



**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.

REFERENCES

1. Flenady V, Middleton P, Smith GC, Duke W, Erwich JJ, Khong TY, Neilson J, Ezzati M, Koopmans L, Ellwood D, Fretts R, Frøen JF, for the Lancet's Stillbirths Series steering committee. Stillbirths: the way forward in high-income countries. *Lancet*. 2011; 377(9778):1703-1717.
2. Lawn JE, Blencowe H, Pattinson R, Cousens S, Kumar R, Ibiebele I, Gardosi J, Day LT, Stanton C for the Lancet's Stillbirths Series steering committee. Stillbirths: Where? When? Why? How to make the data count? *Lancet*. 2011; 377(9775):1448-63. doi: 10.1016/S0140-6736(10)62187-3.
3. Flenady V, Koopmans L, Middleton P, Frøen JF, Smith GC, Gibbons K, Coory M, Gordon A, Ellwood D, McIntyre HD, Fretts R, Ezzati M. Major risk factors for stillbirth in high-income countries: a systematic review and meta-analysis. *Lancet*. 2011; 377(9774):1331-1340.
4. Gardosi J, Madurasinghe V, Williams M, Malik A, Francis A. Maternal and fetal risk factors for stillbirth: population based study. *BMJ*. 2013; 346:f108.
5. Mohangoo AD, Buitendijk SE, Szamotulska K, Chalmers J, Irgens LM, Bolumar F, Nijhuis JG, Zeitlin J, for the EURO-PERISTAT Scientific Committee. Gestational age patterns of fetal and neonatal mortality in Europe: results from the EURO-PERISTAT Project. *PLoS One*. 2011; 6(11):e24727. doi: 10.1371/journal.pone.0024727.
6. Gissler M, Mohangoo AD, Blondel B, Chalmers J, Macfarlane A, Gaizauskiene A, Gatt M, Lack N, Sakkeus L, Zeitlin J, for the EURO-PERISTAT Group. Perinatal health monitoring in Europe: results from the EURO-PERISTAT project. *Inform Health Soc Care*. 2010; 35(2):64-79.
7. Khoshnood B, Greenlees R, Loane M, Dolk H, for the EUROCAT Project Management Committee and a EUROCAT Working Group. Paper 2: EUROCAT public health indicators for congenital anomalies in Europe. *Birth Defects Res A Clin Mol Teratol*. 2011; 91 (Suppl 1):S16-22. doi: 10.1002/bdra.20776.
8. Mohangoo AD, Blondel B, Gissler M, Velebil P, Macfarlane A, Zeitlin J, for the EURO-PERISTAT Scientific Committee. International comparisons of fetal and neonatal mortality rates in high-income countries: should exclusion thresholds be based on birth weight or gestational age? *PloS One* (in press).



Figure 7.1 Fetal mortality rates per 1000 total births in 2010

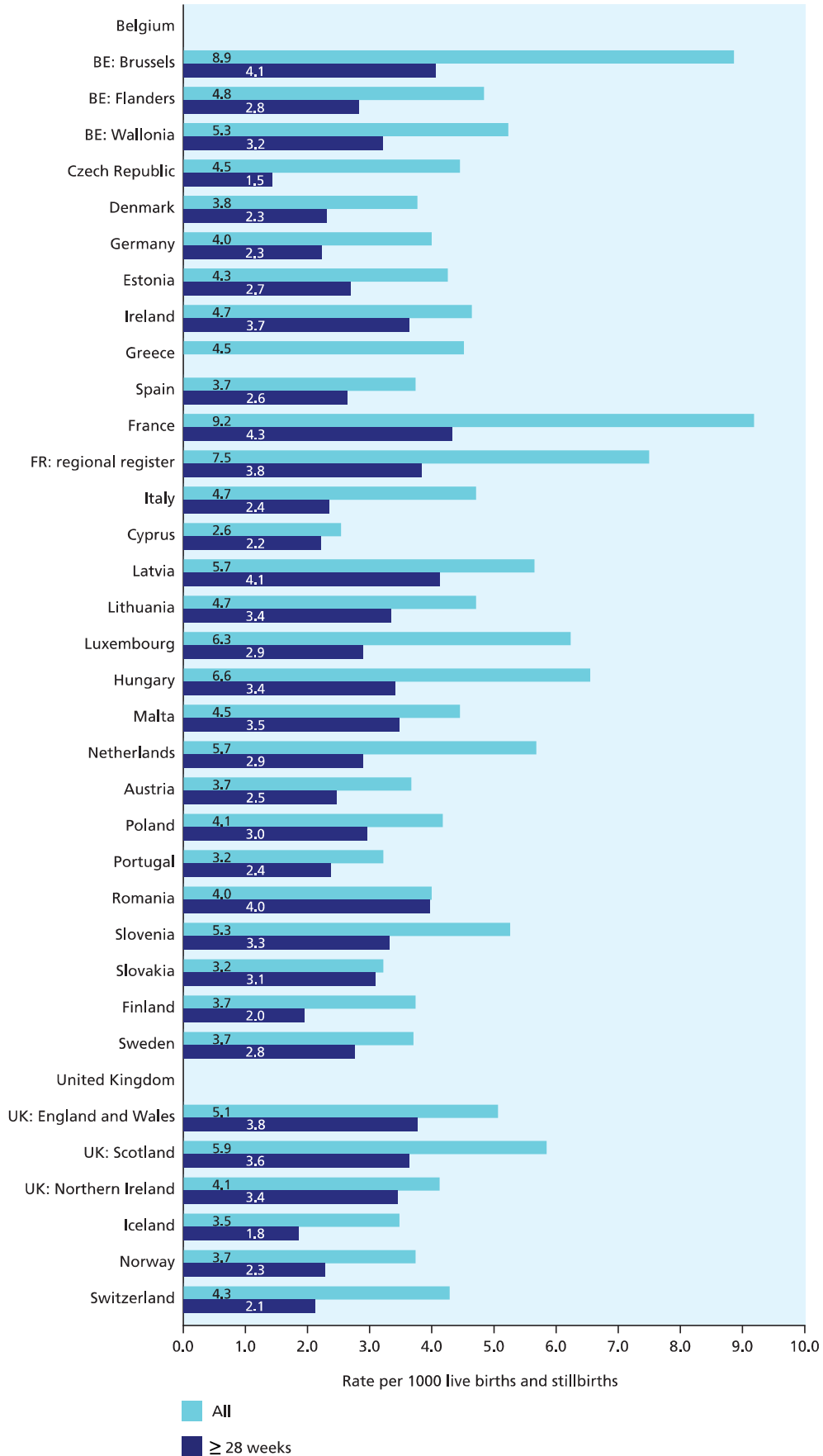


Figure 7.2 Percentage of fetal deaths by gestational-age and birthweight groups from all countries contributing data by these subgroups in 2010

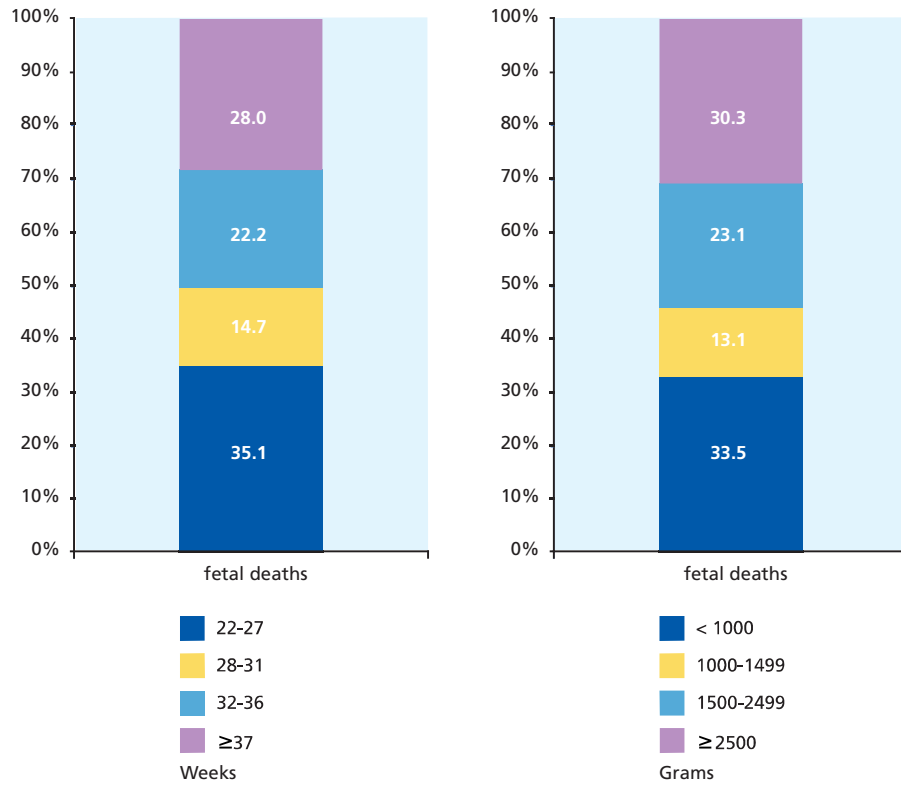
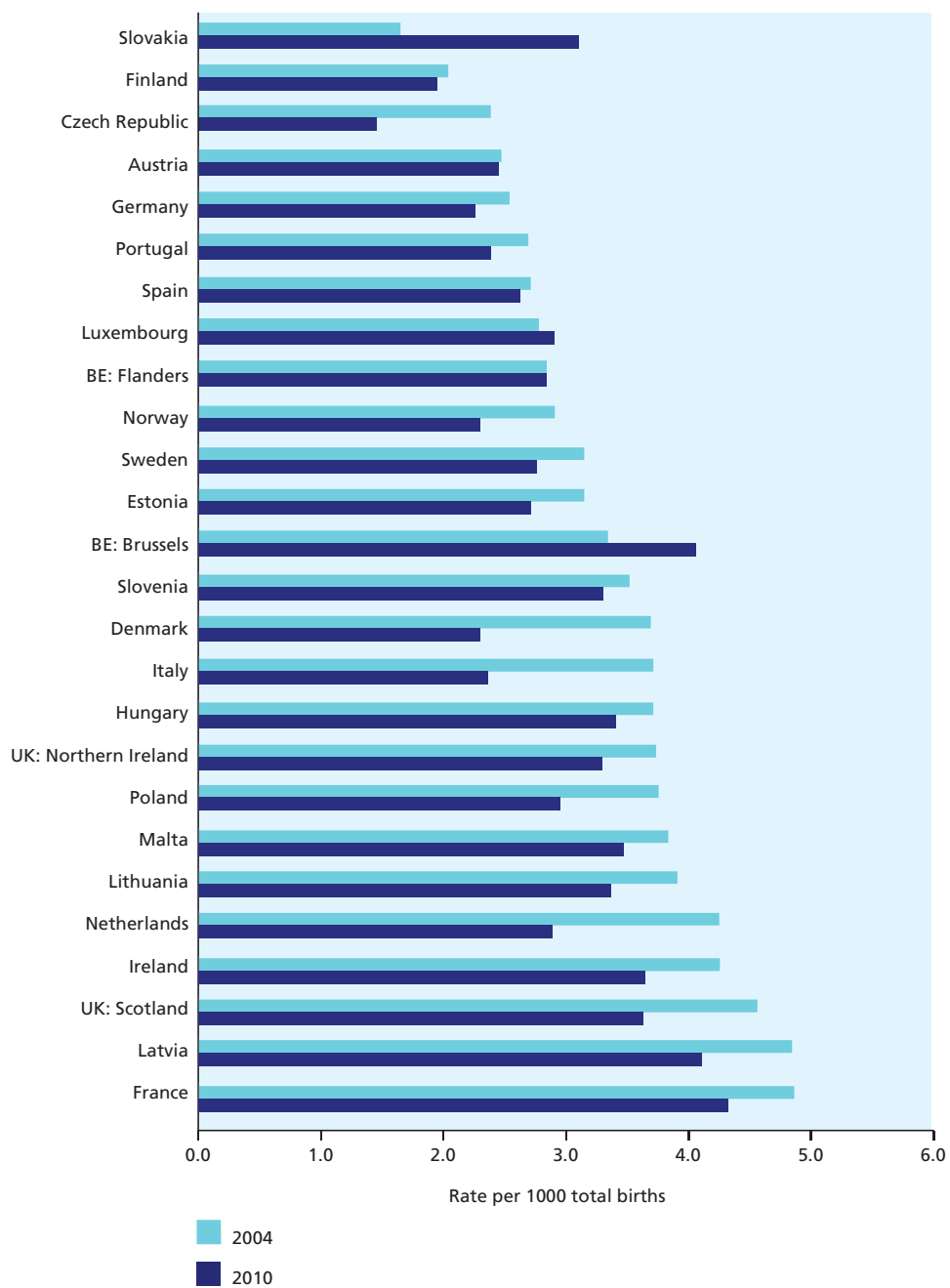




Figure 7.3 Comparison of fetal mortality rates at or after 28 weeks in 2004 and 2010



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 result 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.

REFERENCES

1. EURO-PERISTAT project in collaboration with SCPE, EUROCAT and EURONEOSTAT. Better statistics for better health for pregnant women and their babies in 2004. *European Perinatal Health Report 2008*. Available at www.europeristat.com.
2. Richardus JH, Graafmans WC, Verloove-Vanhorick SP, Mackenbach JP, EuroNatal International Audit Panel, EuroNatal Working Group. Differences in perinatal mortality and suboptimal care between 10 European regions: results of an international audit. *BJOG*. 2003; 110(2):97-105.
3. Ozminkowski RJ, Wortman PM, Roloff DW. Inborn/outborn status and neonatal survival : a meta-analysis of non-randomised studies. *Stat Med*. 1988; 7(12):1207-21.
4. Mohangoo AD, Buitendijk SE, Szamotulska K, Chalmers J, Irgens LM, Bolumar F, Nijhuis JG, Zeitlin J, for the EURO-PERISTAT Scientific Committee. Gestational age patterns of fetal and neonatal mortality in Europe: results from the EURO-PERISTAT project. *PLoS One*. 2011; 6(11):e24727. doi: 10.1371/journal.pone.0024727.
5. Khoshnood B, Greenlees R, Loane M, Dolk H; EUROCAT Project Management Committee; EUROCAT Working Group. Paper 2: EUROCAT public health indicators for congenital anomalies in Europe. *Birth Defects Res A Clin Mol Teratol*. 2011; 91(Suppl 1):S16-22. doi: 10.1002/bdra.20776.
6. Smith L, Draper ES, Manktelow BN, Pritchard C, Field DJ. Comparing regional infant death rates: the influence of preterm births <24 weeks of gestation. *Arch Dis Child Fetal Neonatal Ed*. 2013; 98(2):F103-7. doi: 10.1136/fetalneonatal-2011-301359.
7. Kollée LA, Cuttini M, Delmas D, Papiernik E, den Ouden AL, Agostino R, Boerch K, Bréart G, Chabernaude JL, Draper ES, Gortner L, Künzel W, Maier RF, Mazela J, Milligan D, Van Reempts P, Weber T, Zeitlin J, MOSAIC Research group. Obstetric interventions for babies born before 28 weeks of gestation in Europe: results of the MOSAIC study. *BJOG*. 2009; 116(11):1481-91.



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

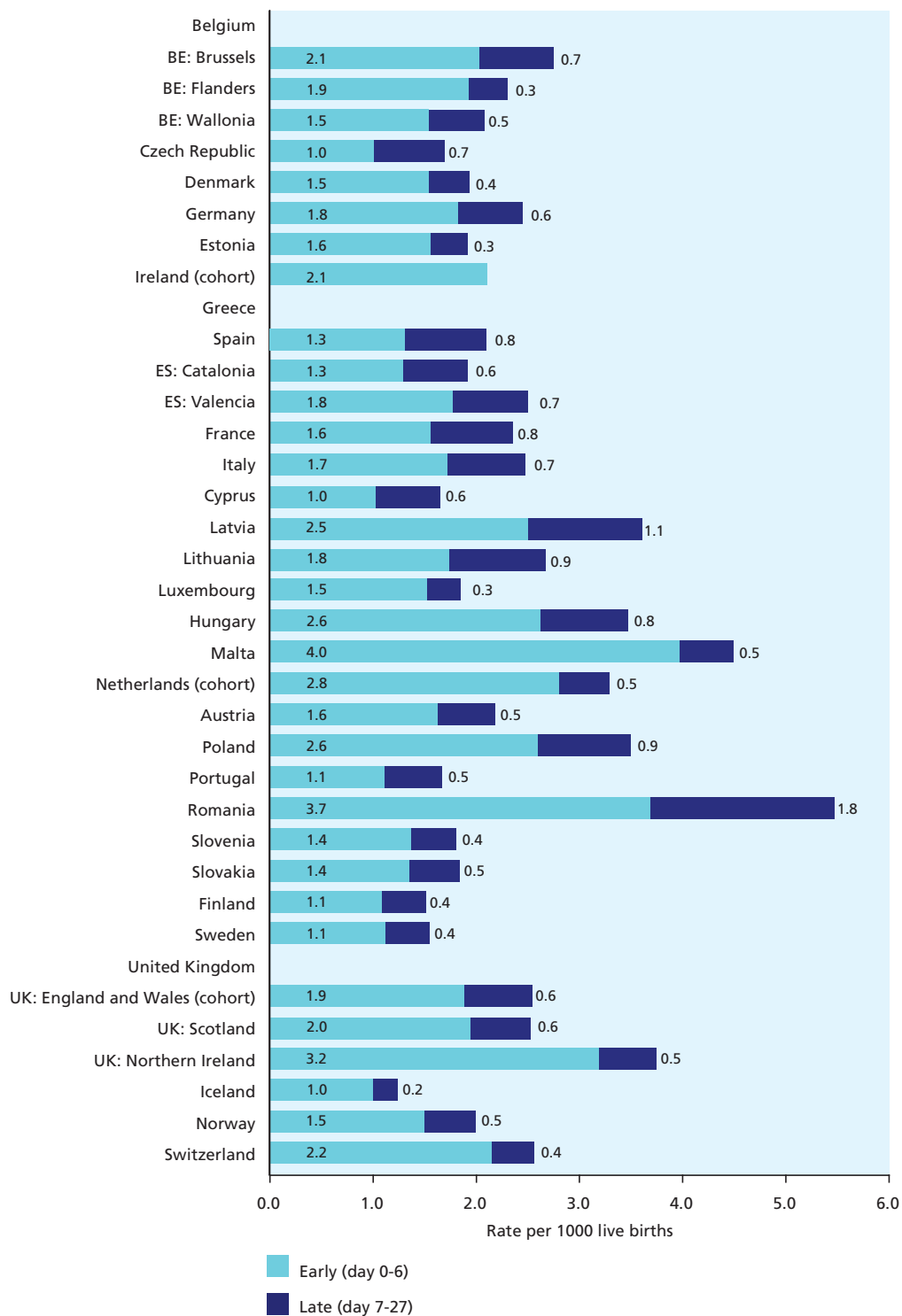
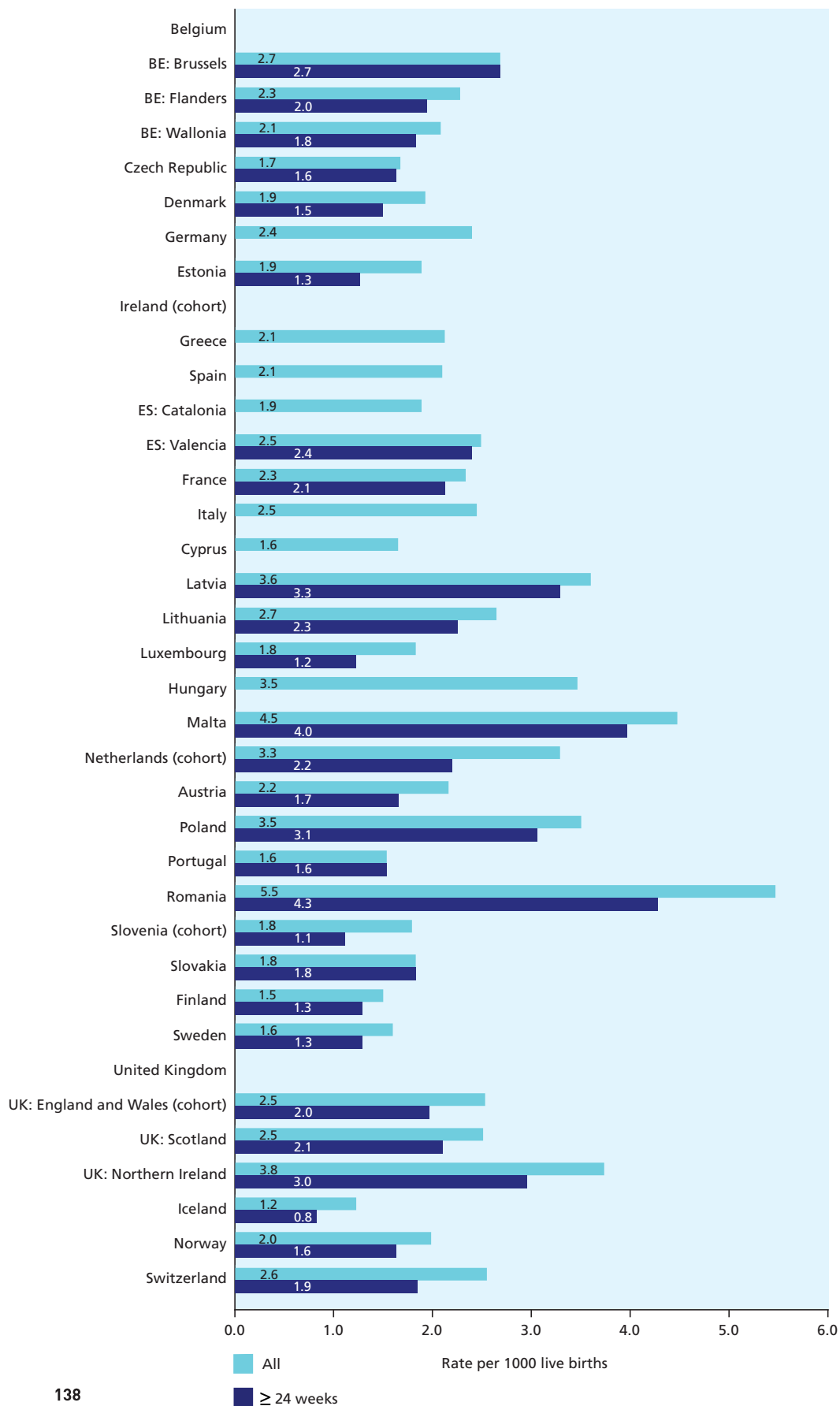


Figure 7.5 Neonatal mortality rates per 1000 live births for all live births and live births at and after 24 weeks of gestation in 2010



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

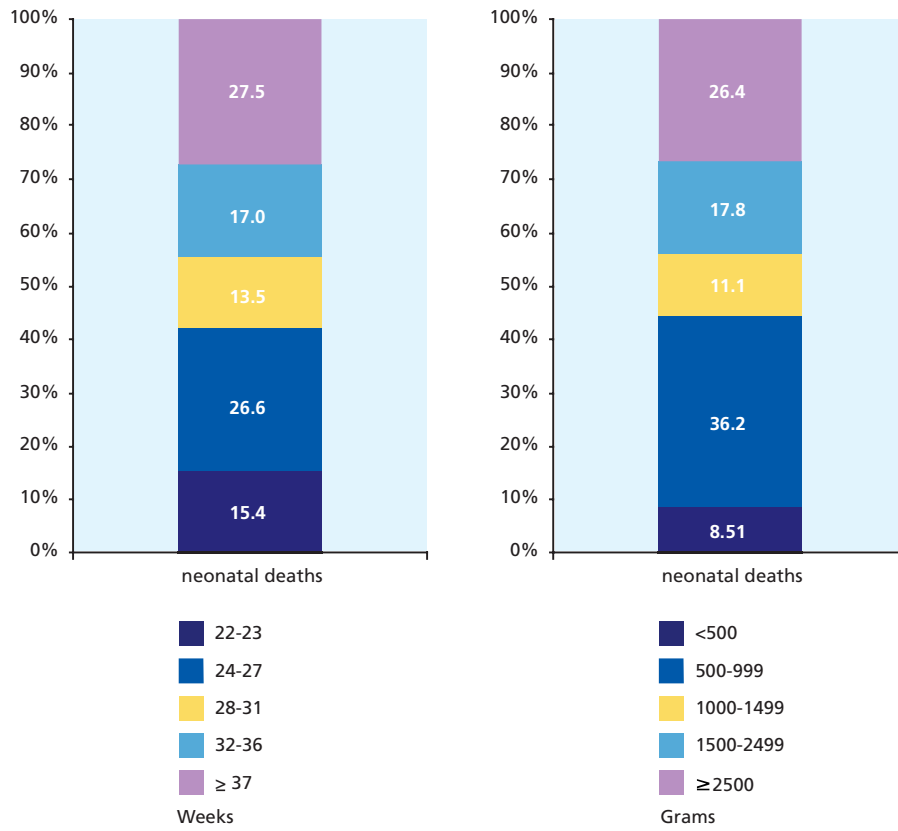
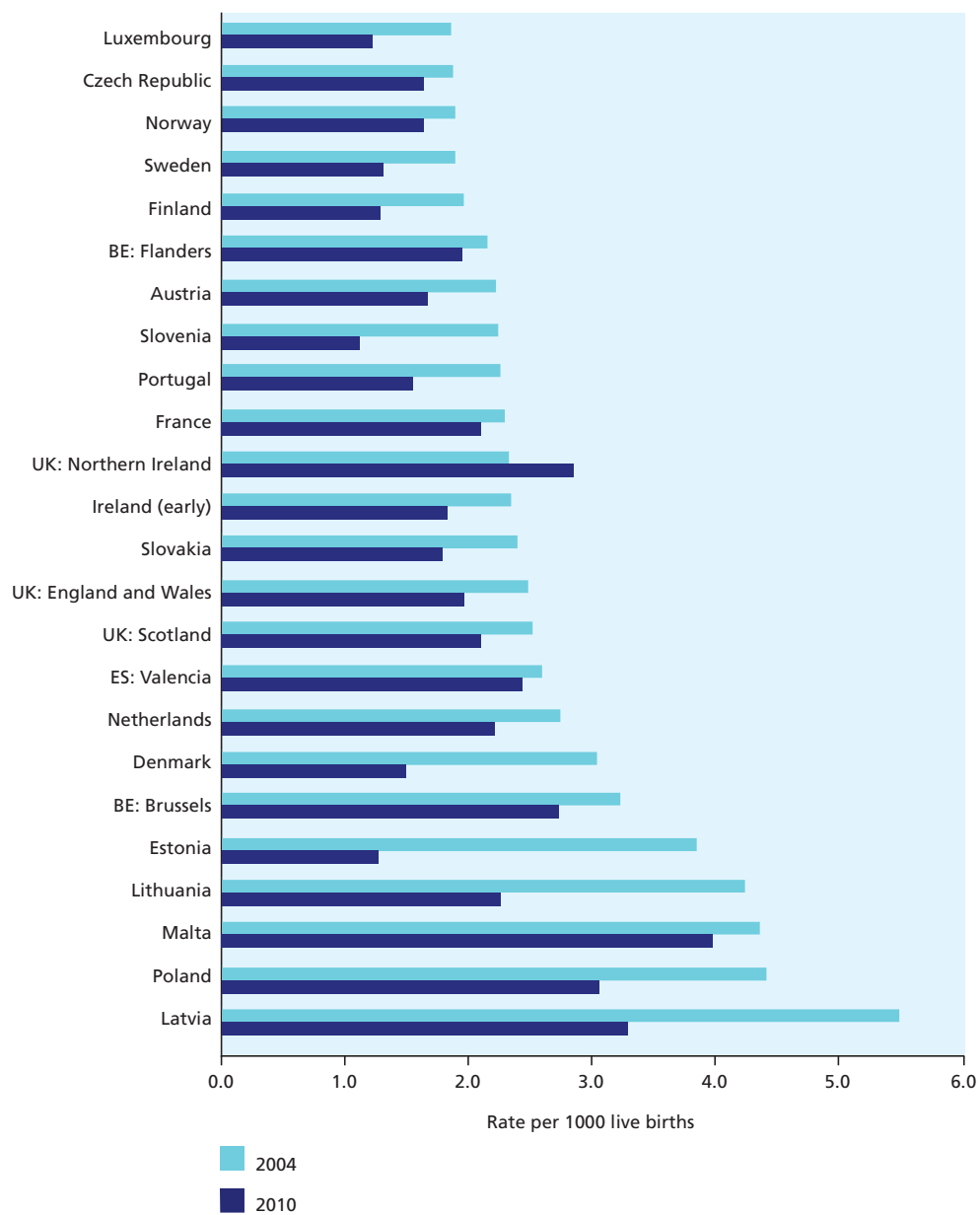


Figure 7.7 Comparison of neonatal mortality rates at or after 24 weeks in 2004 and 2010



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.



REFERENCES

1. Kim BI, Lee KS, Khoshnood B, Hsieh HL, Chen TJ, Mittendorf R. Impact of increased neonatal survival on postneonatal mortality in the United States. *Paediatr Perinat Epidemiol.* 1996; 10(4):423-31.
2. Tomashek KM, Hsia J, Iyasu S. Trends in postneonatal mortality attributable to injury, United States, 1988-1998. *Pediatrics.* 2003; 111:1219-25.
3. Arntzen A, Mortensen L, Schnor O, Cnattingius S, Gissler M, Andersen AM. Neonatal and postneonatal mortality by maternal education--a population-based study of trends in the Nordic countries, 1981-2000. *Eur J Public Health.* 2008; 18:245-51.
4. Singh GK, Kogan MD. Persistent socioeconomic disparities in infant, neonatal, and postneonatal mortality rates in the United States, 1969-2001. *Pediatrics.* 2007;119:e928-39.

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

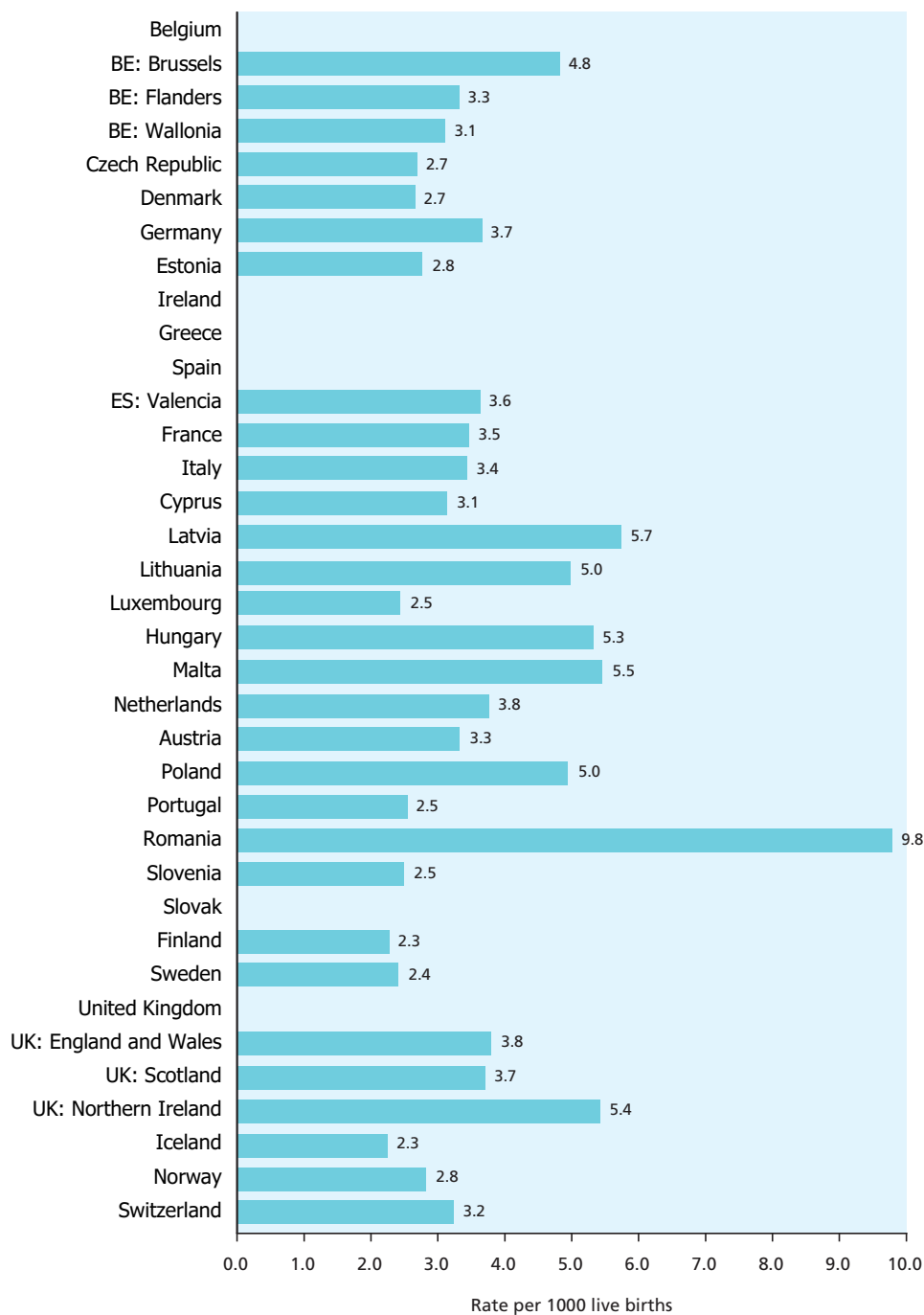




Figure 7.9 Distribution of infant deaths by gestational-age and birthweight subgroups in 2010

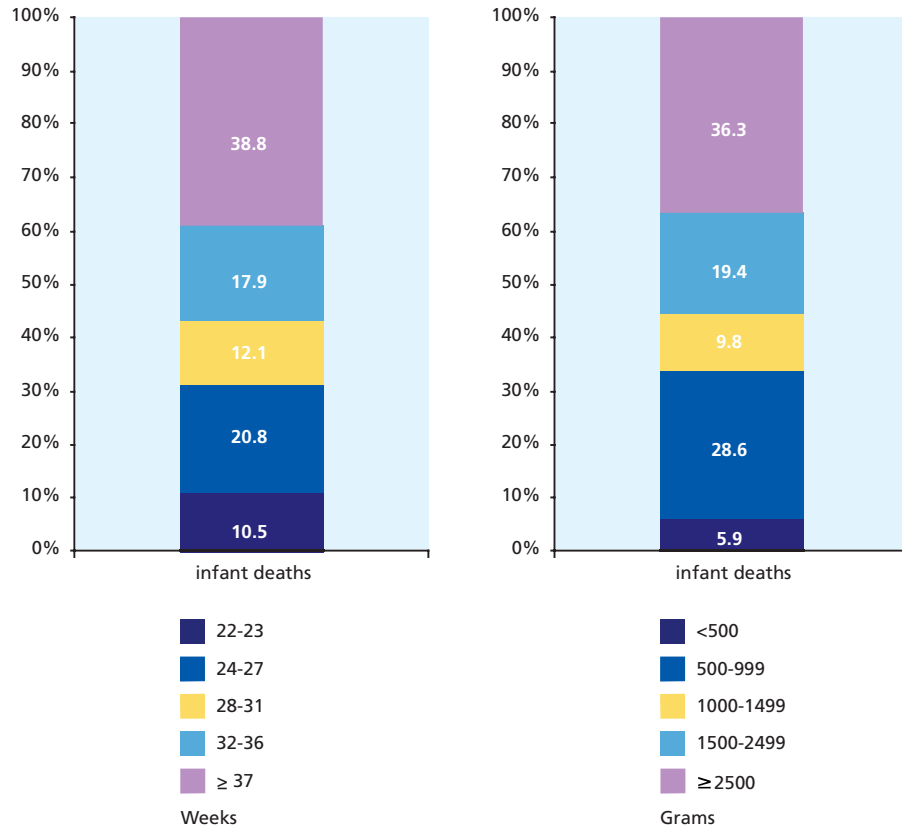
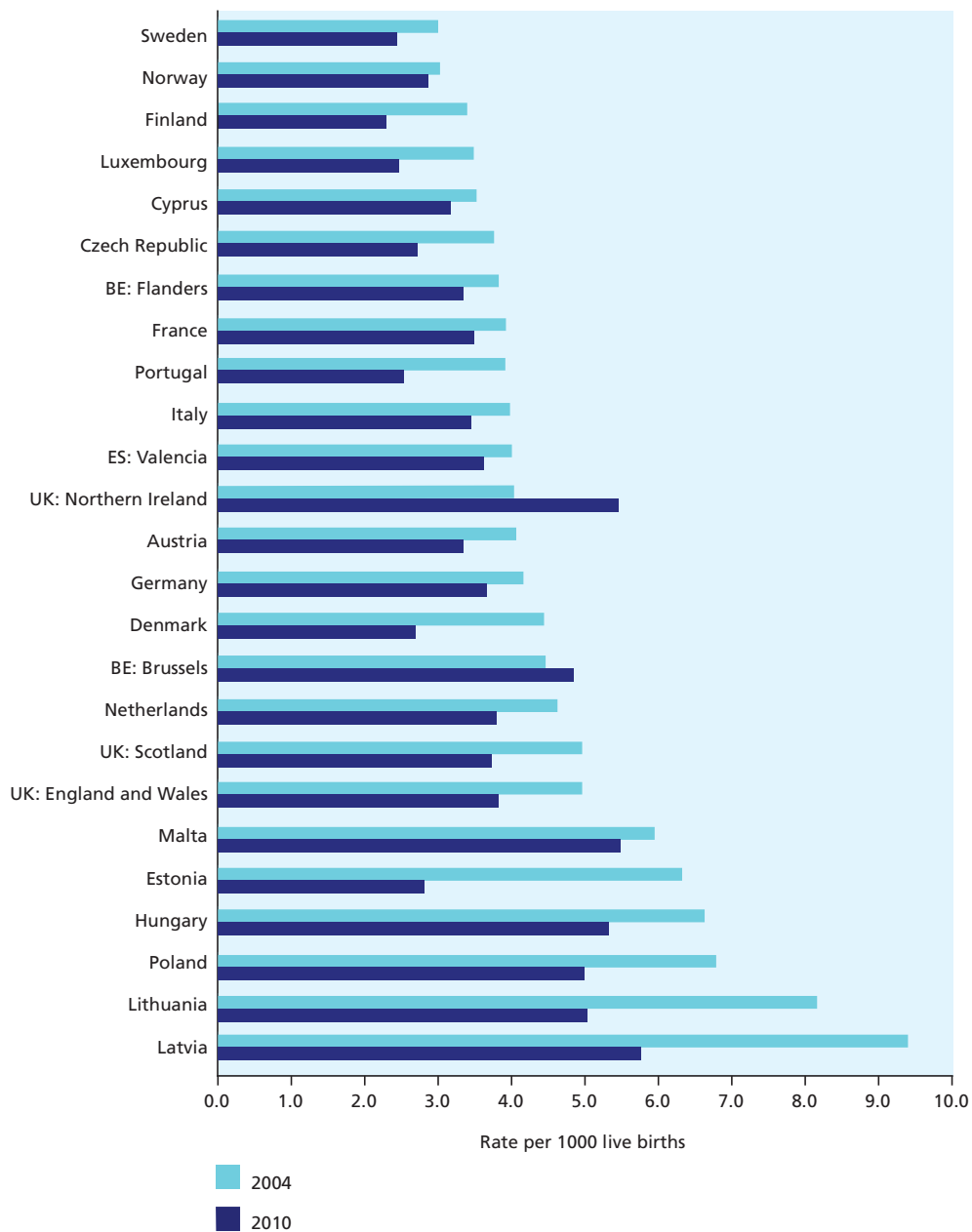


Figure 7.10 Comparison of infant mortality rates at or after 22 weeks (2010 vs. 2004)



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.

REFERENCES

1. McIntire DD, Bloom SL, Casey BM, Leveno KJ. Birthweight in relation to morbidity and mortality among newborn infants. *N Engl J Med*. 1999; 340:1234-1238.
2. Flenady V, Koopmans L, Middleton P, Frøen JF, Smith GC, Gibbons K, Coory M, Gordon A, Ellwood D, McIntyre HD, Fretts R, Ezzati M. Major risk factors for stillbirth in high-income countries: a systematic review and meta-analysis. *Lancet*. 2011; 377:1331-40.
3. Jarvis S, Glinianaia SV, Torrioli MG, Platt MJ, Miceli M, Jouk PS, Johnson A, Hutton J, Hemming K, Hagberg G, Dolk H, Chalmers J, on behalf of the Surveillance of Cerebral Palsy in Europe (SCPE) collaboration of European Cerebral Palsy Registers. Cerebral palsy and intrauterine growth in single births: European collaborative study. *Lancet*. 2003; 362:1106-1111.
4. Barker, D. In utero programming of chronic disease. *Clin Science*. 1998; 95:115-12.
5. Thornton JG, Hornbuckle J, Vail A, Spiegelhalter DJ, Levene M, GRIT study group. Infant wellbeing at 2 years of age in the Growth Restriction Intervention Trial (GRIT): multicentred randomised controlled trial. *Lancet*. 2004; 364(9433):513-20.
6. Zhang X, Decker A, Platt RW, Kramer MS. How big is too big? The perinatal consequences of fetal macrosomia. *Am J Obstet Gynecol*. 2008; 198(5):517.e1.
7. Graafmans WC, Richardus JH, Borsboom GJ, Bakketeig L, Langhoff-Roos J, Bergsjø P, Macfarlane A, Verloove-Vanhorick SP, Mackenbach JP, for the EuroNatal working group. Birthweight and perinatal mortality: a comparison of "optimal" birthweight in seven Western European countries. *Epidemiology*. 2002; 13(5):569-74.



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

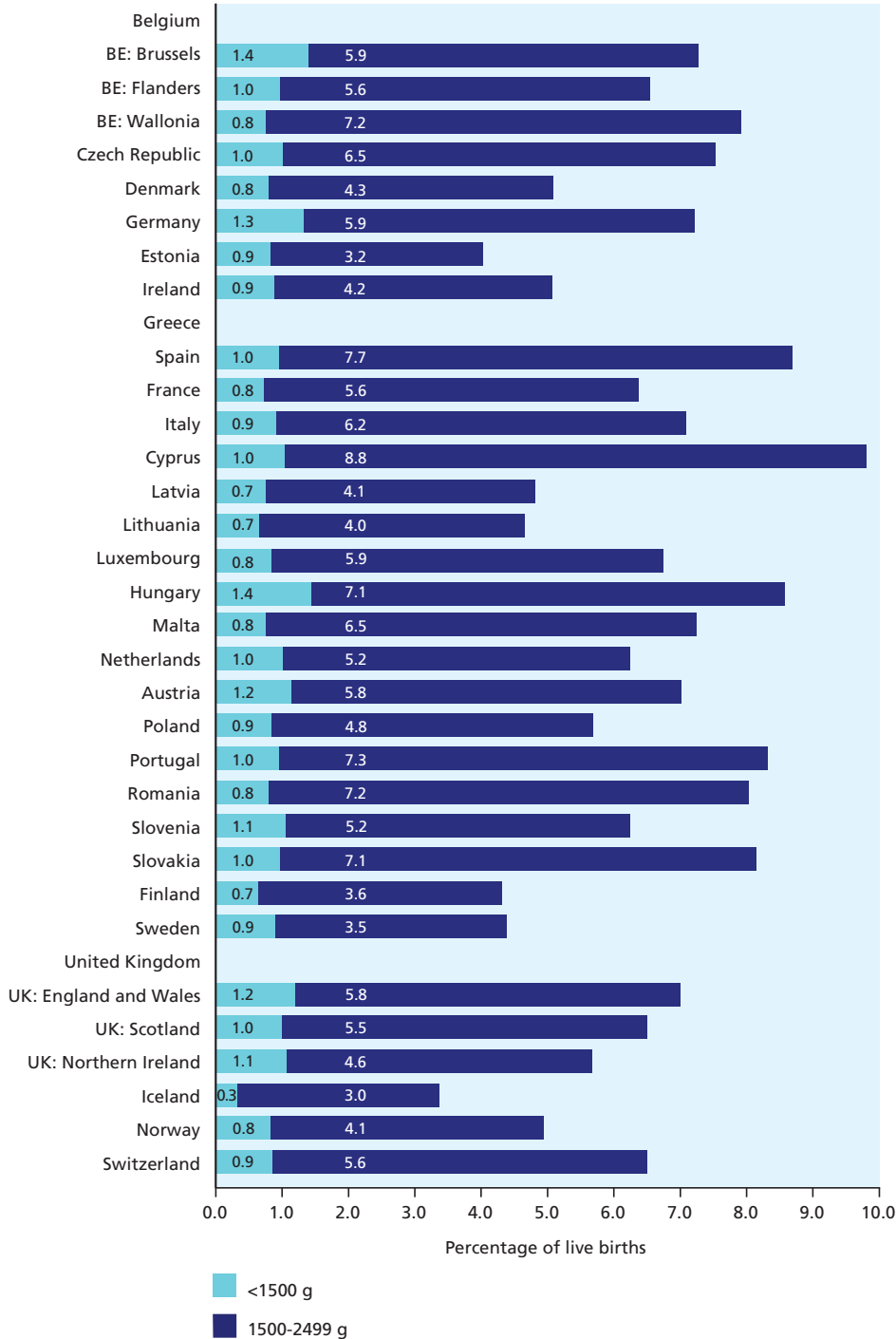
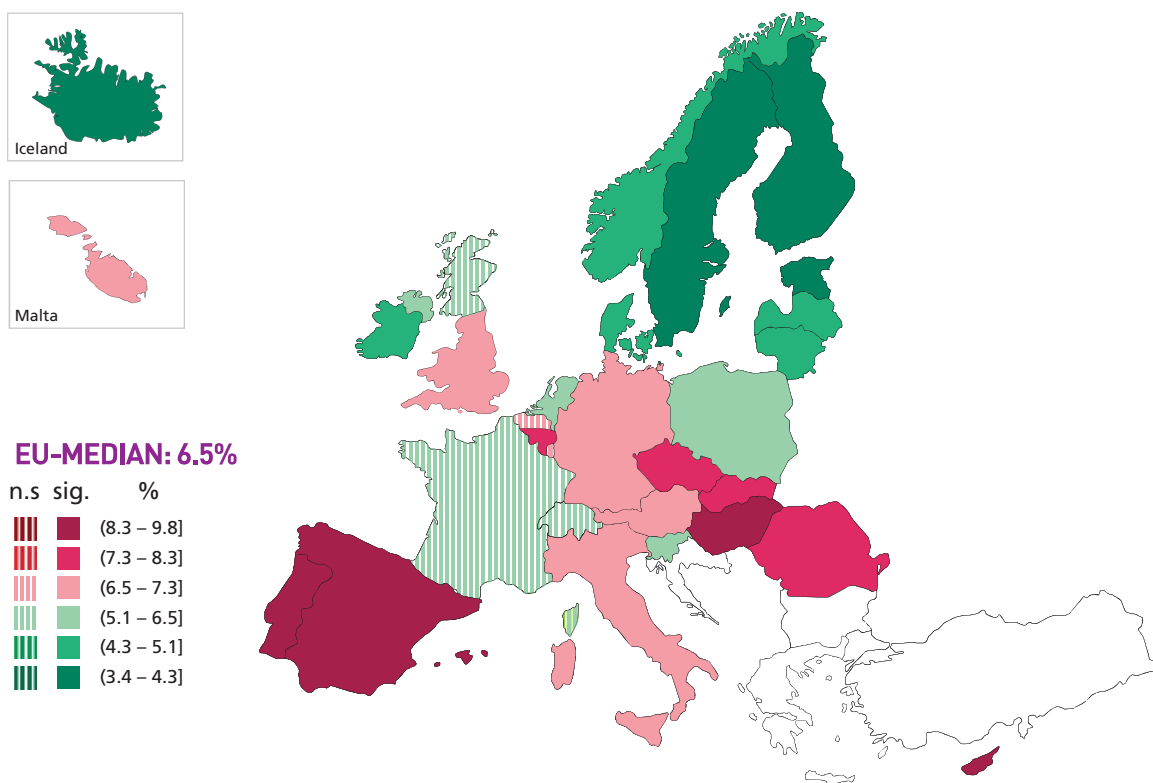


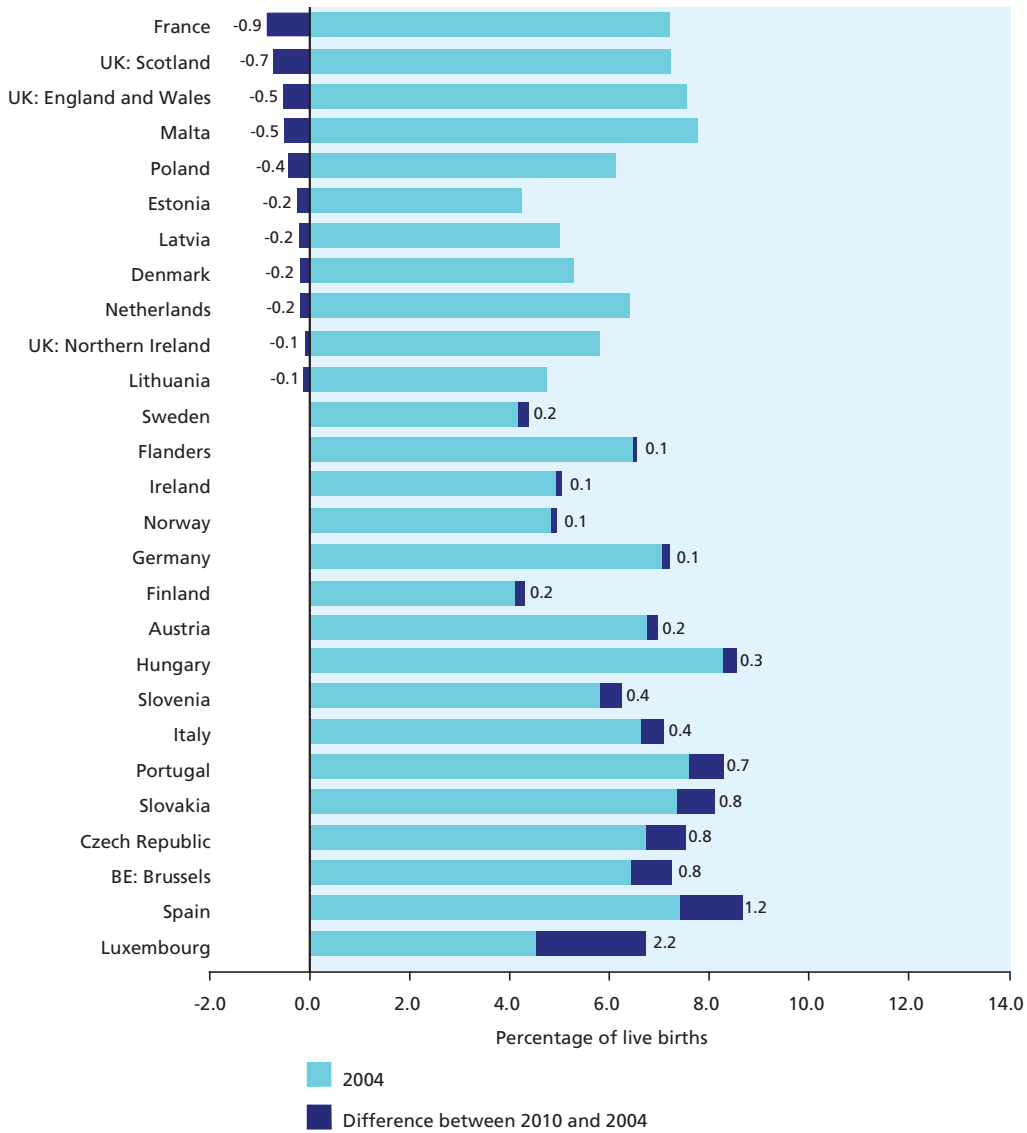
Figure 7.12 Map of distribution of live births with low birth weight (< 2500 grams) in 2010



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.

REFERENCES

1. EURO-PERISTAT project in collaboration with SCPE, EUROCAT and EURONEOSTAT. Better statistics for better health for pregnant women and their babies in 2004. *European Perinatal Health Report 2008*. Available at www.europeristat.com, 2008.
2. Larroque B, Ancel PY, Marret S, Marchand L, Andre M, Arnaud C, Pierrat V, Rozé JC, Messer J, Thiriez G, Burguet A, Picaud JC, Bréart G, Kaminski M, for the EPIPAGE Study group. Neurodevelopmental disabilities and special care of 5-year-old children born before 33 weeks of gestation (the EPIPAGE study): a longitudinal cohort study. *Lancet*. 2008; 371(9615):813-20.
3. Zeitlin J, Draper ES, Kollee L, Milligan D, Boerch K, Agostino R, Gortner L, Van Reempts P, Chabernaude JL, Gadzinowski J, Bréart G, Papiernik E, MOSAIC research group. Differences in rates and short-term outcome of live births before 32 weeks of gestation in Europe in 2003: results from the MOSAIC cohort. *Pediatrics*. 2008; 121(4):e936-44.
4. Kramer MS, Demissie K, Yang H, Platt RW, Sauve R, Liston R. The contribution of mild and moderate preterm birth to infant mortality. Fetal and Infant Health Study Group of the Canadian Perinatal Surveillance System. *JAMA*. 2000; 284(7):843-9.
5. Boyle EM, Poulsen G, Field DJ, Kurinczuk JJ, Wolke D, Alfirvic Z, Quigley MA. Effects of gestational age at birth on health outcomes at 3 and 5 years of age: population based cohort study. *BMJ*. 2012; 344:e896.
6. Crump C, Sundquist K, Sundquist J, Winkleby MA. Gestational age at birth and mortality in young adulthood. *JAMA*. 2011; 306(11):1233-40.
7. Blencowe H, Cousens S, Oestergaard MZ, Chou D, Moller AB, Narwal R, Adler A, Vera Garcia C, Rohde S, Say L, Lawn JE. National, regional, and worldwide estimates of preterm birth rates in the year 2010 with time trends since 1990 for selected countries: a systematic analysis and implications. *Lancet*. 2012; 379(9832):2162-72.
8. Zeitlin J, Szamotulska K, Drewniak N, Mohangoo AD, Chalmers J, Sakkeus L, Irgens I, Gatt M, Gissler M, Blondel B and the EURO-PERISTAT Preterm Study Group. Preterm birth time trends in Europe: a study of 19 countries. *BJOG* (in press)
9. Zeitlin J, Blondel B, Alexander S, Breart G and the PERISTAT Study Group. Variation in post-term rates in Europe: reality or artifact. *BJOG*. 2007; 114(9):1097-103.
10. Blondel B, Morin I, Platt RW, Kramer MS, Usher R, Breart G. Algorithms for combining menstrual and ultrasound estimates of gestational age: consequences for rates of preterm and post-term birth. *BJOG*. 2002; 109(6):718-20.
11. Wingate MS, Alexander GR, Buekens P, Vahratian A. Comparison of gestational age classifications: date of last menstrual period vs. clinical estimate. *Annals Epidemiol* 2007; 17(6):425-30.



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

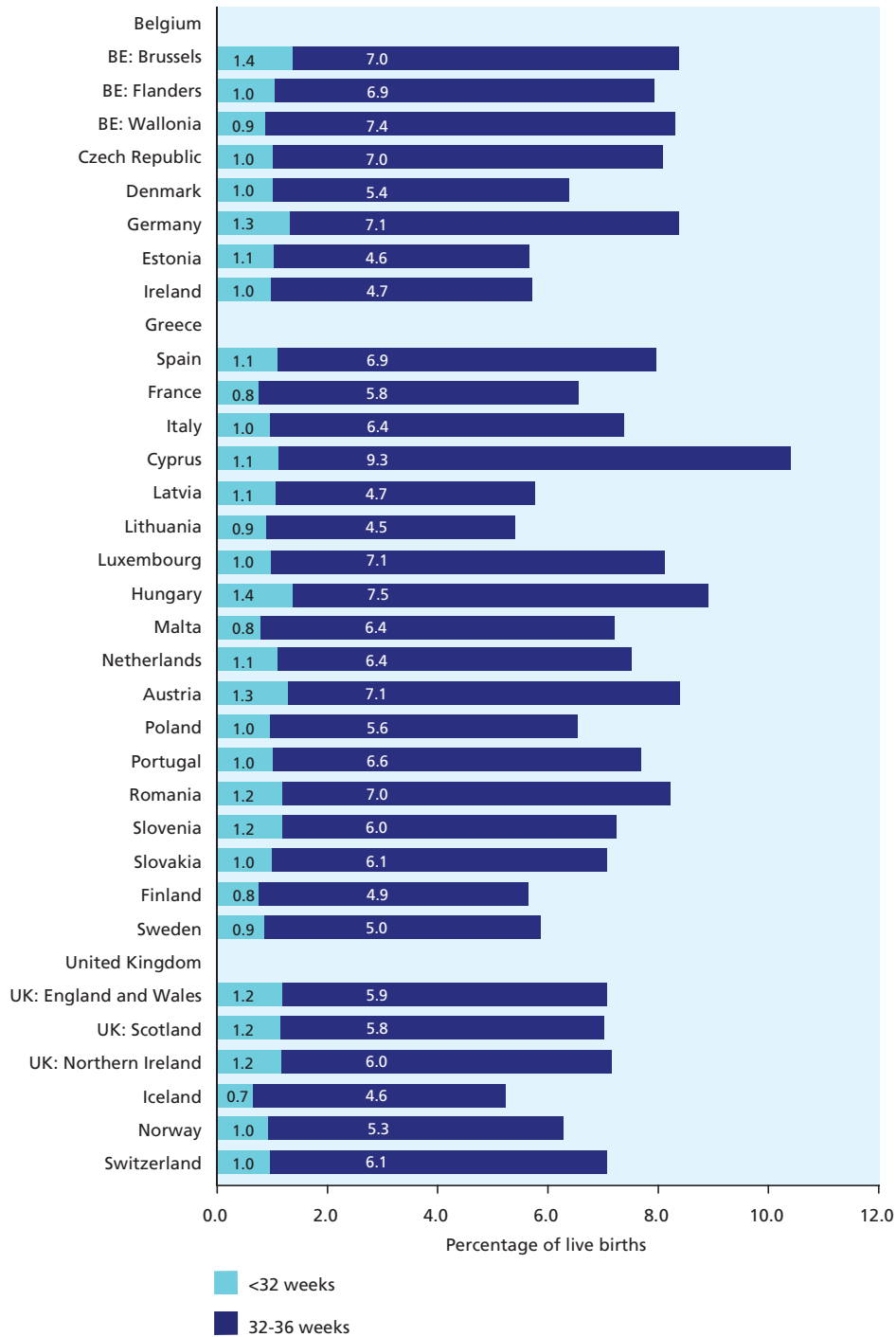
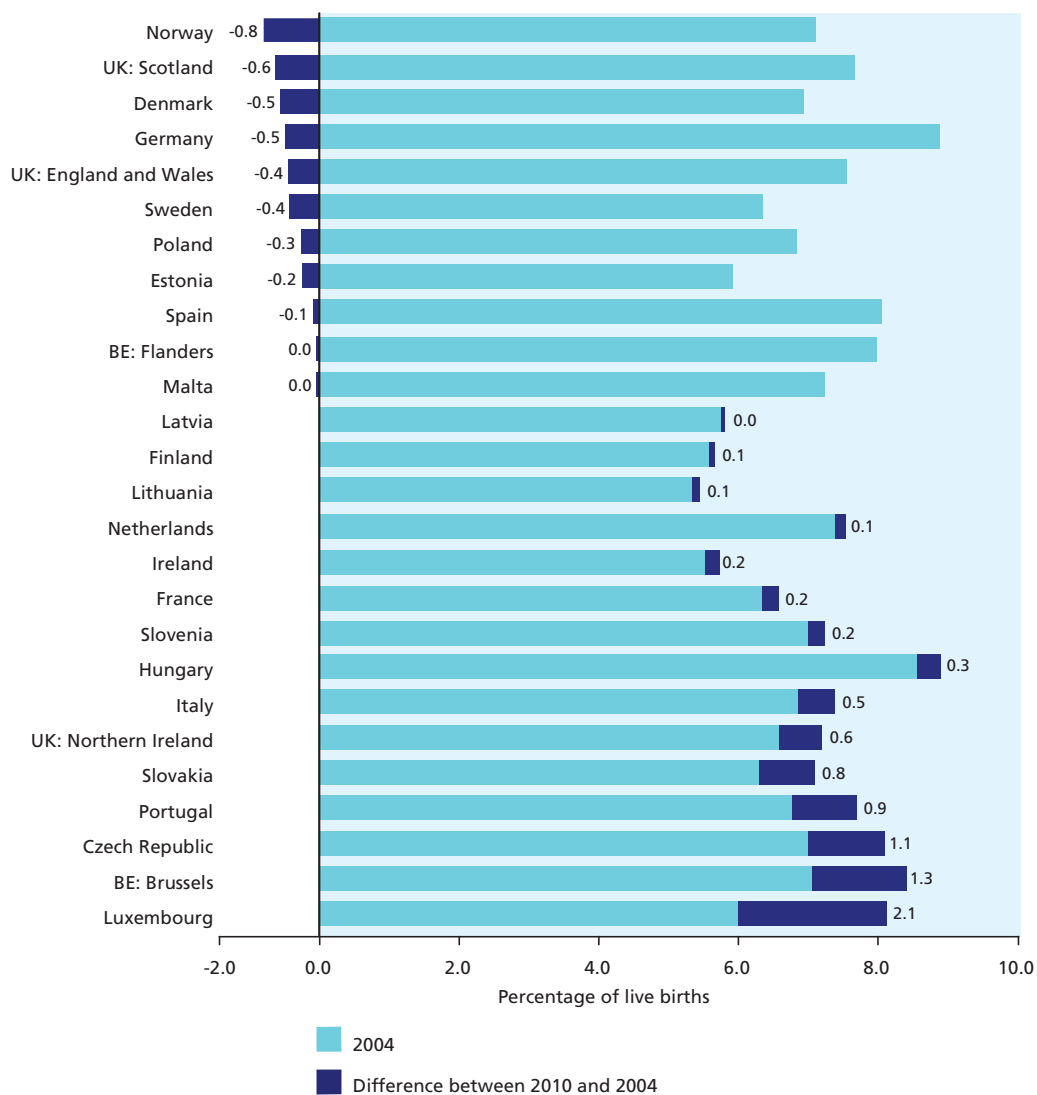


Figure 7.15 Percentage of preterm live births in 2004 and difference between 2010 and 2004



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

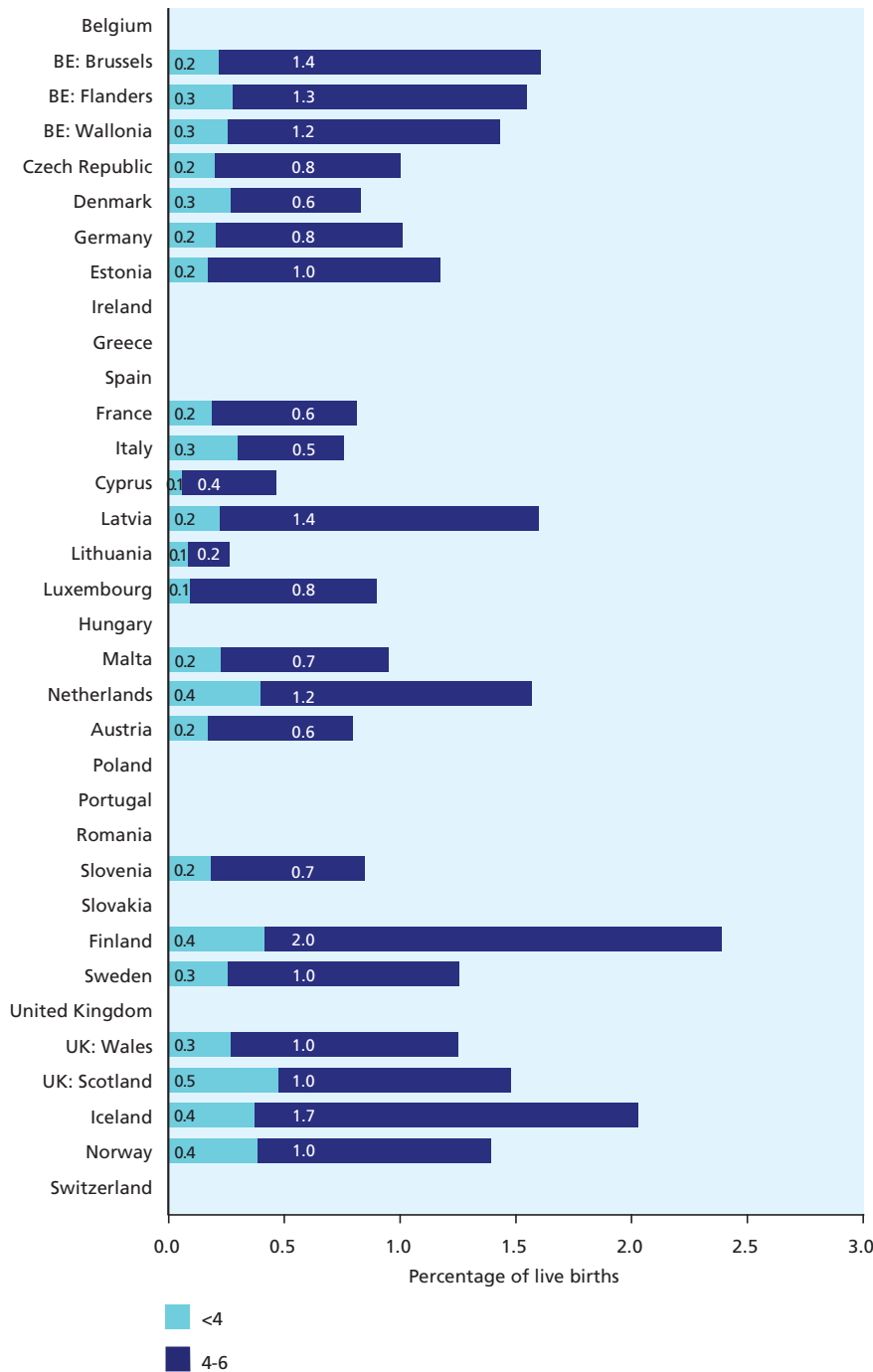
One to two percent of children born alive have difficulties at birth that require resuscitation.

REFERENCES

1. AAP-ACOG. The Apgar score. *Pediatrics*. 2006; 117:1444-7.
2. MacLennan A for the International cerebral palsy task force. A template for defining a causal relation between acute intrapartum events and cerebral palsy: international consensus statement. *BMJ*. 1999; 319:1054-9.
3. Casey BM, McIntire D, Kenneth JL. The continuing value of the Apgar score for the assessment of newborn infants. *N Engl J Med*. 2001; 344:467-71.
4. Whitelaw A. Does Apgar score predict outcome in individual extremely preterm infants? *Acta Paediatrica*. 2007; 96: 154-5.



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.

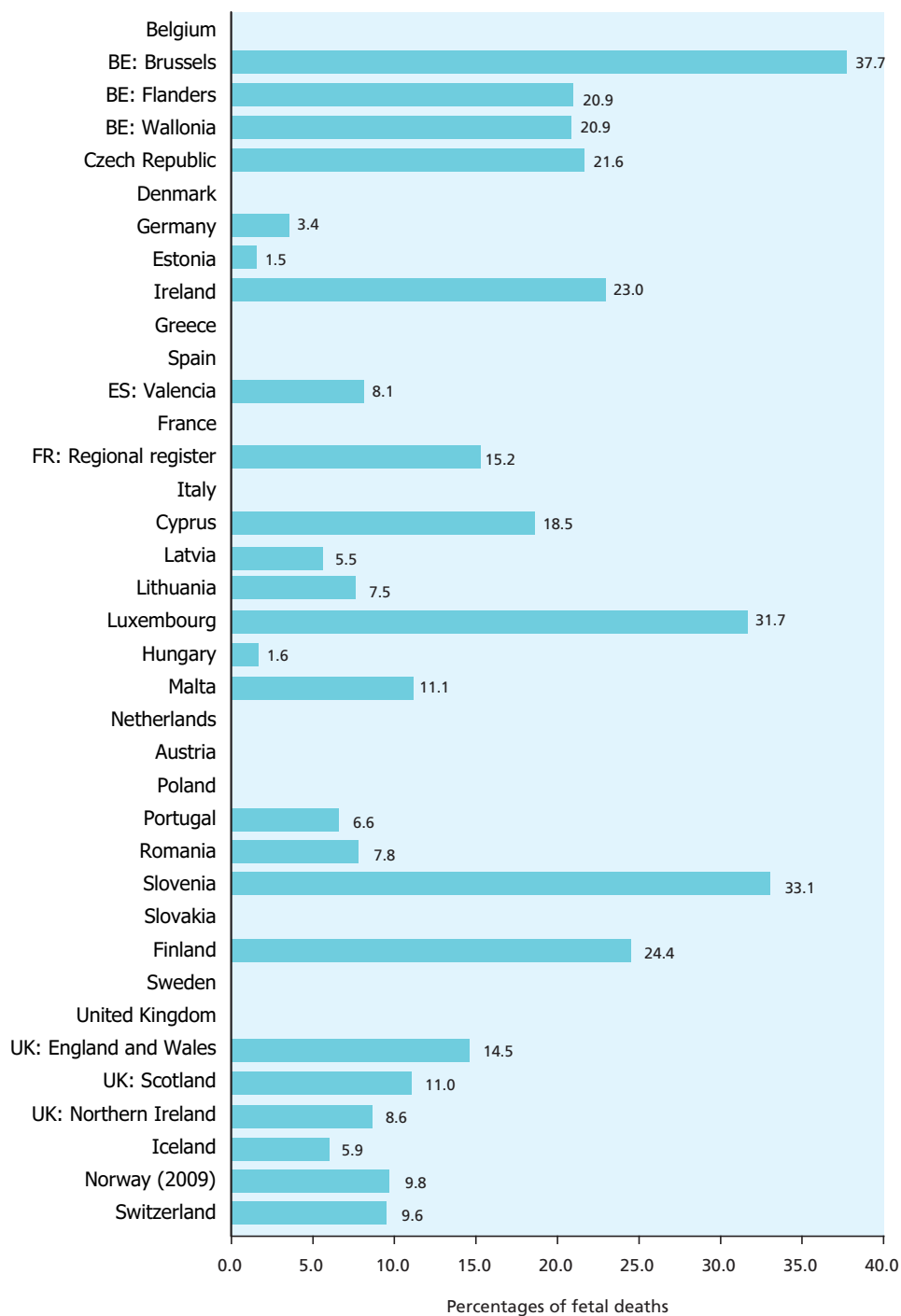
KEY POINTS

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.

REFERENCES

1. Boyd PA, De Vigan C, Khoshnood B, Loane M, Garne E, Dolk H, EUROCAT Working Group. Survey of prenatal screening policies in Europe for structural malformations and chromosome anomalies, and their impact on detection and termination rates for neural tube defects and Down's syndrome. *BJOG*. 2008;115:689-96.
2. Garne E, Loane M, Dolk H, De Vigan C, Scarano G, Tucker D, Stoll C, Gener B, Pierini A, Nelen V, Rosch C, Gillerot Y, Feijoo M, Tincheva R, Queisser-Luft A, Addor MC, Mosquera C, Gatt M, Barisic I. Prenatal diagnosis of severe structural congenital malformations in Europe. *Ultrasound Obstet Gynecol*. 2005; 25(1):6-11.
3. Papiernik E, Zeitlin J, Delmas D, Draper ES, Gadzinowski J, Kunzel W, Cuttini M, Dilallo D, Weber T, Kollee L, Bekaert A, Bréart G, and the MOSAIC Research Group. Termination of pregnancy among very preterm births and its impact on very preterm mortality: results from 10 European population-based cohorts in the MOSAIC study. *BJOG*. 2008; 115:361-368.
4. Garne E, Berghold A, Johnson Z, Stoll C. Different policies on prenatal ultrasound screening programmes and induced abortions explain regional variations in infant mortality with congenital malformations. *Fetal Diagn Ther*. 2001; 16(3):153-7.
5. Garne E, Khoshnood B, Loane M, Boyd P, Dolk H. Termination of pregnancy for fetal anomaly after 23 weeks of gestation: a European register-based study. *BJOG*. 2010; 117:660-666.
6. Loane M, Dolk H, Garne E, Greenlees R, for the EUROCAT Working Group. Paper 3: EUROCAT data quality indicators for population-based registries of congenital anomalies. *Birth Defects Res A Clin Mol Teratol*. 2011; 91(Suppl 1):S23-30. doi: 10.1002/bdra.20779.
7. EUROCAT Special Report. Prenatal Screening Policies in Europe, 2010. <http://www.eurocat-network.eu/prenatalscreeninganddiagnosis/generalinformation/policiesineuropeancountries>.

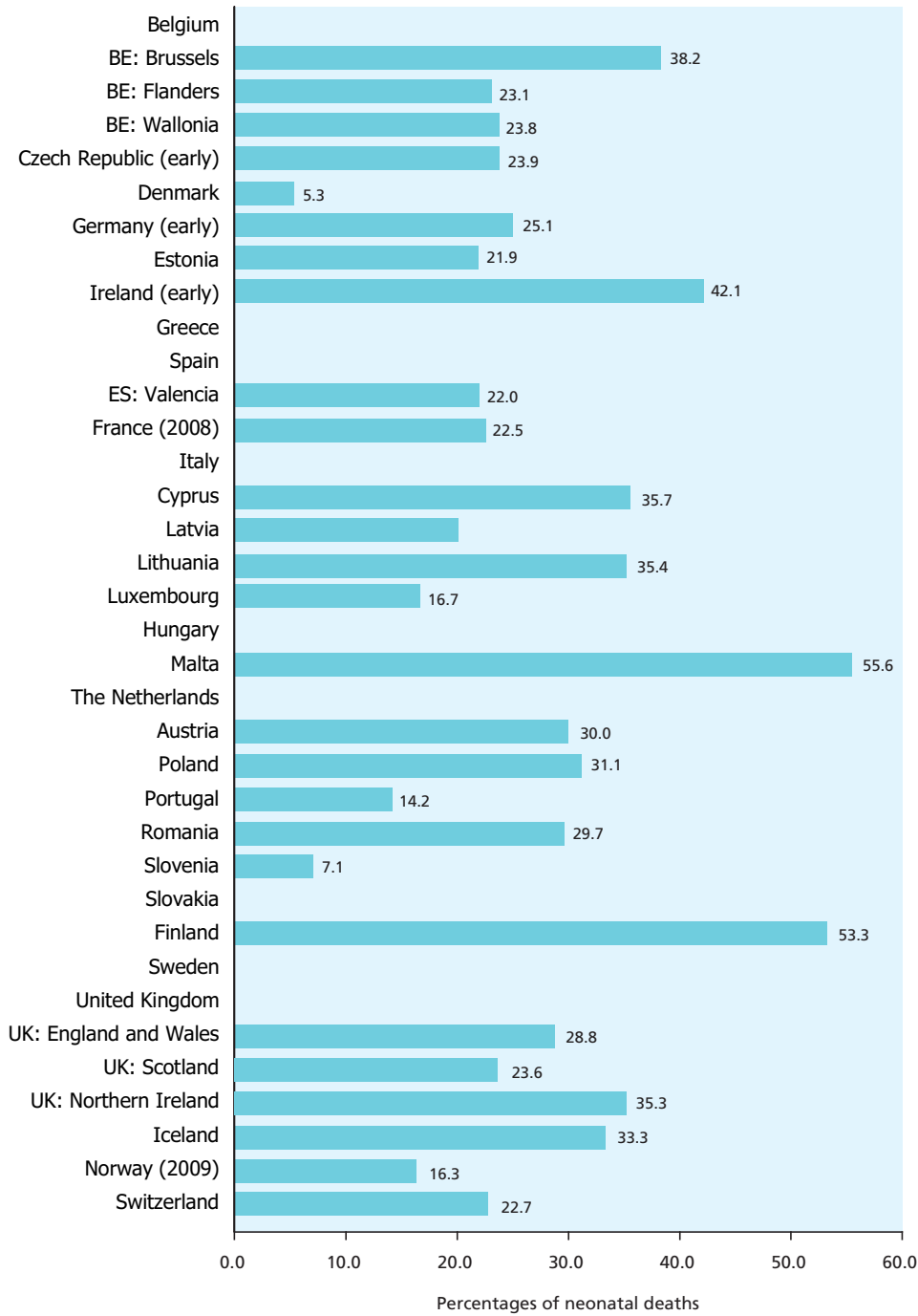
Figure 7.17 Percentage of fetal deaths due to congenital anomalies in 2010



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

