



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 SPCE (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, EUROCAT⁶ 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

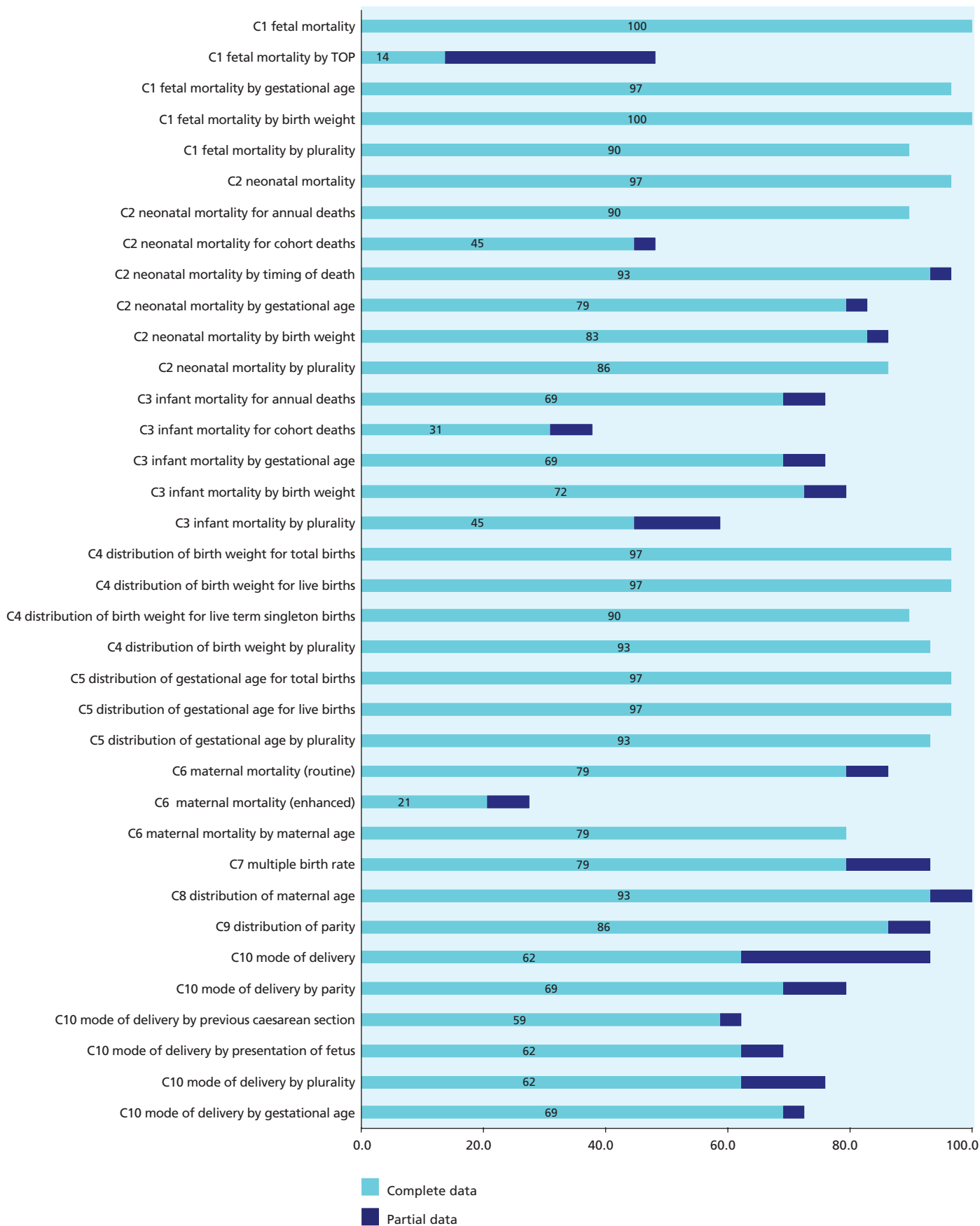
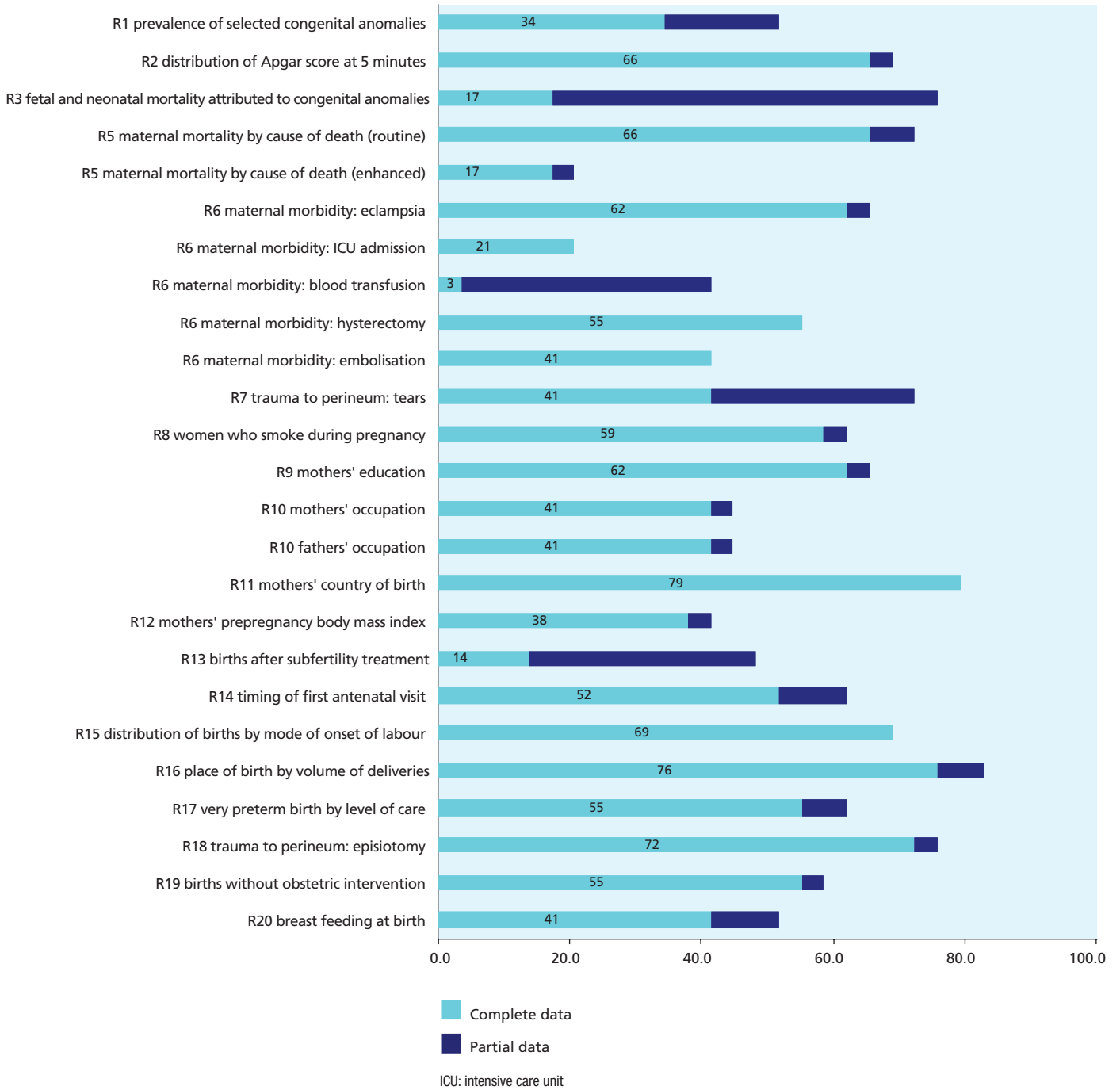




Figure 3.2 Percentage of countries that provided the EURO-PERISTAT recommended indicators in 2010



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 report⁵ 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	14 898	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.

REFERENCES

1. Zeitlin J, Wildman K, Bréart G, Alexander S, Barros H, Blondel B, Buitendijk S, Gissler M, Macfarlane A, PERISTAT Scientific Advisory Committee. PERISTAT: indicators for monitoring and evaluating perinatal health in Europe. *Eur J Public Health*. 2003; 13 (3 Suppl):29-37.
2. Zeitlin J, Wildman K, Bréart G, Alexander S, Barros H, Blondel B, Buitendijk S, Gissler M, Macfarlane A. Selecting an indicator set for monitoring and evaluating perinatal health in Europe: criteria, methods and results from the PERISTAT project. *Eur J Obstet Gynecol Reprod Biol*. 2003; 111(Suppl 1):S5-S14.
3. Gissler M, Mohangoo A, 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. *Informatics for Social and Health Care*. 2010; 35(2):64-79.
4. Blondel B, Lelong N, Kermarrec M, Goffinet F, for the National Coordination Group of the National Perinatal Surveys. Trends in perinatal health in France from 1995 to 2010. Results from the French National Perinatal Surveys. *J Gynecol Obstet Biol Reprod (Paris)*. 2012; 41(4):e1-e15.
5. 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.
6. EUROCAT. European Surveillance of Congenital Anomalies. www.eurocat-network.eu.
7. Cans C, Surman G, McManus V, Coghlan D, Hensey O, Johnson A. Cerebral palsy registries. *Semin Pediatr Neurol*. 2004; 11:18-23.
8. 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.
9. 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(6):660-666.
10. 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).
11. Bouvier-Colle MH, Mohangoo A, Gissler M, Novak-Antolic Z, Vutuc C, Szamotulska K, Zeitlin J, for The EURO-PERISTAT Scientific Committee. What about the mothers? An analysis of maternal mortality and morbidity in perinatal health surveillance systems in Europe. *BJOG*. 2012; 119(7):880-890.
12. Lack N, Blondel B, Mohangoo A, Sakkeus L, Cans C, Bouvier-Colle MH, Macfarlane A, Zeitlin J. Reporting of perinatal health indicators for international comparisons—enhancing the appearance of geographical plots. *Eur J Public Health*. first published online January 7, 2013.
13. Gourbin G, Masuy-Stroobant G. Registration of vital data: are live births and stillbirths comparable all over Europe? *Bull World Health Organ*. 1995; 73(4):449-60.
14. European Commission, Commission Regulation (EU) No 328/2011, dated 5 April 2011. <http://eur-ex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:090:0022:0024:EN:PDF>.



15. Deneux-Tharoux C, Berg C, Bouvier-Colle M-H, Gissler M, Harper M, Nannini A, Alexander S, Bréart G, Buekens P. Underreporting of pregnancy-related mortality in the United States and Europe. *Obstetr Gynecol.* 2005; 106(4):684-92.
16. Zeitlin J, Szamotulska K, Drewniak N, Mohangoo AD, Chalmers J, Sakkeus L, Irgens L, Gatt M, Gissler M, Blondel B, for the EURO-PERISTAT Preterm Study Group. Time trends in preterm birth: an analysis of 19 European countries. *BJOG* (in press).
17. MacDorman MF, Mathews TJ. Behind international rankings of infant mortality: how the United States compares with Europe. *Int J Health Serv.* 2010; 40(4):577-88.
18. Joseph KS, Liu S, Rouleau J, Lisonkova S, Hutcheon JA, Sauve R, Allen AC, Kramer MS; Fetal and Infant Health Study Group of the Canadian Perinatal Surveillance System. Influence of definition based versus pragmatic birth registration on international comparisons of perinatal and infant mortality: population based retrospective study. *BMJ.* 2012; 344:e746. doi: 10.1136/bmj.e746.
19. Gissler M, Louhiala P, Hemminki E. Nordic Medical Birth Registers in Epidemiological Research. *Eur J Epidemiol.* 1997; 13:169–175.
20. Gissler M, Surcel H-M. Combining health register data and biobank data. Special Issue on Reshaping Health Statistics. *Stat J Internat Ass Official Stats.* 2012; 28:53-58.

