
Malta	2	20 135	2	9.9	1.2	35.9	0.0
Netherlands	2	920 339	45	4.9	3.6	6.5	8.8
Austria	2	387 002	10	2.6	1.2		2.5
Poland	1	2 007 525	58	2.9	2.2	3.7	4.4
Portugal	1	513 839	30	5.8	3.9	8.3	7.7
Romania	4	1 090 698	229	21.0	18.4	23.9	NA
Slovenia	2	82 236	12	14.6	7.5	25.5	11.5
Slovakia	2	212 896	22	10.3	6.5	15.7	NA
Finland	2	298 967	14	4.7	2.6	7.9	7.9
Sweden	2	541 694	17	3.1	1.7	4.8	2.0
United Kingdom	4,10,14	3 912 666	269	6.9	6.1	7.7	7.7
Iceland	2	23 722	0	0.0	0.0	15.6	NA
Norway							3.5
Switzerland	1	383 055	21	5.5	3.4	8.4	5.5

NA: not available
NOTES: Data from the Czech Republic in 2010 come from the registry of parturients and will not include maternal deaths in pregnancy and after pregnancy.
Switzerland had 4 maternal deaths in 2003 and 4 in 2004 for 144 930 live births.

C6_B Maternal mortality ratio from enhanced system in 2006-2010

			Maternal mortality ratio per 100 000 live births		
Country/coverage	Live births N	Maternal deaths N	Ratio	95%	CI
Estonia	78 271	2	2.6	0.3	9.2
Netherlands	920 339	71	7.7	6.0	9.7
France (2005-2009)	4 065 057	369	9.1	8.2	10.1
United Kingdom (2006-2008)	2 282 217	261	11.4	10.0	12.8
Portugal (2003-2007)	539 483	62	11.5	8.8	14.7
Slovenia (2006-2009)	82 236	12	14.6	7.5	25.5

C7: Multiple birth rate by number of fetuses per 1000 women in 2010

		Number of women		Multiple maternity rate per 1000 women		
Country/coverage	Source	All stated	Not stated	Twins	Triplets+	Multiples
Belgium						
BE: Brussels	1	24 500	0	22.6	0.6	23.2
BE: Flanders	3	68 645	0	18.9	0.3	19.2
BE: Wallonia	1	37 780	0	16.8	0.2	17.0
Czech Republic	1	114 406	0	21.0	0.1	21.1
Denmark	1	62 203	0	20.9	0.1	21.0
Germany	1	625 615	0	18.5	0.4	18.9
Estonia	1	15 646	0	14.7	0.3	15.0
Ireland	1	74 313	0	16.8	0.3	17.1
Greece						
Spain	1	478 037	0	20.2	0.4	20.6
France	2	796 066	0	17.4	0.3	17.7
Italy	5	537 633	1100	15.0	0.7	15.7
Cyprus (2007)	1	8355	0	25.1	1.4	26.5
Latvia	1	19 003	0	12.6	0.1	12.7
Lithuania	1	30 568	0	12.9	0.3	13.1
Luxembourg	1	6440	0	18.3	0.2	18.5
Hungary						
Malta	1	3952	0	18.7	1.5	20.2
Netherlands	1	175 871	0	17.7	0.3	18.0
Austria	1	77 592	0	17.2	0.4	17.6
Poland	1	409 372	0	13.4	0.3	13.7
Portugal	1	100 229	0	15.1	0.2	15.4
Romania	1	213 053	2	9.0	0.2	9.1
Slovenia	1	22 000	0	18.5	0.2	18.7
Slovakia	1	55 012	0	14.5	0.2	14.7
Finland	1	60 421	0	15.3	0.2	15.5
Sweden	1	113 488	0	14.0	0.3	14.3
United Kingdom	4,10,14	799 286	0	15.5	0.2	15.7
UK: England and Wales	4	715 467	0	15.4	0.2	15.7
UK: Scotland	14	58 791	0	15.6	0.2	15.8
UK: Northern Ireland	10	25 028	0	15.3	0.2	15.5
Iceland	1	4834	0	14.3	0.0	14.3
Norway	1	61 539	0	16.4	0.4	16.7
Switzerland	1	78 784	0	18.4	0.3	18.7

NOTES: Data from Romania were based on the number of live born or stillborn babies and not on the number of women delivering live births or stillbirths; rates were recalculated with women as the denominator.
Data from Cyprus are from 2007.

C8: Distribution of maternal age for women delivering live births or stillbirths in 2010

		Number of women		Percentage of women by maternal age				
Country/coverage	Source	All stated	Not stated	<20	20-24	25-29	30-34	35+
Belgium								
BE: Brussels	1	24 499	1	2.0	13.0	28.5	33.3	23.2
BE: Flanders	3	68 645	0	1.8	13.3	37.2	33.3	14.3
BE: Wallonia	1	37 774	6	3.8	17.5	34.0	28.7	16.0
Czech Republic	1	114 356	50	2.9	13.4	31.0	37.2	15.4
Denmark	1	62 189	0	1.4	11.1	30.1	36.5	20.9
Germany	1	625 615	0	2.1	13.1	28.0	33.1	23.6
Estonia	1	15 646	0	2.3	16.4	32.5	28.2	20.7
Ireland	1	74 298	15	2.7	10.9	23.8	34.7	27.9
Greece (2009)	1	114 766	0	2.8	11.8	27.0	35.2	23.3
Spain	1	478 037	0	2.5	9.1	20.8	38.1	29.5
France	1	14 527	154	2.5	14.5	33.2	30.6	19.2
Italy	5	532 319	6414	1.4	8.9	21.2	33.7	34.7
Cyprus (2007)	1	8354	0	2.0	15.3	36.6	30.6	15.5
Latvia	1	19 001	2	5.9	23.5	32.6	23.4	14.7
Lithuania	1	30 565	3	3.8	17.7	35.9	27.7	14.9
Luxembourg	1	6437	3	1.8	10.5	27.6	36.9	23.3
Hungary	1	90 722	0	5.9	14.0	27.7	34.8	17.5
Malta	1	3952	0	6.5	14.2	32.5	31.3	15.5
Netherlands	1	175 864	7	1.4	10.4	30.1	36.5	21.6
Austria	1	77 592	0	3.2	15.9	31.3	29.9	19.7
Poland	1	409 372	0	4.5	19.4	36.9	27.3	11.8
Portugal	1	100 227	2	4.0	13.2	26.5	34.6	21.7
Romania	1	213 055	0	10.6	24.8	29.6	24.1	10.9
Slovenia	1	22 000	0	1.2	12.0	35.2	36.2	15.4
Slovakia	1	54 970	42	7.3	18.6	31.8	29.7	12.6
Finland	1	60 421	0	2.3	15.1	32.2	32.3	18.0
Sweden	1	113 014	474	1.6	13.4	28.8	33.8	22.5
United Kingdom	4,10,14	798 614	20	5.7	19.0	27.6	28.0	19.7
UK: England and Wales	4	715 467	0	5.7	19.1	27.6	27.9	19.7
UK: Scotland	14	58 119	20	6.4	18.3	27.5	27.9	19.9
UK: Northern Ireland	10	25 028	35	5.1	16.0	28.6	30.4	19.9
Iceland	1	4834	0	3.1	16.7	32.5	28.7	19.1
Norway	1	61 534	5	2.2	15.0	31.0	32.3	19.5
Switzerland	1	78 784	0	1.1	10.0	26.5	36.6	25.8

NOTES: Data from Hungary and Romania are based on the number of live born or stillborn babies and not on the number of women delivering live births or stillbirths; data from Greece are based on an inclusion criterion of 24+ weeks of gestation; data from Cyprus are from 2007, and data from Greece from 2009).

C9: Distribution of parity for women delivering live births or stillbirths in 2010

		Number of women		Percentage of women by number of previous births			
Country/coverage	Source	All stated	Not stated	0	1	2	3+
Belgium							
BE: Brussels	1	24 425	75	44.2	31.1	15.9	8.8
BE: Flanders	3	68 645	0	45.9	35.4	12.6	6.2
BE: Wallonia	1	37 687	93	44.7	33.3	14.0	7.9
Czech Republic	1	114 406	0	48.1	35.8	11.6	4.5
Denmark	1	62 189	0	44.5	36.8	14.0	4.7
Germany	1	625 615	0	49.8	33.6	11.3	5.3
Estonia	1	15 646	0	42.7	37.5	13.7	6.2
Ireland	1	74 309	4	41.5	33.0	16.5	9.1
Greece							
Spain	1	478 037	0	53.0	36.5	7.8	2.7
France	1	14 533	148	43.3	34.5	14.4	7.8
Italy	5	511 495	27 238	52.0	35.8	9.4	2.8
Cyprus (2007)	1	8323	31	49.3	32.1	13.7	4.9
Latvia	1	19 003	0	48.6	34.3	11.4	5.7
Lithuania	1	30 568	0	47.5	37.4	10.2	4.9
Luxembourg	1	6440	0	47.3	34.5	13.1	5.2
Hungary	1	90 335	0	47.4	32.6	12.1	8.0
Malta	1	3952	0	51.4	32.5	11.7	4.5
Netherlands	1	175 871	0	48.1	34.3	12.3	5.2
Austria	1	77 592	0	48.0	34.7	12.0	5.3
Poland	1	409 362	10	50.8	34.9	9.6	4.7
Portugal	1	100 120	109	53.4	34.9	8.6	3.0
Romania	1	213 055	0	52.6	30.5	8.6	8.3
Slovenia	1	22 000	0	50.2	36.4	9.8	3.5
Slovakia	1	52 858	2154	39.6	30.8	14.9	14.7
Finland	1	60 419	2	42.2	33.6	14.5	9.7
Sweden	1	113 488	0	46.3	35.3	12.8	5.6
United Kingdom							
UK: England	6	662 913	0	42.9	31.8	13.8	11.5
UK: Wales	8	29 163	7036	52.9	28.6	11.7	6.8
UK: Scotland	12	56 405	124	47.0	33.9	12.8	6.3
UK: Northern Ireland	17	25 221	138	41.4	34.0	16.1	8.5
Iceland	1	4833	1	39.4	33.5	20.8	6.3
Norway	1	61 539	0	42.9	35.5	15.2	6.4
Switzerland	1	78 486	298	50.2	35.8	10.9	3.1

NOTES:
Data from Romania are based on the number of live born or stillborn babies and not on the number of women delivering live births or stillbirths
Data from Switzerland are based on the number of previous live births (regardless of the number of week of gestation) by women delivering a live birth or stillbirth at or after 22 weeks of gestation; unstated refers to women delivering stillbirths.
In Lithuania it is not possible to distinguish between missing parity and women with no previous births.
Data from Cyprus are from 2007.

C10: Mode of delivery in 2010

				Percentage of total births by mode of delivery					
Country/coverage	Source	All stated	Not stated	Vaginal - spontaneous	Vaginal - instrumental	Vaginal - total	Caesarean - no labour or elective	Caesarean - during labour or emergency	Caesarean - total
Belgium									
BE: Brussels	1	25 009	89	71.5	8.3	79.8	9.7	10.4	20.2
BE: Flanders	3	69 976	0	69.6	10.4	79.9	11.3	8.8	20.1
BE: Wallonia	1	38 310	120	71.6	7.5	79.1	10.4	10.5	20.9
Czech Republic	1	113 917	489	75.1	1.8	76.9	12.7	10.4	23.1
Denmark	2	63 460	53	71.0	6.9	77.9	9.4	12.8	22.1
Germany	1	619 903	17 761	62.2	6.4	68.7	15.4	15.9	31.3
Estonia	1	15 884	0	74.0	4.9	78.8	7.8	13.4	21.2
Ireland	1	75 564	31	56.6	16.4	73.0	NA	NA	27.0
Greece									
Spain	4	377 713	0	62.7	15.1	77.8	NA	NA	22.2
ES: Catalonia	7	82 975	1096	59.4	12.5	71.9	NA	NA	28.1
France	1	14 731	172	66.9	12.1	79.0	11.3	9.7	21.0
Italy	5	546 133	1435	58.6	3.4	62.0	24.9	13.1	38.0
Cyprus (2007)	1	8591	12	45.3	2.5	47.8	38.8	13.4	52.2
Latvia	1	19 246	0	74.0	1.6	75.6	11.5	13.0	24.4
Lithuania	1	30 977	0	73.5	1.3	74.8	9.4	15.8	25.2
Luxembourg	1	6560	0	59.9	10.2	70.0	17.9	12.1	30.0
Hungary	4	90 920	0	NA	NA	67.7	NA	NA	32.3
Malta	1	4036	0	63.0	3.9	66.9	16.4	16.7	33.1
Netherlands	1	177 607	1 231	72.9	10.0	83.0	7.7	9.4	17.0
Austria	1	78 989	0	65.6	5.6	71.2	NA	NA	28.8
Poland	2	402 578	248	64.6	1.4	66.0	NA	NA	34.0
Portugal	3	100 130	150	48.8	14.9	63.7	NA	NA	36.3
Romania	5	174 692	0	62.5	0.5	63.1	3.8	33.1	36.9
Slovenia	1	22 404	12	77.5	3.5	80.9	8.3	10.8	19.1
Slovakia	1	55 825	0	68.6	2.0	70.6	0.0	0.0	29.4
Finland	1	61 368	3	74.5	8.6	83.2	6.6	10.2	16.8
Sweden	1	114 621	514	75.2	7.6	82.9	8.9	8.2	17.1
United Kingdom									
UK: England	6	661 926	987	62.8	12.6	75.4	9.9	14.7	24.6
UK: Wales	7	32 523	126	61.3	12.6	73.9	11.1	15.0	26.1
UK: Scotland	12	57 166	272	59.7	12.6	72.2	11.9	15.9	27.8
UK: Northern Ireland	17	24 884	475	57.0	13.1	70.1	14.6	15.2	29.9
Iceland	1	4903	0	78.6	6.5	85.2	NA	NA	14.8
Norway	1	62 591	0	73.0	9.9	82.9	6.6	10.5	17.1
Switzerland	3	79 565	711	55.8	11.0	66.9	NA	NA	33.1

NA: not available.
NOTE: Data from Cyprus are from 2007.

RECOMMENDED INDICATORS

R1: Prevalence of selected congenital anomalies

(please see section of report provided by EUROCAT)

R2: Distribution of Apgar scores at 5 minutes in 2010

		Number of live births		Percentage of live births by Apgar score	
Country/coverage	Source	All stated	Not stated	<4	<7
Belgium					
BE: Brussels	1	24 742	133	0.2	1.6
BE: Flanders	3	69 575	60	0.3	1.5
BE: Wallonia	1	38 083	145	0.3	1.4
Czech Republic	1	116 399	0	0.2	1.0
Denmark	1	62 902	371	0.3	0.8
Germany	1	632 780	2781	0.2	1.0
Estonia	1	15 774	42	0.2	1.2
Ireland					
Greece					
Spain					
France	1	14 602	159	0.2	0.8
Italy	4	538 177	6814	0.3	0.8
Cyprus (2007)	1	8529	46	0.1	0.5
Latvia	1	19 043	96	0.2	1.6
Lithuania	1	30 763	68	0.1	0.3
Luxembourg	1	6493	26	0.1	0.9
Hungary					
Malta	1	4013	5	0.2	0.9
Netherlands	1	177 649	168	0.4	1.6
Austria	1	78 609	89	0.2	0.8
Poland					
Portugal					
Romania					
Slovenia	1	22 292	6	0.2	0.9
Slovakia					
Finland	1	51 920	9271	0.4	2.4
Sweden	1	114 129	577	0.3	1.0
United Kingdom					
UK: Wales	8	33 173	2860	0.3	1.2
UK: Scotland	12	56 756	395	0.5	1.5
Iceland	1	4886	0	0.4	2.0
Norway	1	62 345	30	0.4	1.4
Switzerland					

NA: not available.
NOTE: Data from Cyprus are from 2007.

R3: Fetal and neonatal deaths due to congenital anomalies in 2010

		Fetal deaths due to CA (TOP included)	Fetal deaths due to CA (TOP not included)	Percentage of fetal deaths due to CA	Early neonatal deaths due to CA	Late neonatal deaths due to CA	Percentage of total neonatal deaths due to CA
Country/coverage	Source	N	N	%	N	N	%
Belgium							
BE: Brussels	1	84		37.7	17	9	38.2
BE: Flanders	3		71	20.9	31	6	23.1
BE: Wallonia	1	43		20.9	13	6	23.8
Czech Republic	4	99		21.6	27	NA	23.9
Denmark	3			NA	5	7	5.3
Germany (early)	1		72	3.4	179	NA	25.1
Estonia	3		1	1.5	7	0	21.9
Ireland (early)	1		81	23.0	67	NA	42.1
Greece							
Spain							
ES: Catalonia							
ES: Valencia	3		16	8.1	20	7	22.0
France (2008)	3			NA	275	153	22.5
FR: Regional register	1		16	15.2	NA	NA	NA
Italy							
Cyprus (2007)	3		5	18.5	4	1	35.7
Latvia	2		6	5.5	6	8	20.3
Lithuania	1		11	7.5	17	12	35.4
Luxembourg	2	13		31.7	2	0	16.7
Hungary	2		6	1.6	NA	NA	NA
Malta	1		2	11.1	9	1	55.6
Netherlands							
Austria	3			NA	37	14	30.0
Poland	1			NA	331	120	31.1
Portugal	1		22	6.6	16	8	14.2
Romania	2		67	7.8	236	108	29.7
Slovenia	1	39		33.1	3	0	7.1
Slovakia							
Finland	4		44	24.4	34	15	53.3
Sweden							
United Kingdom							
UK: England and Wales	4	540		14.5	427	175	28.8
UK: Scotland	11		32	11.0	28	6	23.6
UK: Northern Ireland	14		9	8.6	32	9	35.3
Iceland	1		1	5.9	2	0	33.3
Norway (2009)	1		21	9.8	26	7	16.3
Switzerland	1		28	9.6	30	16	22.7

NA: not available; TOP: termination of pregnancy; CA: congenital anomaly.
NOTES: Some countries were able to provide data on fetal deaths without TOP and others were unable to do so and their data therefore includes terminations of pregnancy at 22+ weeks.
Data from Cyprus are from 2007.

R4: Prevalence of cerebral palsy

(please see section of report provided by SCPE)

R5: Maternal mortality by cause of death in 2006-2010

			Percentages of maternal deaths by cause of death											
Country/region	Source	Maternal deaths	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII
Belgium															
BE: Brussels	2	8	0.0	12.5	12.5	0.0	12.5	25.0	25.0	0.0	0.0	12.5	0.0	0.0	0.0
BE: Flanders	3	11	0.0	0.0	0.0	18.2	9.1	0.0	36.4	0.0	9.1	27.3	0.0	0.0	0.0
BE: Wallonia	2	17	0.0	0.0	23.5	11.8	17.6	17.6	11.8	0.0	0.0	0.0	0.0	0.0	17.6
Czech Republic	1	23	0.0	0.0	0.0	4.3	0.0	4.3	0.0	0.0	0.0	91.3	0.0	0.0	0.0
Denmark (2005-09)	3	10	0.0	0.0	50.0	0.0	10.0	10.0	0.0	0.0	0.0	20.0	0.0	0.0	10.0
Germany	1	89	0.0	0.0	6.7	10.1	0.0	2.2	1.1	2.2	0.0	73.0	0.0	3.4	1.1
Estonia	2	2	0.0	0.0	0.0	50.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	50.0
Ireland															
Greece															
Spain	1	74	1.4	9.5	23.0	24.3	9.5	5.4	13.5	0.0	5.4	0.0	1.4	4.1	2.7
France	3	345	2.3	4.3	12.2	15.9	0.6	9.6	10.1	0.0	1.2	19.4	11.0	6.4	7.0
Italy															
Cyprus	2	3	33.3	0.0	0.0	33.3	0.0	0.0	0.0	33.3	0.0	0.0	0.0	0.0	0.0
Latvia	2	27	7.4	11.1	7.4	29.6	3.7	7.4	3.7	0.0	3.7	3.7	7.4	14.8	0.0
Lithuania	2	7	0.0	0.0	0.0	57.1	14.3	0.0	0.0	0.0	0.0	28.6	0.0	0.0	0.0
Luxembourg	2	3	0.0	0.0	66.7	33.3	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Hungary															
Malta	2	2	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	100.0	0.0	0.0
Netherlands (enhanced)	3	71	2.8	0.0	15.5	7.0	2.8	15.5	0.0	0.0	0.0	11.3	22.5	22.5	0.0
Austria	2	9	0.0	0.0	33.3	33.3	0.0	22.2	0.0	0.0	0.0	11.1	0.0	0.0	0.0
Poland	1	58	6.9	10.3	15.5	29.3	0.0	6.9	6.9	0.0	1.7	10.3	1.7	10.3	0.0
Portugal															
Romania	2	229	2.2	20.1	9.2	13.5	4.8	7.0	5.7	0.9	2.6	4.4	10.0	17.0	2.6
Slovenia (2006-09)		7	0.0	0.0	28.6	14.3	14.3	28.6	0.0	0.0	0.0	0.0	14.3	0.0	0.0
Slovakia															
Finland	2	14	14.3	0.0	7.1	14.3	14.3	7.1	21.4	7.1	7.1	0.0	7.1	0.0	0.0
Sweden	2	17	0.0	0.0	6.3	25.0	0.0	12.5	25.0	0.0	0.0	12.5	12.5	0.0	6.3
United Kingdom	4,10,14	266	3.8	4.5	12.0	6.8	6.4	9.4	5.3	0.0	1.5	22.9	6.0	20.7	0.8
Iceland															
Norway															
Switzerland	1	21	4.8	0.0	14.3	19.0	4.8	0.0	19.0	0.0	9.5	4.8	14.3	9.5	0.0

Causes of death: I Ectopic pregnancy; II Pregnancy with abortive outcome (excl. ectopic); III Hypertensive disorders; IV Haemorrhage; V Chorioamnionitis/Sepsis; VI Other thromboembolic causes;VII Amniotic fluid embolism; VIII Complications of anaesthesia; IX Uterine rupture; X Other direct causes; XI Indirect causes: diseases of the circulatory system; XII Indirect causes: other; XIII Unspecified obstetric cause/Unknown.

R6: Incidence of severe maternal morbidity in 2010

			Rates per 1000 women Blood transfusion							
Country/coverage	Source	Number of women	Eclampsia	ICU admission	3 units or more	5 units or more	Other amount	No units specified	Hysterectomy	Embolisation
Belgium										
Czech Republic	1	114 407	0.2	NA	NA	NA	NA	NA	0.3	NA
Denmark	1	62 203	0.5	NA	NA	NA	NA	NA	NA	NA
Germany	1	625 615	0.6	4.9	NA	NA	14.3	NA	1.0	0.0
Estonia	1	15 646	0.3	NA	NA	NA	NA	3.9	1.3	NA
Ireland										
Greece										
Spain										
ES: Catalonia										
ES: Valencia	6	37 236	0.3	NA	NA	NA	NA	8.1	0.5	NA
France	5	832 799	0.9	2.0	NA	NA	NA	6.5	0.7	1.4
Italy										
Cyprus										
Latvia	1	19 003	0.9	NA	NA	NA	NA	3.9	1.2	NA
Lithuania	1	30 568	0.4	NA	NA	NA	NA	NA	NA	NA
Luxembourg	1	6440	NA	3.7	NA	NA	NA	NA	NA	NA
Hungary										
Malta	1	3952	0.0	NA	0.6	0.1	0.7	0.0	0.3	NA
Netherlands										
Austria	4	78 989	0.2	NA	NA	NA	NA	NA	NA	NA
Poland	2	402 826	0.5	0.3	NA	NA	NA	12.3	0.3	0.3
Portugal	7	101 495	0.4	NA	NA	NA	NA	11.9	0.7	0.0
Romania	5	213 055	0.4	NA	NA	NA	NA	NA	NA	0.0
Slovenia	1	22 000	0.4	NA	NA	NA	NA	8.8	0.4	NA
Slovakia										
Finland	1,5	60 421	0.1	NA	NA	NA	NA	22.7	0.4	0.3
Sweden	1	113 488	0.1	NA	NA	NA	NA	NA	0.1	0.7
United Kingdom										
UK: Wales	6,7	32 649	NA	NA	NA	NA	NA	NA	0.0	0.2
UK: Scotland	2	56 529	0.1	NA	NA	NA	NA	NA	0.2	0.0
Iceland	1+4	4834	0.6	0.4	NA	NA	NA	NA	0.2	0.0
Norway	1	61 539	0.5	18.4	NA	NA	NA	18.0	0.3	0.1
Switzerland	3	78 784	0.6	2.3	NA	NA	NA	10.1	0.7	0.4

ICU: intensive care unit; NA: not available.
NOTE: Data from Iceland comes from a linked datasource

R7: Incidence of tears to the perineum in 2010

				Percentage of women by				
Country/coverage	Source	All stated	Not stated	No	1st degree	2nd degree	3rd degree	4th degree
Belgium								
Czech Republic								
Denmark	1	48 885	0	48.3	24.4	23.2	3.7	0.5
Germany	1	422 893	0	64.3	16.5	17.4	1.7	0.1
Estonia *	1	12 426	0	99.1	NA	NA	0.9	
Ireland								
Greece								
Spain								
ES: Valencia	5	28 180	0	80.8	12.2	6.4	0.6	0.0
France**	1	11 335	210	57.4	41.8		0.8	
Italy								
Cyprus (2007)	1	4055	55	83.3	14.1	2.0	0.3	0.2
Latvia**	1	14 548	0	81.5	18.1		0.4	
Lithuania								
Luxembourg	1	4567	0	64.7	18.3	14.5	1.7	0.8
Hungary								
Malta ***	1	2700	0	53.1	46.9			
Netherlands*	1	81 181	64 627	NA	NA	NA	4.8	
Austria		56 209	0	98.0	0.2	0.1	1.1	0.6
Poland	2	265 654	54	97.0	2.5	0.4	0.1	0.0
Portugal	7	55 938	19	83.8	10.6	5.0	0.6	0.0
Romania	5	110 061	155	94.7	1.6	3.6	0.1	0.0
Slovenia	1	17 965	0	86.2	7.7	5.9	0.2	0.0
Slovakia								
Finland	5	50 574	0	95.1	1.1	2.8	1.0	0.1
Sweden	1	94 042	0	NA	NA	NA	3.4	0.2
United Kingdom								
UK: England	6	495 973	928	47.9	19.4	29.6	3.0	0.2
UK: Wales	7	24 159	0	51.9	23.2	22.5	2.2	0.2
UK: Scotland	12	39 876	1224	50.1	16.8	30.0	2.9	0.2
Iceland	1	4834	0	37.9	22.7	35.2	3.9	0.3
Norway**	1	51 236	0	46.2	51.5		2.3	
Switzerland	3	52 649	218	54.4	21.3	21.2	2.9	0.2

NA: not available.
NOTES: * data refers to third and fourth degree tears; ** data refers to first and second degree tears combined and third and fourth degree tears combined; *** refers to all tears; data from Cyprus are from 2007.

R8: Percentage of women who smoked during pregnancy in 2010

		Definition of period		Period 1			Period 2		
Country/coverage	Source	Period 1	Period 2	All stated N	Not stated N	Smokers %	All stated N	Not stated N	Smokers %
Belgium									
Czech Republic	1		During				114 407	0	6.2
Denmark	1		During				60 947	1 256	12.8
Germany	1		During				625 615	0	8.5
Estonia	1	1st Trim	During	15 111	535	9.1	15 111	535	7.8
Ireland									
Greece									
Spain									
ES: Catalonia	7	Before	3rd Trim	NA	NA	26.7	NA	NA	14.4
ES: Valencia	6	1st Trim		4629	53	15.8			
France	1	Before	3rd Trim	13 933	748	30.6	14 087	594	17.1
Italy									
Cyprus	1	1st Trim		8312	43	11.5			
Latvia	1			19 003	0	10.4			
Lithuania	1	Before	During	30 568	0	7.0	30 568	0	4.5
Luxembourg	1		3rd Trim				6 370	70	12.5
Hungary									
Malta	1	1st Trim		3952	0	8.2			
Netherlands	4	1st Trim	> 1st Trim	1441	7	10.5	1441	7	6.2
Austria									
Poland	3	Before	3rd Trim	2765	128	24.6	2697	196	12.3
Portugal									
Romania									
Slovenia	1	1st Trim		22 000	0	11.0			
Slovakia									
Finland	1	1st Trim	> 1st Trim	59 120	1301	15.5	59 120	1301	10.0
Sweden	1	1st Trim	3rd Trim	110 212	3276	6.5	108 843	4645	4.9
United Kingdom	1	Before or during	During	15 315	NA	26.0	15 315	0	12.0
UK: England	1	Before or during	During	7139	NA	26.0	7139	0	12.0
UK: Wales	1	Before or during	During	2571	NA	33.0	2571	0	16.0
UK: Scotland	12		During				53 087	3442	19.0
UK: Northern Ireland	1	Before or during	During	2592	NA	28.0	2592	0	15.0
Iceland									
Norway	1	1st Trim	3rd Trim	52 501	9 038	18.6	51 100	10 439	7.6
Switzerland									

NA: not available; Trim: trimester
NOTES: Before is before pregnancy, During is unspecified point during pregnancy. Data from Cyprus are from 2007

R9: Distribution of mothers' educational level in 2010

Country/coverage	Source	All stated	Not stated	Primary %	Secondary, any %	Postsecondary, any %
Belgium						
BE: Brussels	1	22 965	2133	11.2	48.3	40.5
BE: Flanders	3	62 438	6402	4.4	47.1	48.5
BE: Wallonia	1	29 546	8884	3.9	53.9	42.2
Czech Republic	1	106 808	7599	11.0	67.0	22.0
Denmark	1	58 834	3369	0.5	52.9	46.6
Germany						
Estonia	1	15 613	9	1.0	59.4	39.6
Ireland						
Greece						
Spain	6	455 040	23 419	15.1	51.9	33.1
France	1	14 060	616	2.4	45.7	51.8
Italy	4	527 778	17 263	5.2	72.1	22.7
Cyprus (2007)	1	8302	53	2.5	36.8	60.6
Latvia	1	19 246	0	16.3	42.5	41.2
Lithuania	1	30 472	96	2.8	39.2	58.0
Luxembourg	1	6082	478	8.4	44.2	47.4
Hungary						
Malta	1	2987	1049	0.3	63.9	35.8
Netherlands						
Austria	1	72 069	6920	0.0	63.0	37.0
Poland	3	408 878	494	5.7	52.8	41.6
Portugal	1	98 618	1611	18.1	51.2	30.7
Romania		200 131	12 924	9.8	60.3	29.9
Slovenia	1	19 108	3308	7.7	49.6	42.6
Slovakia						
Finland	1	51 775	8441	--	46.2	53.8
Sweden						
United Kingdom	1	15 726	NA	--	49.0	51.0
UK: England	1	7335	NA	--	50.0	50.0
UK: Wales	1	2633	NA	--	55.0	45.0
UK: Scotland	1	3108	NA	--	46.0	54.0
UK: Northern Ireland	1	2650	NA	--	44.0	56.0
Iceland						
Norway (2009)	1	53 452	8159	0.6	47.2	52.6
Switzerland						

NOTES: Brussels, France, Cyprus, Lithuania, Malta, Poland, Portugal, Romania and Finland provided data on maternal educational divided by their own subgroups. Data from Cyprus are from 2007
Not stated includes unknown, missing and others.

R10: Distribution of parents' occupational classification

(will be published in October 2013)

R11: Distribution of mothers' country of birth in 2010

Country/coverage	Source	Definition	All stated	Not stated	Percentage of women born outside of country or of foreign origin using another definition
Belgium					
BE: Brussels	1	Country of birth	24 398	21	66.2
BE: Flanders	3	Country of birth	66 412	2428	22.4
BE: Wallonia	1	Country of birth	37 568	212	25.2
Czech Republic	1	Country of birth	117 446	0	2.6
Denmark	4	Country of birth	61 476	727	15.2
Germany	1	Ethnicity	625 615	0	16.9
Estonia	1	Ethnicity	15 634	12	24.9
Ireland	1	Country of birth	74 176	137	24.6
Greece					
Spain	1	Country of birth	475 535	0	23.6
France	1	Country of birth	14 038	643	18.3
Italy	4	Citizenship	528 745	4120	19.0
Cyprus (2007)	1	Country of birth	8320	35	32.7
Latvia	1	Nationality at birth	18 989	14	30.2
Lithuania	1	Nationality at birth	30 568	0	12.8
Luxembourg	1	Country of birth	6367	73	66.0
Hungary					
Malta	1	Nationality at birth	3946	6	9.2
Netherlands	1	Country or nationality at birth or ethnicity	175 871	0	21.1
Austria	1	Country of birth	78 989	0	29.3
Poland	1	Nationality at birth	409 372	0	0.04
Portugal	1	Country of birth	99 885	31	19.0
Romania					
Slovenia					
Slovakia					
Finland	1	Country of birth	58 164	50	6.2
Sweden	1	Country of birth	113 488	0	24.4
United Kingdom	4,10,14	Country of birth	799,082	0	24.0
UK: England and Wales	4	Country of birth	715,467	0	25.2
UK: Scotland	10	Country of birth	58,139	0	13.9
UK: Northern Ireland	14	Country of birth	25,476	0	13.5
Iceland	1	Nationality at birth	4834	0	12.1
Norway	1	Country of birth	59 431	2131	24.8
Switzerland	1	Country of birth	76 021	2763	41.1

NOTE: Data from Cyprus are from 2007.

R12: Distribution of mothers' prepregnancy body mass index (BMI) in 2010

		Prepregnancy body mass index		Percentage of women			
Country/coverage	Source	All stated	Not stated	<18.5	18.5-24.9	25.0-29.9	≥30.0
Belgium							
BE: Brussels	1	20 125	4375	5.7	61.5	22.3	10.4
BE: Flanders	3	66 598	1288	5.3	58.2	24.0	12.4
BE: Wallonia	1	31 780	6000	7.1	58.2	21.1	13.6
Czech Republic							
Denmark	1	60 995	1208	6.8	59.2	21.4	12.6
Germany	1	556 960	68 655	3.6	60.1	22.6	13.7
Estonia							
Ireland							
Greece							
Spain							
France	1	13 644	1037	8.3	64.6	17.3	9.9
Italy							
Cyprus							
Latvia							
Lithuania							
Luxembourg							
Hungary							
Malta	1	2767	1185	5.2	59.1	23.0	12.7
Netherlands							
Austria							
Poland	3	2813	80	8.7	65.7	18.5	7.1
Portugal							
Romania							
Slovenia	1	21 958	42	4.7	67.5	18.8	9.0
Slovakia							
Finland	1	59 123	1298	3.6	61.9	22.5	12.1
Sweden	1	105 974	7514	2.5	60.0	24.9	12.6
United Kingdom							
UK: England and Wales							
UK: Scotland	12	46 919	9610	2.6	49.0	27.7	20.7
UK: Northern Ireland							
Iceland							
Norway	1	24 963	36 599	4.2	62.2	22.4	12.3
Switzerland							

R13: Percentage of all pregnancies following subfertility treatment in 2010

		Number of women		Percentage of women by type of fertility treatment			
Country/coverage	Source	Stated	Not stated	OI	IUI +/- OI	IVF, ICSI, IVM, FET	All treatments
Belgium							
BE: Brussels	1	22 583	1917	1.1	NA	3.6	NA
BE: Flanders	3	66 443	2210	NA	2.1	3.6	5.9
BE: Wallonia	1	36 397	1383	0.3	NA	3.8	NA
Czech Republic							
Denmark							
Germany							
Estonia	1	15 646	0	NA	NA	2.0	NA
Ireland							
Greece							
Spain							
France	1	13 677	1004	2.3	1.0	2.3	5.6
Italy	4	537 629	52	0.6	0.3	1.0	1.9
Cyprus (2007)	1	8237	118	NA	NA	NA	6.3
Latvia	1	19 003	NA	NA	NA	0.7	NA
Lithuania	1	30 568	NA	0.5	NA	NA	NA
Luxembourg	1	6436	4	0.8	0.9	2.4	4.1
Hungary	4	90 722	NA	NA	NA	0.7	NA
Malta	1	3952	NA	NA	NA	NA	1.6
Netherlands	1	124 084	51 787	1.2	1.3	1.5	4.1
Austria							
Poland							
Portugal							
Romania							
Slovenia	1	22 000	NA	0.4	0.1	2.3	2.8
Slovakia							
Finland	1	60 421	NA	0.7	0.6	2.3	3.5
Sweden							
United Kingdom	3	798 634	0	NA	NA	1.7	NA
Iceland	1	4 834	NA	NA	NA	3.6	NA
Norway	1	61 562	NA	0.1	NA	2.7	NA
Switzerland	2	78 784	NA	NA	NA	1.8	NA

OI: ovulation induction only; IUI: intrauterine insemination; IVF: in vitro fertilisation; ICSI: intracytoplasmic sperm injection; IVM: in vitro maturation; FET: frozen embryo transfer; NA: not available.
NOTES: Not stated is 0 if unknown cases were not listed.
Flanders - OI and IUI + OI combined. The Netherlands had serious concerns about the quality of these data. Norway data on OI are underreported. Cyprus data are from 2007 and combine all available treatments.
In Switzerland, the data include pregnancies following treatments performed in Switzerland in 2010.

R14: Distribution of timing of first antenatal visit in 2010

		Number of women		Percentage of women by timing of antenatal care			
Country/coverage	Source	All stated	Not stated	1st trimester	2nd trimester	3rd trimester	No care
Belgium							
Czech Republic	1	112 215	2191	92.4	6.7	0.9	0.0
Denmark							
Germany	1	582 477	46 099	95.0	4.0	1.0	0.0
Estonia	1	15 553	93	94.3	4.9	0.8	0.0
Ireland	1	72 810	1503	79.2	18.8	2.0	0.0
Greece							
Spain							
ES: Valencia	6	4615	67	92.8	5.3	1.9	0.0
France	1	13 787	894	92.1	6.6	1.2	0.1
Italy	4	522 773	14 908	96.6	2.8	0.6	0.0
Cyprus (2007)	1	8297	58	90.2	6.9	2.7	0.1
Latvia	1	19 003	0	91.7	5.5		2.8
Lithuania	1	28 406	2162	82.6	14.9	2.5	0.0
Luxembourg	1	6354	86	94.7	4.2	0.8	0.3
Hungary							
Malta	1	3899	53	66.8	30.4	2.7	0.0
Netherlands	1	161 722	14 149	87.3	6.5	6.2	0.0
Austria							
Poland	3	2799	94	97.9	1.8	0.3	0.0
Portugal							
Romania	1	212 199	43 584	62.5	15.1	1.9	0.0
Slovenia	1	21 934	66	93.7	5.4	0.7	0.2
Slovakia							
Finland	1	59 413	1008	96.6	2.5	0.7	0.2
Sweden							
United Kingdom							
UK: Scotland	12	45 715	10 814	87.2	10.5	2.3	0.0
UK: England	6	485 555	177 358	77.6	12.8	9.6	0.0
Iceland							
Norway							
Switzerland							

NOTES: First trimester: Less than 15 completed weeks of gestation; Second trimester: 15-27 completed weeks of gestation; Third trimester: 28 completed weeks of gestation or more. Data from Latvia refer to second and third trimesters.
Mode of delivery was collected by for singletons and twins separately and thus in some countries triplets are not included in the denominators.
Data from Cyprus are from 2007.

R15: Distribution of births by mode of onset of labour in 2010

				Percentage of total births by mode of onset of labour		
Country/coverage	Source	All stated	Not stated	Spontaneous	Caesarean	Induced
Belgium						
BE: Brussels	1	24 959	11	62.5	9.6	27.9
BE: Flanders	3	77 881	0	68.5	10.2	21.4
BE: Wallonia	1	38 174	149	56.6	10.4	33.0
Czech Republic	1	114 180	0	77.4	12.7	10.0
Denmark	1	63 495	0	73.9	9.3	16.7
Germany	1	619 903	0	62.4	15.4	22.2
Estonia	1	15 601	268	70.4	19.4	10.2
Ireland						
Greece						
Spain						
ES: Valencia	6	4090	324	68.0	NA	32.0
France	1	14 814	33	66.0	11.2	22.7
Italy	4	515 562	32 006	67.0	17.1	15.9
Cyprus (2007)	1	8517	5	48.0	38.5	13.5
Latvia	1	16 752	0	78.6	13.1	8.3
Lithuania	1	30 977	0	69.3	23.9	6.8
Luxembourg	1	6560	0	55.9	17.9	26.2
Hungary						
Malta	1	4020	0	56.2	15.8	28.0
Netherlands	1	176 853	596	70.9	7.7	21.4
Austria						
Poland						
Portugal						
Romania						
Slovenia	1	21 995	0	74.0	7.9	18.1
Slovakia						
Finland	1	61 242	0	74.7	6.5	18.8
Sweden	1	114 415	720	77.4	8.9	13.7
United Kingdom						
UK: England	6	527 317	21 281	67.6	11.4	21.0
UK: Wales	7	32 684	600	67.0	10.7	22.3
UK: Scotland	12	57 256	93	60.5	16.8	22.7
UK: Northern Ireland	17	24 733	632	56.0	16.4	27.6
Iceland	1	4902	1	71.0	6.9	22.1
Norway	1	61 975	0	73.7	8.3	18.0
Switzerland						

NOTES: Mode of onset of labour was collected by plurality (singletons and twins) and by gestational age groups. For some countries, data exclude triplets and babies with missing gestational age leading to a small discrepancy with total number of births. Data from Cyprus are from 2007.

R16: Distribution of place of birth by volume of deliveries in 2010

Country/ coverage	Source	All stated	Not stated	<500	500-999	1000-1499	1500-2999	3000-4999	≥5000	Home	Other
Belgium											
BE: Brussels	1	25 097	2	0.0	0.0	15.0	45.3	39.2	0.0	0.5	0.0
BE: Flanders	3	67 976	0	4.9	32.8	22.3	40.1	0.0	0.0	1.1	0.0
BE: Wallonia	1	38 430	0	7.9	28.8	32.9	21.1	9.0	0.0	0.4	0.0
Czech Republic	1	115 113	0	3.2	28.4	25.2	23.2	19.9	0.0	0.0	0.0
Denmark	1	63 504	9	0.5	4.4	7.9	31.4	28.1	26.5	1.2	0.0
Germany	6	637 664	0	16.1	33.7	25.0	22.9	2.3	0.0	0.0	0.0
Estonia	1	15 884	0	17.6	17.5	0.0	16.6	47.6	0.0	0.6	0.0
Ireland	1	75 595	0	0.0	0.0	3.2	27.2	13.9	55.1	0.3	0.3
Greece											
Spain											
ES: Valencia	2,3	51 785	221	3.2	8.0	23.6	43.4	8.9	12.6	0.1	0.1
France	1	14 893	10	2.5	14.8	20.5	43.2	18.3	0.8	0.0	0.0
Italy	4	546 520	1100	7.3	24.3	24.4	29.6	11.7	2.6	0.1	0.0
Cyprus (2007)	1	8602	0	61.9	25.7	12.4	0.0	0.0	0.0	0.0	0.0
Latvia	1	19 246	0	11.9	26.5	16.8	11.2	0.0	32.3	0.6	0.6
Lithuania	1	30 977	0	19.4	8.8	17.4	6.6	47.5	0.0	0.1	0.2
Luxembourg	1	6440	0	3.4	10.0	19.3	67.2	0.0	0.0	0.1	0.0
Hungary											
Malta	1	4036	0	10.4	0.0	0.0	0.0	89.3	0.0	0.2	0.0
Netherlands	1	177 192	1646	0.8	11.1	17.8	40.9	1.7	0.0	16.3	11.4
Austria	1	78 989	0	12.6	28.8	20.4	32.7	4.3	0.0	1.3	0.0
Poland	2	402 826	0	11.1	26.3	20.7	31.7	8.6	1.7	0.0	0.0
Portugal	3	100 194	86	1.1	2.5	7.1	45.6	26.2	5.3	0.1	12.0
Romania											
Slovenia	1	21 997	3	2.2	25.5	6.0	35.7	0.0	30.5	0.0	0.1
Slovakia											
Finland	1	44 267	0	4.0	14.1	11.9	35.0	34.9	27.6	0.0	0.2
Sweden	1	115 135	102	0.5	5.9	6.0	36.5	21.3	29.8	0.1	0.0
United Kingdom											
UK: England	4	621 661	62 038	2.0	0.8	1.2	24.2	39.8	28.7	2.7	0.6
UK: Wales	9	35 274	0	4.0	1.6	3.5	49.4	20.3	17.1	3.7	0.4
UK: Scotland	10,11	58 264	0	3.5	1.7	4.3	8.8	39.3	41.0	1.4	0.0
UK: Northern Ireland	14	25 313	2	0.2	3.9	15.5	28.6	29.8	21.6	0.4	0.1
Iceland	1	4903	0	16.6	10.6	0.0	0.0	71.0	0.0	1.8	0.0
Norway	1	62 594	0	10.3		16.4	26.0	26.6	19.9	0.5	0.4
Switzerland	1	79 551	725	18.3	36.1	17.9	21.2	4.2	0.0	0.7	1.5

NOTES: In Switzerland, "other place" refers to birthing homes, in the Netherlands, other refers to maternity homes.
In the Czech Republic, data are only available on units with 3000+ deliveries, in Norway data were given for 500-1499 as one group. Data from Cyprus are from 2007.

R17: Percentage of very preterm infants delivered in units without a NICU in 2010

Country/ coverage	Source	Classifications of maternity units				Number of births 22-31 weeks of GA	Percentage of very preterm births by classification of maternity unit of birth			
		Lowest level	Intermediate		Highest level		Lower level	Intermediate		Highest level
			I	II				I	II	
Belgium										
BE: Brussels	1		Level II	--	Level III (MIC NIC)	338		6.5	0.0	93.5
BE: Flanders	3		Level II	--	Level III	910		22.4	0.0	77.6
BE: Wallonia	1		Level II	--	Level III (MIC NIC)	314		16.6	0.0	83.4
Czech Republic	1	Other hospital	Intermediate care perinatal centre	--	Regional perinatal centre	1236	10.0	7.8	0.0	82.1
Denmark										
Germany										
Estonia	1	General hospital	Specialised Hospital	Central Hospital	Regional hospital	200	7.5	0.0	70.0	22.5
Ireland										
Greece										
Spain										
ES: Valencia	3	Without NICU			With NICU	452	11.9	0.0	0.0	88.1
France	1	Level 1	Level 2A	Level 2B	Level 3	219	8.7	10.0	11.4	69.9
Italy		Maternity, No neonatology or NICU		Neonatology	NICU	5833	7.9		9.0	83/1
Cyprus (2007)	1	Non-NICU			NICU	114	75.4	0.0	0.0	24.6
Latvia		Level I	Level II		Level III	256	13.7	42.2	0.0	44.1
Lithuania	1		Level IIA without NICU	Level IIB-regional	Level III-university	345	0.0	8.7	15.7	75.7
Luxembourg	1	Maternity without NICU			Maternity with NICU	92	37.0	0.0	0.0	63.0
Hungary										
Malta	1	Maternity without NICU			Maternity with NICU	41	2.4	0.0	0.0	97.6
Netherlands	1	Home	In hospital, under midwife supervision	Maternity without NICU	Maternity with NICU	2582	2.2	0.7	31.3	65.8
Austria										
Poland										
Portugal	5		Level II-Private	Level II – Perinatal support hospital	Level III – Differentiated perinatal support hospital	893	0.0	0.8	6.7	92.5

MIC: maternal intensive care; NICU: neonatal intensive care unit; NOTE: Portugal - number of deliveries of a live birth, not known for private level I units
NOTES: Unplanned deliveries out of hospital have not been included in this table; Data from Cyprus are from 2007.
In Italy, data do not include spontaneous fetal deaths under 26 weeks of gestation or TOPs.

R17: Percentage of very preterm infants delivered in units without a NICU in 2010 (cont.)

Country/ coverage	Source	Classifications of maternity units				Number of births 22-31 weeks of GA	Percentage of very preterm births by classification of maternity unit of birth			
		Lowest level	Intermediate		Highest level		Lower level	Intermediate		Highest level
			I	II				I	II	
Slovenia	1		Level 2 no NICU, all other facilities		Level 3 with NICU	335	0.0	9.0	0.0	91.0
Slovakia										
Finland	1	Other hospital	Regional hospital	Central hospital	University hospital	559	0.0	1.4	14.3	84.3
Romania										
Sweden										
United Kingdom										
UK: Scotland	12	Community maternity unit with medical support+ GP Obstetrics	Community maternity unit	Obstetrician + co-located midwifery-led unit	Obstetrician-led unit	809	0.0	0.5	44.5	55.0
Norway	1	Home/planned delivery	Midwife-led unit	Emergency obstetric care unit	University hospital	687	0.4	0.7	29.5	69.3
Switzerland										

R18: Episiotomy rate in 2010

		Number of women delivering vaginally		Episiotomy	
Country/coverage	Source	All stated	Not stated	Yes	No
Belgium					
BE: Brussels	1	19 687	42	36.1	63.9
BE: Flanders	3	55 934	0	54.0	46.0
BE: Wallonia	1	29 935	95	45.4	54.6
Czech Republic	1	97 062	0	51.2	48.8
Denmark	1	48 885	0	4.9	95.1
Germany	1	422 893	0	27.7	72.3
Estonia	1	12 426	0	16.0	84.0
Ireland					
Greece					
Spain	4	3145	79	43.0	57.0
France	1	11 393	152	26.9	73.1
Italy					
Cyprus (2007)	1	4063	45	75.0	25.0
Latvia	1	14 548	0	19.8	80.2
Lithuania					
Luxembourg	1	4562	5	36.1	63.9
Hungary					
Malta	1	2699	1	31.1	68.9
Netherlands	1	143 861	1 947	30.3	69.7
Austria					
Poland	2	265 708	0	67.5	32.5
Portugal	7	55 957	0	72.9	27.1
Romania	5	110 216	0	68.2	31.8
Slovenia	1	17 963	2	36.1	63.9
Slovakia					
Finland	1	50 574	0	24.1	75.9
Sweden	1	94 247	0	6.6	93.4
United Kingdom					
UK: England	6	496 901	0	19.4	80.6
UK: Wales	7	24 159	0	20.1	79.9
UK: Scotland	12	41 028	72	23.6	76.4
UK: Northern Ireland					
Iceland	1	4834	0	7.2	92.8
Norway	1	51 352	0	18.8	81.2
Switzerland	3	52 867	0	27.7	72.3

NOTE: Data from Cyprus are from 2007.

R19: Births without obstetric intervention
(will be published in October 2013)

R20: Percentage of infants breast fed at birth in 2010

		Number of newborn		Breastfed newborns		
Country/coverage	Source	All stated	Not stated	Yes, exclusively	Yes, mixed	Yes, all
Belgium						
Czech Republic	1	116 252	147	85.6	10.3	95.9
Denmark						
Germany						
Estonia						
Ireland	1	75 155	90	45.9	8.1	54.0
Greece						
Spain						
ES: Catalonia	7	NA	NA	68.8	12.9	81.7
ES: Valencia	3	48 698	3 110	67.4	13.1	80.4
France	1	14 176	585	60.2	8.5	68.7
Italy						
Cyprus (2007)	1	8449	126	16.8	48.9	65.7
Latvia	1	18 603	167	88.4	8.5	97.0
Lithuania						
Luxembourg	1	6266	294	80.8	7.2	88.0
Hungary						
Malta	1	4001	17	56.6	11.9	68.5
Netherlands	4	1444	4	74.5	0.0	74.5
Austria						
Poland	4	372 400	0	NA	NA	86.6
Portugal	6	17 472	5	65.2	33.4	98.6
Romania						
Slovenia	1	21 980	20	83.5	13.5	96.9
Slovakia						
Finland						
Sweden						
United Kingdom	1	15 722	NA	NA	NA	81.0
UK: England	1	7335	NA	NA	NA	83.0
UK: Wales	1	2633	NA	NA	NA	71.0
UK: Scotland	1	2650	NA	NA	NA	64.0
UK: Northern Ireland	1	3108	NA	NA	NA	74.0
Iceland						
Norway						
Switzerland	4	29 145	1 094	57.6	37.9	95.5

NA: not available.
NOTES: Cyprus: Perinatal survey in 2007
The Netherlands: no data on mixed feeding
Poland: National health survey in 2009
Portugal: National breast feeding registry which was set up recently; coverage rate: 55% of public hospitals; includes term newborns from July 2010 to June 2011, from birth to the day of maternity discharge (maximum 6 days)
Switzerland: includes healthy term newborns in participating hospitals and birthing homes; coverage rate: 38%
UK: no question on mixed feeding, only intended mixed feeding

APPENDIX C:

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
					P= Population H= H ospital O= Other	C= Country level O= Other	U = Unknown	O= Obligatory V= Voluntary	Y= Yes N= No		
BE: Brussels	1	CEpiP	2008	2010	P	C	U	O	N		
BE: Brussels	2	Death certificates database (Brussels Health and Social Observatory)	2006	2010	P	C	U	O			
BE: Flanders	1	SPE	1987	2010	H	O	100%	O	N	SPE	
BE: Wallonia	1	CEpiP	2008	2010	P	O	U	O			
BE: Wallonia	2	Death certificates database (French Community of Belgium)		2010	P	C	U	O			
Czech Republic	1	Institute for Health Statistics and Information of the Czech Republic (UZIS CR)		2010	P	C	99,3%	O			99,3 births in the Czech Republic, however missing about 24% of perinatal deaths in 2010
Czech Republic	2	UZIS CR and CSU (combination of 1 and 3)		2010	P	C		O			
Czech Republic	3	Czech Statistical Office		2010	P	C	100%	O			Vital statistics
Czech Republic	4	Professional Database of the Czech Society of Perinatal Medicine		2010	H	C	100%	V			99,5% of all births in the Czech Republi 100% of hospital births c,
Denmark	1	The Medical Birth	1973	2010	P	C	± 100 %		Y	SSI, Statens Serum Institut, under the Danish Ministry of Health	Hospital and home births included
Denmark	2	The National Patient Register	1977	2010	P	C	± 100 %		N	SSI, Statens Serum Institut, under the Danish Ministry of Health	Contains information on all contacts with the Danish hospitals

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Denmark	3	The Danish Causes of Death Register	1970	2009	P	C	100%	O	N	SSI, Statens Serum Institut, under the danish Ministry of Health	Causes of death, civil status and causes of death related data
Denmark	4	The Centralized Civil Register		2010	P						
Germany	1	AQUA	2008	2010	H	C	99.5%	O	N	Regional offices such as BAQ for Bavaria and the national office AQUA-Institute	German Perinatal Register
Germany	2	Destatis	1834	2010	P	C	99.9%	O	Y	Statistisches Bundesamt Wiesbaden	Federal Statistical Office
Germany	3	AQUA and Destatis									AQUA (live births and fetal deaths), destatis (live births and neonatal and infant deaths)
Germany	4	Destatis_TOP	1976	2010	P	C	Very good coverage	O	N	Destatis	TOP register only includes gestational age information not birthweight
Germany	5	AQUA and Destatis_TOP									
Germany	6	AQUA + QUAG	1999	2010	O	C	80%	V	N	Gesellschaft für Qualität in der außer-klinischen Geburtshilfe e.V. (QUAG)	AQUA augmented by German home births register
Estonia	1	Estonian Medical Birth Register	1992	2010	H	C	100%	O	Y	Estonian Medical Birth Registry, National Institute for Public Health, Estonia	Includes all deliveries in Estonia, including home deliveries
Estonia	2	Estonian Cause of Death Register	1945;83	2010-2011	P	C	Very good coverage	O	Y	Estonian Cause of Death Registry, National Institute for Public Health	Includes all deaths on the territory of Estonia, partly court decisions and deaths abroad of Estonian residents
Estonia	3	Linked Data from EMSR (Medical Birth) and SPR (Causes of Death	1992	2010	O	C	Underestimation in 2008 was 0,12% of total births	O	Y	Estonian Institute for Population Studies, Tallinn UNiversity for Euro-Peristat project	Some births, occurring to residents abroad, can be registered in later years

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Estonia	4	Health Statistics Database								National Institute for Health Development, Department of Health Statistics www.tai.ee	
Ireland	1	National Perinatal Reporting System (NPRS)	1985	2010	P	C	100%	O	N	The National Perinatal Reporing System (NPRS), managed by the Health Research and Information Division (HRID) at the Economic and Social Research Institute (ESRI)	The birth notification form (BNF) is completed where the birth takes place (either hospital/ home).
Greece	1	National Statistics Office		2009							
Spain	1	National Institute for Statistics.	1854	2010	P	C		O	N	Instituto Nacional de Estadística (INE)	Collects Vital Statistics among others statistics,
Spain	2	Perinatal Mortality Register of the Valencian Region		2010	H	O	Very complete	V			All perinatal and infant deaths occurring in the Valencian Community are registered
Spain	3	Neonatal Screening Register of the Valencian Region		2010							All live births occurring in the Valencia Community
Spain	4	Hospital Discharge Register from Spain	1988	2010	H	C		O	N	(CMBD nacional)	All procedures carried out in Spanish Public Hospitals
Spain	5	Hospital Discharge Register for the Valencian Region		2010							
Spain	6	Maternal Health Surveillance Register from the Valencian Region		2010							
ES: Catalonia	7	Birth Register		2010	H	C		V		Mother and Child Health Programme, Public Health Agency Catalonia.	

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
France	1	National Perinatal Survey	1995	2010	P	C	99.6%	V	N	INSERM U953	Representative sample of births in France.
France	2	Civil Registration	1900	2010	P	C	100%	O	N	INSEE (National Institute Of Statistics and Economics Studies)	Recording of births, deaths on the French territory
France	3	CépiDc: National centre of statistics for medical causes of death	1968	2006-2010	P	C	100%	O	N	National centre of statistics for medical causes of death (CépiDc)	
France	4	National confidential survey on maternal mortality, ENCMM	1996	2006-2009	P	C	100%	V	Y	Inserm U953	
France	5	PMSI	1997	2010	H	C	99%	O	N	ATIH : Technical agency of hospitalization information	Linkage of hospital episodes is feasible. covers both public and private hospitals in France and the overseas districts
France: Regional register	1	Register for Disabled Children and Stillbirths	1988	2010	P	O	99%	O	N	RHEOP-Register for Disabled Children and Perinatal Observatory	Includes registration of stillbirths, spontaneous fetal deaths and terminations of pregnancy (TOP).
Italy	1	Survey on induced abortion	1979	2010	H	C	95%	O	N	National Institute of Statistics of Italy (ISTAT)	Data are collected using an individual form containing information on the woman and on the operation.
Italy	2	Survey on hospital discharges for miscarriage	1979	2010	H	C	86%	O	N	National Institute of Statistics of Italy (ISTAT)	Data are collected using an individual form containing information on the woman and on the operation.
Italy	3	Istat Vital Statistics System on Causes of death	1887	2010	P	C		O	N	National Institute of Statistics of Italy (ISTAT)	

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Italy	4	Birth certificates (CEDAP, Certificato di assistenza al parto)		2010	P	C		O	N		
Italy	5	Multiple sources, including neonatal/infant deaths		2010	O	C		O	Y		
Italy	6	Multiple sources2, induced abortions, miscarriages and CEDAP		2010	P	C		O	N		
Cyprus	1	Perinatal Health Survey 2007, Statistical Service of Cyprus	2007	2007	O	C	31.5% representative sample	V	N	Cyprus Health Monitoring Unit of Ministry of Health, Cyprus Statistical Service.	Sample of 2707 births (of the year's total births 8602), in both the public and private sectors, for the months February, May, July and October 2007.Weighted to the total number of births from the birth registry
Cyprus	2	Death Register 2004-2010, Health Monitoring Unit, Cyprus Ministry of Health	2004	2007	P	C	99%	O	Y	The Health Monitoring Unit is responsible for the medical part of death data; the Cyprus Statistical Service for the demographic part.	Death certificates, collected and coded by the Health Monitoring Unit.
Cyprus	3	Combined data from Perinatal Health Survey of 2007 and from the Death Register	2004, 2007	2007	P	O		V	N	Statistical Service and Ministry of Health	Covers all residents except nationals who deliver out of the country.
Latvia	1	Newbos Register of Latvia (The Medical Birth Register)	2000	2010	P	C	100%	O		The Centre for Disease Prevention and Control of Latvia	Covers all deliveries, except nationals who deliver out of the country.
Latvia	2	Register of Causes of Death	1996	2010	P	C	100%	O		The Centre for Disease Prevention and Control of Latvia	Also includes Latvians who have died abroad if possible

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Latvia	3	The Medical Birth Register and Register of Cause of Death									Combined data source
Lithuania	1	Medical Date of Births	1993	2010	H	C	99%	O	N	HI HIC responsible for processing, Children's Hospital, Affiliate of Vilnius University Hospital Santariskiu Klinikos Centre of Neonatology responsible for analysing	Standard forms filled in maternity hospitals
Lithuania	2	Database of the Demographic Statistics	1994	2010	P	C	100%	O	Y	Central Statistical Office (Statistics Lithuania)	
Lithuania	3	Causes of Death register	2010	2010	P	C	100%	O	Y	Institute of Hygiene Healf Information Centre (HI HIC)	
Luxembourg	1	Perinatal Health Monitoring System	2009	2010	O	C	100%	O	N	The CRP-Santé has an agreement with the Ministry of Health.	Available in all maternity units
Luxembourg	2	Cause of Death Register- Registre des causes de décès du certificat de décès	1967	2010	P	C	99%	O	Y	Ministry of Health - Direction of Health	
Luxembourg	3	Registre des causes de décès du certificat de décès périnatal	1967	2010	P	C	99%	O	Y	Ministry of Health - Direction of Health	
Hungary	1	Hungarian Central Statistical Office		2010	P						
Hungary	2	National Register of Birth Defects		2010							EUROCAT partner
Hungary	3	National Institute for Quality and Organizational Developments in Healthcare and Medicines (GYEMSZI)		2008						Directorate for Audit and Quality Improvement of Caregivers	

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Hungary	4	National Institute for Quality and Organizational Developments in Healthcare and Medicines (GYEMSZI)		2010							
Malta	1	National Obstetrics Information System	1999	2010	P	C	+100%	V	N	Department of Health Information and Research	Records all births on the Maltese islands
Malta	2	National Mortality Register	1995	2010	P	C	99%	O	N	Department of Health Information and Research	
Malta	3	Linkage of National Obstetrics Information System and National Mortality Register									
Netherlands	1	PRN	1982	2010	P	C	96%	V	Y	The Netherlands Perinatal Registry	The Netherlands Perinatal Registry (PRN) includes data on pregnancies, deliveries, mothers and their babies and care process. PRN is a linked database which includes information from LVR1 (the midwife register), LVRh (the general practitioner register), LVR2 (the obstetrician register) and LNR the paediatrician and neonatologist register"
Netherlands	2	Central Statistics Office		2010	P						
Netherlands	3	Commission on maternal mortality									
Netherlands	4	Survey on breastfeeding and smoking									
Austria	1	Birth statistics	1970	2010	P	C	99%	O	N	Statistics Austria	

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Austria	2	Causes of death statistics	1970	2010	P	C	100%	O	N	Statistics Austria	
Austria	3	birth + cause of death statistics for infant death	1984	2010	P	C	99%	O	Y	Statistics Austria	Linkage of birth statistics and causes of death statistics for infant death
Austria	4	Hospital discharges	1989	2010	H	C	100%	O	N	Ministry of Health and Statistics Austria	Statistics are case-related, subdivided according to so-ciodemographic characteristics (age and gender) and published at Länder (federal province) level.
Poland	1	Central Statistical Office	1946	2010	P	C	100%	O	N	Central Statistical Office	Birth and death certificates
Poland	2	National Health Fund	2009	2010	H	C	100%	O	N	National Health Fund	Includes all hospitalizations except in military or similar hospitals and private hospitalizations
Poland	3	PrAMS Survey	2010	2010	O	C		V	N	Institute of Rural Health in Lublin in collaboration with Chief Sanitary Inspectorate	
Poland	4	National Health Survey	1996	2009	P	C	66% response rate	V	N	Central Statistical office	Survey based on representative sample of 24 th. households
Portugal	1	National Statistics - Live births and fetal, neonatal and infant deaths	1935	2010	P	C	100%	O	N	National Statistics Institute (INE) / Department of Demographic and Social Statistics / Demographic Statistics Unit (INE/DES/DM)	Based on routine data from birth and death certificates at a national level. Includes non-permanent residents
Portugal	2	General Directorate for Health - Maternal Deaths		2007	O	C	U	O	Y	General Directorate for Health	To monitor and improve maternal death estimates

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Portugal	3	General Directorate for Health - Enquiries to the Hospitals	2000	2010	H	C	100% of public hospitals	O	N	National Statistics Institute and General Directorate for Health	Annual enquiries about the human resources and production of the facilities part of the National Health Service: Primary Health Centres and Hospitals
Portugal	4	RENAC - Portuguese Birth Defect Register	1996	2010	P	C	In 2002-2007, mean coverage was 67%	V	Y	Department of Epidemiology, National Health Institute Dr Ricardo Joge.	It considers the notifications from different centers of all cases with at least one major anomaly
Portugal	5	National Register for Very Low Birth weight	1996	2010	P	C	± 100%	V	N	Neonatology Section of the Portuguese Society of Pediatrics.	Network of the Portuguese Neonatology Units that collects data from very preterm or very low birth weight newborns
Portugal	6	Portuguese Breast feeding Register	2010	2011	O	C	Maternity Units: 22 out of 40 public units + 1 private. Primary Health Care Centres: 133 out of 651	V	N	"Mama mater", a Non-Governmental Organization. Project funded by the National Directorate for Health	The Registry is a project of the Breast feeding Observatory from the "Mama mater", a Non-Governmental Organization, to monitor breastfeeding preactices in the country
Portugal	7	Hospital Discharge Data		2010	H	C	100% of public hospitals	O	Y	Central Administration of the Health System (ACSS)	Diagnosis-related Group classification according to ICD9, developed for financial purposes. We have used all cases coded as "Pregnancy, Delivery and Puerperium".
Romania	1	NIS births & NCSIPH fetal/ neonatal/infant deaths	1945	2010	H	C	U	O	N	National Institute for Statistics data for births and fetal/neonatal/ infant deaths and National Center for Statistics and Informatics in Public Health for fetal/ neonatal/ infant deaths	National Center for Statistics and Informatics in Public Health for fetal/ neonatal/ infant deaths validates the cause of death.

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Romania	2	NCSIPH fetal/ neonatal/infant deaths	1945	2010	H	C	U	0	N	National Institute for Statistics data for fetal deaths.	National Center for Statistics and Informatics in Public Health for fetal/ neonatal/infant deaths validates the cause of death
Romania	3	National Institute for Statistics demographic statistics for births	1945	2010	H	C		0	N	NIS	
Romania	4	National Center for Statistics and Informatics in Public Health for maternal deaths	1945	2010		C	100%	0	N	NICSPH	
Romania	5	NCSIPH DRG	2005	2010	H	0	U	0	Y	NCSIPH	NCSIPH data from the DRG system. Public hospitals only.
Slovenia	1	National Perinatal Information System of Slovenia	1986	2010	H	C	100%	0	N	Institute of Public Health	
Slovenia	2	Death certificates database		until 2009		C		0		Institute for Public Health	
Slovakia	1	NCZI SOR SON 2010		2010	P						
Slovakia	2	Statistical Office SR		2010	P						
Finland	1	Medical Birth Register	1987	2010	P	C	100%	0	Yes	National Institute for Health and Welfare THL	Covers all occurring births in Finland despite citizenship or residence.
Finland	2	Cause of Death Register	1936	2010	P	C	100%	0	Yes	Statistics Finland	Includes Finnish citizens and permanent residents (with valid ID number).
Finland	3	Register of Induced Abortions	1977	2010	P	C	99%	0	No	National Institute for Health and Welfare THL	Covers all occurring induced abortions in Finland despite citizenship or residence.

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Finland	4	Register of Congenital Malformations	1963	2010	P	C	100%	O	Yes	National Institute for Health and Welfare THL	Covers all occurring births and termination of pregnancies due to congenital anomalies in Finland despite citizenship or residence, if the mother lived in Finland during pregnancy.
Finland	5	Hospital discharge register	1967	2010	H	C	99%	O	No	National Institute for Health and Welfare THL	Covers all hospital care in Finland despite citizenship or residence.
Finland	6	Population Statistics	1749	2010	P	C	100%	O	Y	Statistics Finland	Includes Finnish citizens and permanent residents (with valid ID number).
Sweden	1	Medical Birth Register	1973	2010	P	C	99.4%	O	Y	The National Board of Health and Welfare	All pregnancies and deliveries in Sweden
Sweden	2	Cause of Death Register	1952	2010	P	C	99.5%	O		the National Board of Health and Welfare	National based registry
Sweden	3	The National Patient Register	1964	2010	H	C		O		The National Board of Health and Welfare	Public and private inpatient care data
United Kingdom	1	Infant Feeding Survey	1975	2010	P	C	51% overall	V	No	Health and Social Care Information Centre	
United Kingdom	2	Confidential Enquiry into Maternal Deaths	1928	2006-2008	P	C	Complete for direct deaths but not for other deaths	O	Deaths linked to births in England and Wales	Formerly CMACE, now MBRRACE-UK Collaboration	Enquiry stopped and has now been re-started by MBRRACE-UK collaboration with online data collection
United Kingdom	3	Human Fertilisation and Embryology Authority	1991	2010	H	C	Procedures carried out under the Human Fertilisation and Embryology Act		N	Human Fertilisation and Embryology Authority	
United Kingdom	4	Civil Registration of births and deaths in England and Wales	1837	2010	P	O: England and Wales	100%	O	N	Office for National Statistics	

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
United Kingdom	5	Civil Registration of births and deaths in England and Wales linked to NHS Numbers for Babies records	2005	2010	p	0: England and Wales	100%	0	Y	Office for National Statistics	
United Kingdom	6	Maternity Hospital Episode Statistics	1989	2010	H	0: England	Births in private hospitals and most home births missing. Many missing data items	0	N	NHS Wales Informatics Service	
United Kingdom	7	Patient Episode Database Wales (PEDW)		04/ 2010-2011	H	0: Wales	Births in private hospitals and most home births missing. Many missing data items.	0	N	NHS Wales Informatics Service	
United Kingdom	8	National Community Child Health Database (NCCHD)	1987	2010	P	0: Wales	100%	0	N	NHS Wales Informatics Service	Based on birth notification
United Kingdom	9	All Wales Perinatal Survey	1993	2010	P	0: Wales	100%	V	N	School of Medicine, Cardiff University	Contributes to MBRRACE-UK (formerly CMACE)
United Kingdom	10	Civil Registration of births and deaths in Scotland	1855	2010	P	0: Scotland	100%	0	N	General Register Office for Scotland, part of National Records of Scotland	
United Kingdom	11	Scottish Stillbirth and Infant Death Enquiry	1977	2010	P	0: Scotland	The population is complete for stillbirths and infant deaths but not for terminations	V	N	Information Services Division of National Services Scotland	
United Kingdom	12	Scottish Morbidity Record (SMR02)	1975	2010	H	0: Scotland	~98%	V	Y	Information Services Division of the NHS National Services Scotland	
United Kingdom	13	Maternity and Neonatal Linked dataset (SMR02, SMR11, Scottish Birth Record, Stillbirth and NeoNatal Deaths records)	1990	2010	H	0: Scotland	~95%	V	Y	Information Services Division at NHS National Services for Scotland	

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
United Kingdom	14	Civil Registration of births and deaths in Northern Ireland	1864 / 1922	2010	P	O: Northern Ireland	100%	O	N	General Register Office for Northern Ireland, data published by Northern Ireland Statistics and Research Agency	
United Kingdom	15	NIMACH and Child Health System	1990s	2010	P	O: Northern Ireland	100%	O	N	Public Health Agency, Northern Ireland	Contributes to MBRRACE-UK (formerly CMACE)
United Kingdom	16	NIMACH	1990s	2010	P	O: Northern Ireland	100%	O	N	Public Health Agency, Northern Ireland	
United Kingdom	17	Child Health System	1990	2101	P	Northern Ireland	100%	O	N	Public Health Agency, Northern Ireland	
Iceland	1	The national birth register	1972	2010	P	C	99%	O	N		
Iceland	2	Cause of death register			P	C		O			
Iceland	3	Prenatal ultrasound database of congenital anomalies	1993	2010	P	C	100%	O	N	Landspitali - Univ. hospital	
Iceland	4	ICU admittion database	?	2010	P	C	100%	O	N	Landspitali - Univ. hospital	
Iceland	5	Angiography database	?	2010	P	C	100%	O	N	Landspitali - Univ. hospital	
Norway	1	Medical Birth Register of Norway	1967	2010	P	C	100% for live births	O	Y	The Medical Birth Registry of Norway, the Norwegian Institute of Public Health	Includes stillbirths and live births 12 weeks GA and up
Norway	2	The National Education Database	1970	2009	P	C	100% for residents	O	Y	Statistics Norway	
Norway	3	Country of Origin	1991	2009	P	C	100%	O	Y	Statistics Norway	
Switzerland	1	BEVNAT, statistics of natural population change (vital statistics)	1871	2010	P	C	± 100%	O	Y	Swiss Federal Statistical Office	Some underreporting of fetal deaths (including TOP) and births occurring outside the country
Switzerland	2	StatLPMA, Assisted Reproductive Technology Statistics	2002	2010	O	C	U	O	N	Swiss Federal Statistical Office	Pregnancies following treatments performed in Switzerland in 2010

Country	Source N°	Source name	Start date	Data from	Type of data	Coverage	Completeness	Participation	Linked Source	Institution	Other comments on data source
Switzerland	3	MS, Hospital Medical Statistics combined with data from the Swiss Federation of Midwifes	1998	2010	H	C	± 99%	O	N	Swiss Federal Statistical Office, Swiss Federation of Midwifes	National hospital data (+ some birthing homes), for indicators C10, R7, R15, R18 and R19 combined with data from the Swiss Federation of Midwifes (births at home and in the remaining birthing homes)
Switzerland	4	BFHI, Baby Friendly Hospital Initiative	1999	2010	H	O	38%		N	Swiss Tropical and Public Health Institute on behalf of UNICEF Switzerland	UNICEF initiative to promote breastfeeding