

## Indicators of fetal and infant health outcomes

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### Abstract

**Objective:** To assess the ability of the member states of the European Union to produce the indicators recommended by the PERISTAT project on perinatal health indicators and to provide an overview of fetal and infant health outcomes for these countries according to the information now available. **Methods:** We used data from the PERISTAT survey of data providers to compute PERISTAT indicators of fetal and infant health. **Results:** National data on fetal mortality are available for all countries, but vary in their definitions. To adjust for these differences in definition, PERISTAT recommends presenting rates by gestational age and birth weight. Not all countries can provide neonatal mortality data by gestational age, birth weight or plurality, as recommended by PERISTAT. Few countries in Europe can report infant mortality rates by birth weight and gestational age. The other recommended indicators are available to varying degrees. **Conclusions:** This overview, which shows that Europe can produce a variety of indicators for monitoring the health of its new-borns, indicates that some key dimensions of perinatal health cannot now be measured with routine health statistics and reveals important disparities in health outcomes throughout Europe. For most indicators, the highest values are between 50 and 100% higher than the lowest values. The reasons for these variations and their importance for the surveillance of perinatal health are discussed.

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### 1. Introduction

Fetal and infant health outcomes are important measures of the overall health of a population and of the quality of health care services for mothers and their babies. Further, they are key to monitoring and understanding the impact of changing health care practices. They are necessary, for example, for measuring the extent and impact of antenatal screening and for monitoring the effect of changing practices in the care of extremely preterm babies.

Ten of the PERISTAT indicators measure fetal and infant health outcomes. Five are included on the core list: C1—fetal mortality rate, C2—neonatal mortality rate, C3—infant mortality rate, C4—birth weight distribution, and C5—gestational age distribution. Many of these core indicators are already available in international databases, such those at WHO, EUROSTAT and OECD. PERISTAT recommends that these indicators be computed and presented differently. In particular, it recommends that they be presented

by sub-groups to address methodological concerns and make them more specific and sensitive measures of overall health status and health care practices.

In addition to the set of core indicators, the PERISTAT list includes five recommended indicators of infant health: two are recommended for immediate implementation (R1—prevalence of selected congenital anomalies and R2—distribution of APGAR score at 5 min). Three require further work and development of data collection systems before they can be implemented at a European level (F1—causes of perinatal death, F2—prevalence of cerebral palsy and F3—prevalence of hypoxic-ischemic encephalopathy).

This analysis assesses the ability of European countries to produce these indicators and provides an overview of health outcomes according to the information now available.

### 2. Methods

The PERISTAT project collected data from the statistical offices and health departments of the participating countries to assess the feasibility of implementing the indicators

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recommended by its scientific advisory committee. The indicator selection process is described in Zeitlin et al. and the survey is presented in Macfarlane et al. (this issue). All data sources used below are referenced in Appendix A and described in more detail in Macfarlane et al.

Data are presented as numbers and rates by country. Confidence intervals are reported in many of the tables to remind the reader that the expected annual rate variation would be more substantial in small countries or regions than in large ones. An appreciation of the magnitude of the random variability in outcomes is important for interpreting differences between countries. The issue of precision is discussed in more depth in Lack et al. (this issue). When data were missing for gestational age or birthweight, rates were calculated using valid values only.

The PERISTAT questionnaire requested indicators in the form of numbers in analytic sub-categories. These data can be used in different ways to improve their usefulness. First, rates specific to key sub-groups can be generated. To make rates more comparable, for example, we might want to compute gestational age-specific rates: the fetal mortality rate at 28 weeks and after would be defined as deaths occurring at or after 28 weeks of gestation, divided by all births at or after 28 weeks. In contrast, an indicator may be separated into the components attributable to key sub-groups: for example, the portion of the neonatal mortality rate attributable to deaths before 28 weeks of gestation, defined as the deaths occurring before 28 weeks of gestation, divided by total live births. Both of these approaches are useful for

understanding these indicators. We use the terminology 'mortality by sub-group' to refer to rates specific to the sub-group; 'mortality for a given sub-group' also refers to a rate specific for that group. 'Mortality attributable to the sub-group', however, refers to rates that use a common denominator.

### 3. Results

#### 3.1. Indicator C1: fetal mortality rate

National data on fetal mortality are available for all countries, as Table 1 shows. The definition used by the PERISTAT project to define fetal deaths was 'all fetal deaths occurring at or after 22 weeks of gestation'. If countries were not able to provide data on deaths according to this definition, we asked them to provide the information that they routinely collected. Most countries were able to provide data according to this gestational age limit, but others could provide these fetal deaths only while excluding deaths with a birth weight below 500 g (Flanders, in Belgium, Ireland's perinatal registry, and the Valencia region of Spain). Finally, Sweden and Denmark do not register fetal deaths before 28 weeks and Italy does not register them before 180 days and the countries of the United Kingdom do not register fetal deaths before 24 weeks of gestation. For the year 2000, France registered stillbirths only from 28 weeks onward, but the limit has since been changed to 22 weeks.

Table 1  
Fetal mortality rates (fetal deaths per 1000 total births)

Member state (coverage)	Source	Fetal deaths	Total births	Data provided for fetal deaths (weeks)	Data for sub-group analysis <sup>a</sup>	Fetal death rate	95% confidence interval	Fetal death rate for births $\geq 28^b$	95% confidence interval
Austria	A1-2001	274	75,707	$\geq 22$	GA, BW, PL	3.6	3.2–4.1	2.6	2.2–3.1
Belgium (Flanders)	B2-2000	278	62,122	$\geq 22$ + $\geq 500$ g	GA, BW, PL	4.5	4.0–5.0	3.2	2.6–3.7
Denmark	DK1-2000	253	67,337	$\geq 28$	GA, BW, PL	3.8	3.3–4.2	3.8	3.3–4.3
Finland	FIN1-2000	227	56,768	$\geq 22$	GA, BW, PL	4.0	3.5–4.5	2.8	2.2–3.3
France	F2-2000	3559	778,341	$\geq 28^c$	PL	4.6	4.4–4.7		
Germany (nine Bundesländer)	D1-2000	2082	557,948	$\geq 22$	GA, BW, PL	3.7	3.6–3.9	2.9	2.8–3.1
Greece (perinatal survey)	EL1-1998	83	14,659	$\geq 22$	GA, BW, PL	5.7	4.5–6.9	4.7	3.5–5.9
Ireland	IR1-1999	285	54,302	$\geq 22$ + $\geq 500$ g	GA, BW, PL	5.3	4.6–5.9	4.2	3.6–4.8
Italy	I-1998	2074	533,624	$\geq 180$ days	GA, BW, PL	4.4	3.9–4.2	3.7	3.6–3.9
Luxembourg	L1,2-2000	30	5,430	$\geq 22$	GA <sup>d</sup> , BW <sup>d</sup> , PL	5.5	3.5–7.5	4.4	2.4–6.4
The Netherlands	NL1-1999	1484	201,600	$\geq 22$	GA, BW, PL	7.4	7.0–7.7	4.6	4.2–4.9
Portugal	P1-1999	696	120,861	$\geq 22$	GA, BW, PL	5.8	5.3–6.2	4.3	3.8–4.7
Spain (Madrid, Valencia, Pais Vasco)	E2-2000	448	86,656	$\geq 22$		5.2	4.7–5.7		
Sweden	S1-2000	345	89,722	$\geq 28$	GA, BW, PL	3.9	3.4–4.3	3.9	3.5–4.3
England and Wales, UK	UK1,5,17-2000	3203	607,644	$\geq 24$	GA <sup>e</sup> , BW, PL	5.3	4.1–5.5		
Northern Ireland, UK	UK7-2000	95	21,794	$\geq 24$	GA, BW, PL	4.4	3.5–5.2	3.3	2.5–4.2
Scotland, UK	UK6-2000	298	52,413	$\geq 24$	GA, BW, PL	5.7	5.0–6.3	4.0	3.5–4.6

<sup>a</sup> GA = gestational age; BW = birthweight; PL = plurality

<sup>b</sup> Calculated for all births 28 weeks and over.

<sup>c</sup> Definition changed in 2001.

<sup>d</sup> Available on data source that includes 5430 out of 5723 births.

<sup>e</sup> Based on an estimate from maternity hospital episode statistics from England.

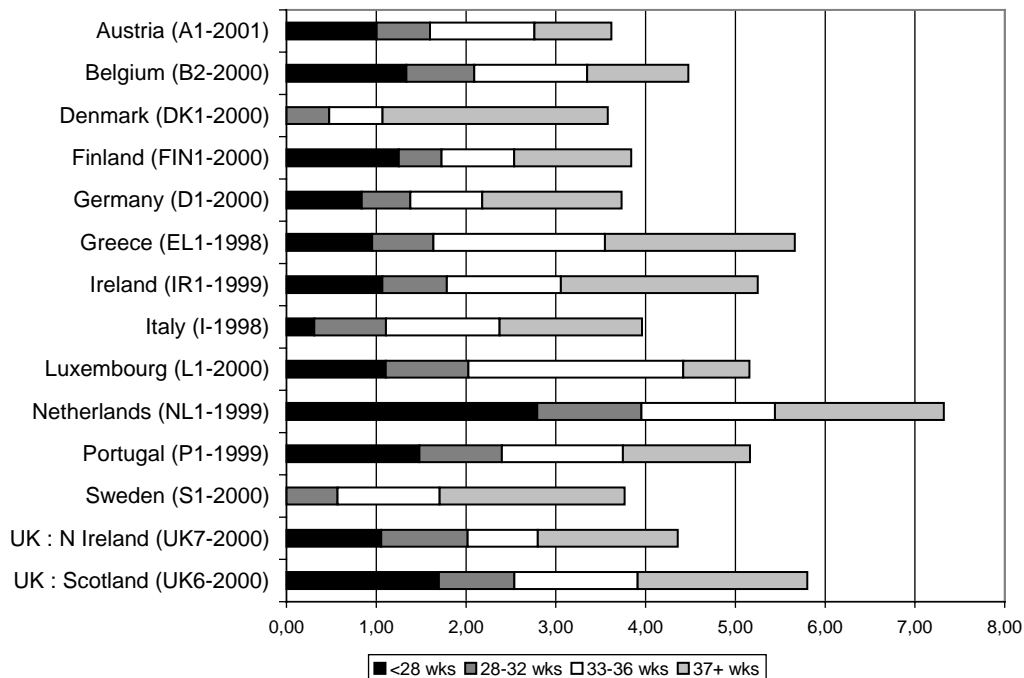


Fig. 1. Fetal mortality rate attributed to gestational age group (per 1000 total births).

To adjust for these differences in definition, PERISTAT recommends presenting rates by gestational age and birth weight. Table 1 presents fetal death rates for births at or after 28 weeks, where available (deaths 28 weeks and over divided by all births 28 weeks and over). Some countries can provide rates adjusted for gestational age or birth weight only for sub-samples of the population. In Germany, for instance, data come from seven *Bundesländer* that represent 73% of all German births. France cannot provide these data by birth weight or gestational age, which are not recorded for either still- or live births. The PERISTAT project also recommends that indicators be shown by plurality. This is possible in almost all countries providing data to the PERISTAT project.

Fetal mortality rates after 28 weeks of gestation vary from 2.6 to 4.7 per 1000 births; Greece, Ireland, Luxembourg, The Netherlands and Portugal have rates over 4 per 1000 births, whereas Austria, Finland and Germany have rates under 3 per 1000 births.

Fig. 1 reports fetal mortality rates and the proportion of deaths attributable to each of four gestational age groups: <28, 28–32, 33–36 and 37 weeks and over. Countries that do not register deaths before 28 weeks have no deaths in this category, as we would expect. This figure illustrates the impact that these differences can have on overall rates. It also shows the substantial variability in the proportion of fetal deaths that occur at term: from one-third to more than one-half of deaths at 28 weeks and later are of term babies.

### 3.2. Indicator C2: neonatal mortality rate

Table 2 presents the data provided to the PERISTAT project on neonatal mortality, classified as early and late

neonatal deaths. In Europe, most countries have neonatal death rates near 3 per 1000 births. Denmark and Sweden have rates under 2.5 while Italy and The Netherlands have rates closer to 4 per 1000 births. Between 70 and 80% of neonatal deaths take place in the first 7 days of life, although the variation is wider in some countries: 88% of deaths in The Netherlands take place in the early neonatal period and only 56% of those in the Valencia region of Spain.

Not all countries can provide neonatal mortality data by gestational age, birth weight or plurality, as recommended by PERISTAT. Some countries can provide information on gestational age and birth weight for deaths, but not for live births. France collects birth weight and gestational age for neonatal deaths on a special certificate, but does not routinely record these data for all births. In the countries of the United Kingdom, birth weight and gestational age are recorded at stillbirth registration, but are not recorded when registering live births. These data items are, however, collected in varying ways through community and hospitals and in confidential inquiries. This means that mortality rates can be derived for specific sub-groups of babies in these countries, but only by using estimates on data from a variety of sources. Some birth registries are able to provide obstetrical data for early neonatal deaths only, since they do not follow-up babies for longer than 7 days after birth.

Fig. 2 displays the portions of the neonatal death rate attributed to the following gestational age groups: <28, 28–32, 33–36, and 37 weeks and over. Extremely preterm babies (<28 weeks) account for the largest portion of neonatal deaths, approximately one third, although countries vary widely. Registration practices are more similar for neonatal than fetal death rates, but some countries exclude all births at

Table 2  
Neonatal mortality rates (per 1000 total births)

Country	Source	Neonatal deaths	Live births	Neonatal mortality rate	95% confidence interval	Early neonatal mortality	95% confidence interval	Late neonatal mortality	95% confidence interval	Proportion deaths <7 days
Austria	A1-2001	226	75,433	3.0	2.6–3.4	2.2	1.9–2.6	0.8	0.6–1.0	0.75
Belgium (Flanders)	B2-2000	188	61,844	3.0	2.6–3.5	2.2	1.8–2.6	0.8	0.6–1.1	0.72
Denmark	DK1-2000	266	67,084	4.0	3.5–4.4	3.3	2.8–3.7	0.7	0.2–1.2	0.82
Finland	FIN1-2000	134	56,541	2.4	2.0–2.8	1.7	1.4–2.0	0.7	0.5–0.8	0.72
France	F2-2000	2297	774,782	3.0	2.8–3.1	2.1	2.0–2.2	0.8	0.8–0.9	0.72
Germany	D2-1999	2041	770,744	2.7	2.5–2.8					
Greece (perinatal survey)	EL1-1998	97	14,277	6.8	5.4–8.1	4.8	3.7–6.0	2.0	1.2–2.7	0.71
Ireland	IR2-1999	218	54,242	4.0	3.5–4.6	3.2	2.7–3.7	0.8	0.6–1.1	0.79
Italy	I-1998	2031	531,650	3.8	3.7–4.0	2.7	2.6–2.8	1.1	1.0–1.2	0.71
Luxembourg	L1-2000	11	5,696	1.9	0.8–3.1	1.6	0.6–2.6	0.4	0.0–0.8	0.92
The Netherlands	NL1-1999	805	200,115	4.0	3.7–4.3	3.5	3.3–3.8	0.5	0.4–0.6	0.88
Portugal	P1-1999	407	120,071	3.4	3.1–3.7	2.5	2.2–2.8	0.9	0.7–1.1	0.73
Spain (Madrid, Valencia, Pais Vasco)	E2-2000	233	85,478	2.7	2.4–3.1	1.5	1.3–1.8	1.2	1.0–1.4	0.56
Sweden	S1-2000	203	89,377	2.3	2.0–2.6	1.7	1.4–1.9	0.6	0.5–0.8	0.73
England and Wales, UK	UK1,8-2000	2307	621,872	3.7	3.6–3.9	2.8	2.7–2.9	0.9	0.8–1.0	0.75
Northern Ireland, UK	UK7,10-2000	78	21,699	3.6	2.8–4.4	2.7	2.0–3.4	0.9	0.5–1.3	0.77
Scotland, UK	UK6,11-2000	212	52,115	4.1	3.5–4.4	2.9	2.4–3.3	1.9	0.9–1.5	0.71

less than 500 g from their registers. For those countries, the overall rates as well as the proportions attributable to early birth are lower. Deaths at term account for 20–40% of the neonatal deaths; the sub-groups of preterm babies between 28 and 32 weeks and between 33 and 36 weeks each represent about 15% of the deaths.

Fig. 3 presents neonatal mortality for infants from singleton versus multiple pregnancies. The figure shows that babies from multiple pregnancies are approximately six times more likely to die during their first month of life as they are more likely than singletons to be born early.

### 3.3. Indicator C3: infant mortality rate

The PERISTAT group included the infant mortality rate (mortality during the first year of life) as a core indicator,

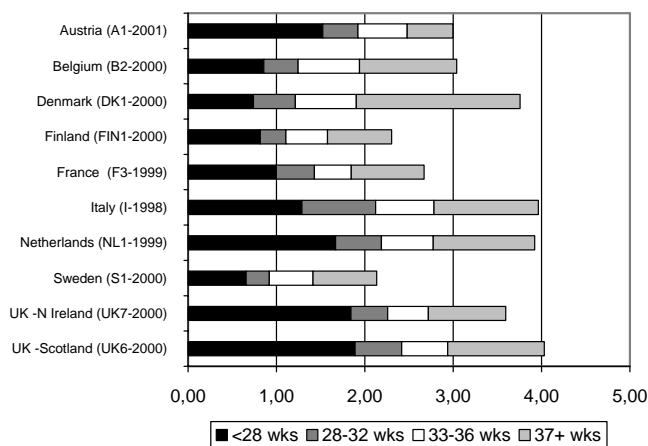


Fig. 2. Neonatal mortality rate attributed to gestational age group (per 1000 live births). Note: Italy had 173 deaths with unknown gestational age (8.5%), these were assumed to follow observed GA distribution.

even though it extends beyond the perinatal period. The infant mortality rate, when presented by gestational age and birth weight, measures the longer-term consequences of perinatal morbidity for such high-risk groups as very pre-term and growth-restricted babies.

Table 3 presents gestational age-specific post-neonatal mortality rates—deaths occurring after the neonatal period and within first year of life—in those countries that could provide this information. At present, few countries in Europe can report infant mortality rates by birth weight and gestational age, because this requires either recording birth weight and gestational age on the death certificate, or linking the annual cohort of infant deaths to their birth records, which contain both indicators.

Furthermore, for birth and death registries, the information available covers deaths in a calendar or other year in

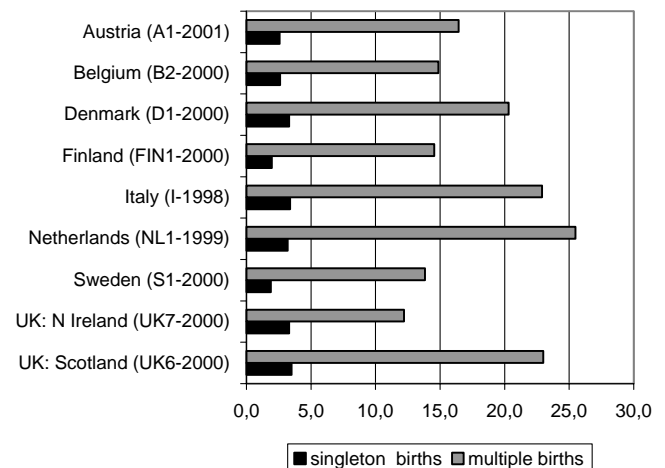


Fig. 3. Neonatal mortality rates by plurality.

Table 3  
Post-neonatal mortality rate by gestational age group (post-neonatal deaths in the year per 1000 live births in the same year)

Member state (coverage if not national)	Source	<28 weeks	95% CI	28–36 weeks	95% CI	>37 weeks	95% CI
Austria	A1-2001	61.8	36.2–87.4	2.4	1.3–3.6	1.1	0.9–1.4
Belgium (Flanders)	B2-2000	66.3	28.4–104.1	6.1	3.8–8.3	1.4	1.2–1.8
Denmark	DK1-2000	36.1	7.8–64.5	3.2	1.4–5.1	0.7	0.5–1.1
Finland	FIN1-2000	7.3 <sup>a</sup>	0.0–21.6	4.5	2.2–6.8	0.9	1.0–1.5
Sweden	S1-2000	12.5	0.0–26.6	1.8	0.7–3.0	0.4	1.0–1.5
Scotland, UK <sup>b</sup>	UK6,11-2000	87.3	50.1–123.9	4.5	2.3–6.7	1.2	0.9–1.5

<sup>a</sup> Only one post-neonatal death <28 weeks of gestation in Finland in 2000.

<sup>b</sup> Unknown gestational ages included in term group.

most countries, so that the deaths in the denominator do not necessarily correspond to the births in the numerator. Where these numbers of deaths and births are stable, the infant mortality rate will be a good estimate of actual cohort death rates. Where they fluctuate significantly, either because of a change in actual mortality or because of small population sizes, the infant mortality rate will fluctuate as well. Finland serves to illustrate the extent of this fluctuation in smaller countries: only one post-neonatal death was registered among babies born at less than 28 weeks of gestation in 2000. Cohort death rates would be ideal, but require linkage between birth and death certificates. This linkage is routinely done in England and Wales [1].

Nonetheless, this table shows that mortality is high among very preterm babies after the neonatal period; it thus provides evidence of the need for a longer time frame for measuring perinatal health outcomes in this population.

3.4. Indicator C4: distribution of birth weight

Table 4 presents live births by birth weight distribution. Fetal deaths were excluded because of variations in registration practices, as explained for indicator C1. The babies at

highest risk, those born weighing less than 1500 g, account for approximately 1% of all live births. Note that some countries do not include births with a birth weight less than 500 g; this difference affects the birth weight distribution less than it does mortality rates, because these births account for less than 0.05% of live births after 22 weeks of gestation.

Babies born weighing less than 2500 g constitute between 4.5% and 8% of all liveborn babies. This group represents less than 5% of babies in Denmark, Finland, Ireland, Luxembourg and Sweden, and more than 7% in Greece, Portugal and Spain. Countries also vary significantly in percentages of higher birth weights; babies weighing more than 4500 g account for less than 1% of total live births in some countries and more than 4% in others (Table 5).

3.5. Indicator C5: distribution of gestational age

Fig. 4 presents data on the gestational age distribution for live births. Estimated preterm birth rates are available in most countries and vary most often from 5 to 8%; the rate in Austria reaches 10%, however. This figure classifies preterm births in two gestational age groups: very preterm births (<32 weeks) and births between 33 and 36 weeks. The

Table 4  
Birthweight distribution, live births

Member state (coverage if not national)	Data source	<500 g (%)	500–1499 g (%)	<1500 g (%)	1500–2500 g (%)	<2500 g (%)	2500–4499 g (%)	>4500 g (%)	Total
Austria	A1-2001	0.03	1.06	1.09	5.54	6.63	92.30	1.08	100
Belgium (Flanders)	B2-2000	n/a	0.90	0.90	5.66	6.56	92.49	0.95	100
Belgium (French community)	B3-2000	0.06	1.18	1.24	6.25	7.48	90.77	1.75	100
Denmark	DK1-2000	0.00	0.83	0.83	4.09	4.92	90.89	4.20	100
Finland	FIN1-2000	0.03	0.73	0.76	3.58	4.34	92.36	3.30	100
France (perinatal survey)	F1-1998	0.00	0.78	0.78	5.99	6.77	92.42	0.81	100
Germany	D2-1999	0.05	1.05	1.10	5.45	6.54	91.82	1.64	100
Greek (perinatal survey)	EL1-1998	0.02	0.96	0.98	6.20	7.19	92.02	0.80	100
Ireland	IR1-1999	n/a	0.82	0.82	4.17	4.99	92.10	3.00	100
Italy	I1-1998	0.3	0.65	0.91	5.01	5.93	91.46	2.61	100
Luxembourg	L2-2000	0.02	0.02	0.04	4.08	4.12	95.09	0.79	100
The Netherlands	NL1-1999	0.04	0.99	1.04	5.50	6.54	91.15	2.31	100
Portugal	P1-1999	0.01	0.95	0.95	6.15	7.10	92.16	0.74	100
Spain (Madrid, Valencia, Pais Vasco)	EL2-2000	n/a	1.22	1.22	7.32	8.53	91.47	n/a	100
Sweden	S1-2000	0.02	0.75	0.77	3.64	4.41	91.33	4.26	100
UK	UK1,6,7-2000	0.06	1.18	1.24	5.24	6.38	90.63	1.75	100

Table 5  
Selected congenital anomalies

Member state (coverage)	Data source	Prevalence of all neural tube defects <sup>a</sup> (per 10,000 births)			Prevalence of Down's syndrome (per 10,000 births)		
		Live births <sup>b</sup>	Live + stillbirths <sup>c</sup>	For births + IA <sup>d</sup>	Live births <sup>b</sup>	Live + stillbirths <sup>c</sup>	Live + stillbirths + IA <sup>d</sup>
Austria	A1-2001	3.05	3.43	–	1.06	1.19	–
Belgium (Flanders)	B2-2000	–	–	–	5.66	5.63	–
Denmark	DK-2000	–	16.4	–	–	8.79	–
Finland	FIN4-2000	2.61	2.77	7.43	9.92	10.06	21.25
France (Paris)	F6-2000	1.28	1.78	15.07	7.14	7.87	34.90
Germany	D2-1999	6.32	–	–	7.39	–	–
Luxembourg	L2-2000	3.72	–	–	–	–	–
Portugal	P2-1999	7.16	–	–	–	–	–
Spain	E3-2000	2.56	–	–	8.79	–	–
Sweden	S1-2000	3.87	3.96	13.83	10.95	11.01	21.07
England and Wales, UK	UK13-2000	4.26	5.74	–	6.00	6.25	–

<sup>a</sup> Defined as: ICD9 740–742.

<sup>b</sup> Cases among live births/live births.

<sup>c</sup> Cases among live + stillbirths/live + stillbirths.

<sup>d</sup> Cases among live + stillbirths + induced abortions/births + induced abortions.

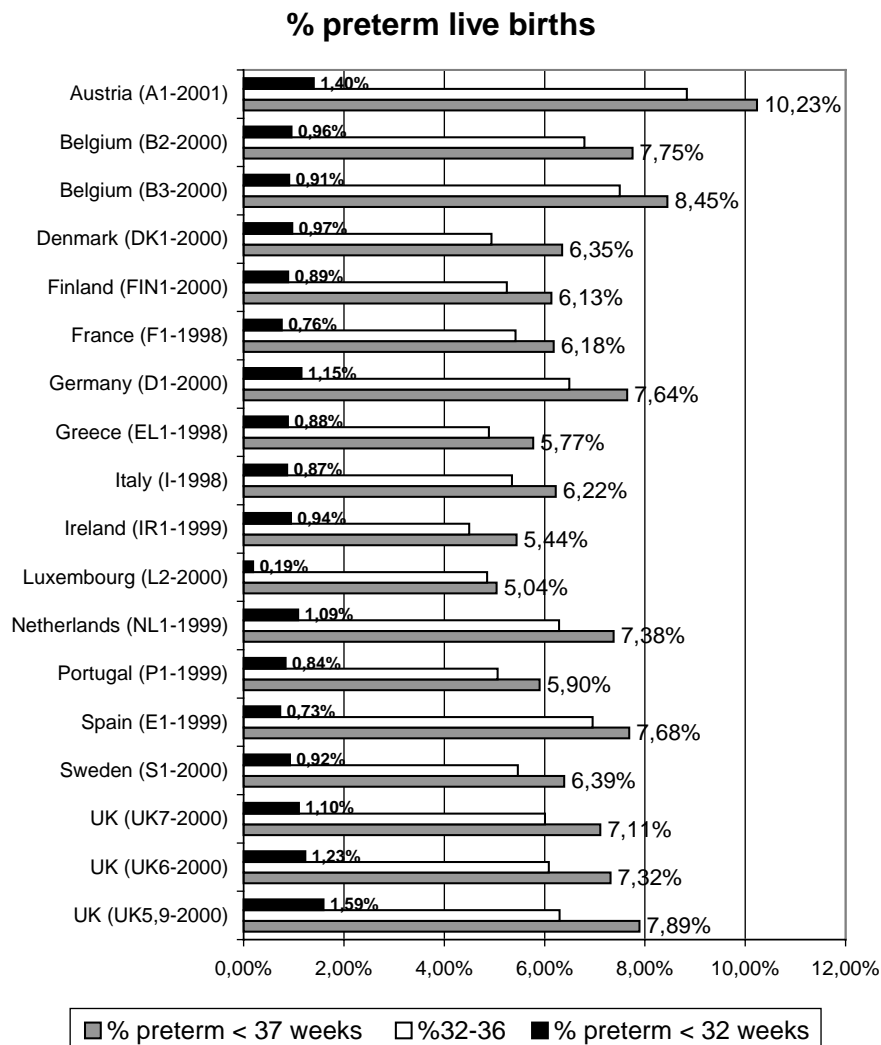


Fig. 4. Percent of preterm live births.



Table 6  
APGAR score (per 1000 births)

Member state (coverage if not national)	Data source	APGAR < 4	APGAR < 7	Total births
Austria	A1-2001	2.2	9.1	75,433
Belgium (Flanders)	B2-2000	2.5	18.1	61,844
Belgium (French community)	B3-2000	2.8	14.4	44,418
Denmark	DK1-2000	1.5	7.3	67,170
France (perinatal survey)	F1-1998	1.1	5.8	13,718
Germany (nine Bundesländer)	D1-2000	1.5	8.8	555,972
Greece (perinatal survey)	EL1-1998	2.3	11.9	14,576
Luxembourg	L2-2000	2.0	9.3	5,404
Sweden	S1-2000	2.0	10.4	88,331
Scotland, UK	UK6-2000	–	13.0	51,393

percentage of live born babies at less than 32 weeks' gestation ranges from 0.7 to 1.4%.

### 3.6. Indicator R1: selected congenital anomalies

This indicator was defined by the PERISTAT project as the number of live births, fetal deaths and induced abortions with neural tube defects or Down's syndrome in relation to the number of all live births, fetal deaths and induced

abortions. This PERISTAT indicator was constructed to permit assessment of prevalence of congenital anomalies from data routinely collected at the national and regional level.

Ten countries provided data on congenital anomalies to the PERISTAT project. The data from France came from a congenital anomaly register that covers Paris, and the data for Finland from a national congenital anomaly register. Most countries without congenital anomaly registers provide data only on live births and total birth prevalence. This indicator measures the proportion of babies born with a specific condition, but does not report the prevalence of the condition itself, as we clearly see by comparing, where available, live birth prevalence with total prevalence including induced abortions.

The prevalence of neural tube defects at birth in these data sources ranges from 1.3 to 7.2 per 10,000 total births, and for Down's syndrome from 1.2 to 11.1 per 10,000.

### 3.7. Indicator R2: APGAR score

Table 6 reports the percentage of live births with an APGAR score less than 4 and less than 7. This information

Table 7  
Cause of death classification and percent deaths due to congenital anomalies (in countries responding to questionnaire on future indicators)

Member state (coverage if not national)	Data source	Description of cause of death classification	Deaths due to congenital anomalies (%)		
			Fetal deaths	Neonatal deaths	Perinatal deaths
Austria	A1-2001	Coded for neonatal deaths only using ICD9 3 digit codes	n/a	30.1	n/a
Belgium (Flanders)	B2-2000	Classification of Hall with eight categories, including unknown. Only neonatal deaths <7 days, induced abortions included	15.6	39.4 (only <7 days)	23.7
Belgium	B1-1995	ICD9; presented as: congenital anomalies, pregnancy related, prematurity, anoxia-RDS, SIDS, others, ill defined conditions; induced abortions included	11.5	34.4	21.1
Denmark	DK1-2000	The Nordic Baltic Perinatal Death Classification, based on the presence of lethal congenital anomalies, moment of death (ante-partum, intrapartum and neonatal), growth restriction, prematurity, and APGAR at 5 min, induced abortions included	Available, not provided	Available, not provided	18.5
Finland	FIN2-2000	ICD10 codes; induced abortions not included <25 weeks	13.2	35.8	19.9
France	F3-1999	ICD9—only neonatal deaths	n/a	25.9	n/a
Germany	D1-2000	ICD9/ICD10—data quality not good because of change from 9 to 10	n/a	Not provided	n/a
Ireland	IR2-1999	Coded using ICD9 codes, data are presented in 13 grouped categories	12.5	40.4	23.6
Luxembourg	L1-2000	Up until 2000, British Paediatric Association classification of diseases 1979; 17 categories; induced abortions not included	32	18.2 (only <7 days)	28.2
Portugal	P1-1999	ICD9; induced abortions not included, but legislation will change soon	Available, not provided	Available, not provided	Available, not provided
England and Wales, UK	UK1-2000	Classification based on Wigglesworth, devised for ICD9. New version based on ICD10 used from 2001	13.9	26.3	18.2
Scotland, UK	UK11-2000	Uses Aberdeen obstetric and paediatric classifications	11.1	25.9	15.5

is available for many, but not all European countries. Very few babies have an APGAR score lower than 4—approximately 2 per 1000 births. From 1 to 1.5% of babies have an APGAR score lower than 7.

### 3.8. Indicators targeted for further development

Three indicators were targeted for further development: causes of perinatal death, prevalence of hypoxic-ischemic encephalopathy, and prevalence of cerebral palsy. These indicators require further work to generate a common classification (cause of death), to develop a valid and comparable indicator for defining the condition (HIE) or to establish methods for generating the indicator from routine data (CP).

Cause of death data exist almost everywhere, at least for neonatal deaths, as shown in Table 7. Most countries code causes of death according to ICD9 or ICD10 and a number were in the process of changing from ICD9 to ICD10. Each country, however, has its own classification system for analysing and reporting these data as column 3 of Table 7 shows. These differences in classification systems mean that it is not possible to produce a comparative table of causes of death. Nonetheless, all classification systems include a category for deaths from congenital anomalies. Approximately 12% of fetal deaths and about one-third of neonatal deaths are due to congenital anomalies.

The PERISTAT survey requested data about hypoxic-ischemic encephalopathy, defined according to ICD10 (a disturbance in cerebral function manifested in the first few days of life by an altered level of consciousness, by a disturbance of muscle tone and posture and by seizures, associated with signs of peripartum hypoxia (ICD10: P91.0)). Three countries reported data based on this definition. The prevalence rate, according to hospital discharge records, was reported to be 6.8 per 10,000 in Denmark, 1.8 per 10,000 in Finland, and 7.8 per 10,000 in Bavaria, Germany. Similar data may be available in other countries, but not presently in use.

PERISTAT did not attempt to collect information about the prevalence of cerebral palsy, because of the complex requirements for collecting relevant data. A European collaboration on this topic, the Surveillance of Cerebral Palsy in Europe (SPCE), has worked with existing registers to compile data and set standards [2].

## 4. Discussion

European countries can provide many of the PERISTAT core and recommended indicators of fetal and infant health and can report most of them by the analytic sub-groups of gestational age, birth weight and plurality. Using these sub-groups makes these indicators both more methodologically sound and more useful for the analysis of overall trends and variations between countries and over time. Most of these data are currently available from national statistical offices

and other organisations, but until now they were not easily accessible to interested parties in other countries.

Unfortunately, very few countries can provide the whole range of indicators according to the definitions and subdivisions requested. Some countries have more work to do than others before they can provide the complete set of PERISTAT indicators. For example, France does not record gestational age or birth weight for either births or fetal deaths at the national level. Spain does not collect these data for fetal deaths. In England, data on gestational age are not systematically collected at the national level in systems which are routinely linked to death data. In Sweden indicators of fetal mortality cannot be provided according to the PERISTAT definitions because deaths are not registered before 28 weeks of gestation. Some countries have no routine systems for collecting information such as APGAR scores or congenital anomalies. Most countries cannot provide gestational age and birth weight specific post-neonatal mortality rates, and many cannot do this for neonatal mortality.

Despite their incompleteness, the existing indicators enable us to identify common European health problems. Mortality indicators underline the importance of continuing public health and clinical efforts to prevent preterm births. Preterm births represent only 5–10% of births, but account for more than two-thirds of neonatal deaths. Although only approximately 1% of all live births are very preterm, they constitute an important challenge for health systems, as they require highly specialised care to achieve optimal health outcomes. Births before 32 weeks' gestation account for 35–60% of neonatal deaths. Information from the few countries able to provide infant mortality data by gestational age and birth weight indicates that these babies have a high excess mortality throughout their first year of life. A focus on multiple births is also important, since neonatal mortality is six to seven times higher for babies from multiple pregnancies than from singleton pregnancies.

Data on causes of death and selected congenital anomalies show that congenital anomalies remain an important cause of mortality and morbidity during the perinatal period; congenital anomalies are responsible for approximately 15% of fetal deaths and 30% of neonatal deaths. PERISTAT also collected information on neural tube defects and Down's syndrome. These conditions were selected based on their relatively high prevalence, and the likelihood they will be identified during pregnancy or early in the neonatal period. Neural tube defects have been shown to be responsive to primary prevention efforts with folic acid in early pregnancy [3]. The higher rate of Down's syndrome among older women has important implications for the ever-increasing percentage of women delaying childbirth. Most countries are able only to provide live birth or total birth prevalence of these conditions from data at a national level. Since it is essential to also include data on induced abortions on grounds of fetal anomaly to estimate the overall prevalence of these conditions, complete analyses of congenital



anomalies will depend on the availability of data from registers. These registers also make it possible to validate data provided from national sources. A comparison with the congenital anomaly register data in the UK showed that these conditions were relatively well ascertained in the birth register [4]. The data on neural tube defects and Down's syndrome provided to the PERISTAT project from national registers is consistent with estimates of live birth prevalence given by EUROCAT for the years 1995–1999 [5]; systematic comparative analyses should be undertaken as part of a system of routine reporting, however.

This overview provides data for one point in time, usually 1999 or 2000. We therefore cannot use these indicators to monitor trends, although this is one of the principal uses of health information systems. If implemented and available routinely, these indicators could provide valuable and currently unavailable information for the surveillance of trends. For example, the proportion of preterm babies appears to be rising in North America, especially the proportion of very preterm births [6,7]. These trends have not been monitored systematically in Europe, and some European countries appear to have experienced a reduction in overall preterm birth rates over the past few decades [8,9].

Another high-risk group that could be monitored with these indicators are babies with a low 5 min APGAR score. The APGAR score takes into account skin colour, respiratory effort, muscle tone and reflex irritability and is universally used to summarise the physical condition of babies after delivery. The 5 min score is associated with survival in infancy and with the prevalence of major neurological abnormalities and minor disabilities in childhood [10,11]. Babies with an APGAR score below 7 account for up to 1.5% of the total population of births.

The PERISTAT indicators can also be used to monitor the health consequences when groups of higher-risk births increase in number. For example, indicators of health outcomes for babies from singleton and multiple pregnancies make it possible to assess the impact of the trend of increasing multiple births related to the overall rise in maternal age at birth and use of artificial fertility techniques [12].

Generating hypotheses about differences in indicators between countries and monitoring their development is another key objective of a European health information system. This overview reveals important disparities in health outcomes throughout Europe. These variations may be due to many factors: social and demographic characteristics of the childbearing population, methodological differences in the construction of indicators, medical practices, and variations in quality of prenatal or delivery care. Bréart et al. (this issue) discuss the impact of characteristics of the childbearing population on some of these health outcomes.

Identifying and minimising variations in indicators based solely on methodological differences is essential for comparative analyses. The PERISTAT indicators include analytical sub-groups that make it possible to construct more comparable indicators. Groups for which under-registration

may be a problem or where there are discordant definitions can be excluded or analysed separately, as done in this review. For some indicators, however, more research needs to be done before recommendations for improving comparability can be made. For example, the measurement of gestational age partly depends on the definition used and on the extent to which ultrasound is used to date pregnancies. Differences between countries may therefore reflect recording practices as well as real differences in the preterm birth rate [13]. The potential biases arising from measurement differences are discussed in Lack et al., this issue, but the implications of these differences for inter-country comparisons are not clear. Similarly, the use of the APGAR score for comparisons between countries requires further study. Analysing these indicators within key sub-populations, as suggested for other indicators, may be one way to improve comparability. Information on whether preterm births are induced or spontaneous could help us to understand current trends. Collecting the APGAR score by gestational age groups would make it possible to identify the sources of variability in the overall score.

Differences in medical practices are also known to affect health outcomes. For example, screening for congenital anomalies affects mortality rates [14,15]. If screening is widely used within a country and induced abortions follow the detection of anomalies, that country may have a relatively high fetal mortality rate in pregnancies before 28 weeks of gestation, assuming that late terminations are registered as stillbirths. Conversely, countries where anomaly screening is not widespread may have higher fetal mortality rates after 28 weeks or around term, than do countries that screen more widely. Cause of death data help explain these differences. Data from congenital anomaly registries will be necessary for understanding these differences in screening practices.

Differences in medical practices in the care of very preterm babies also have an impact on mortality rates. A European study carried out in 11 countries described the different approaches towards resuscitation of very preterm babies [16]. The proportion of neonatologists who would withhold resuscitation in the delivery room from a 24-week 560 g neonate ranged from 2% in Germany to 63% in The Netherlands. Of those who would resuscitate, opinion would change if the parents opposed resuscitation for 6% in Italy up to 40% in the UK. Even in the same country, different physicians have very different attitudes regarding viability and this clearly affects outcome [17]. Countries that abstain from treatment of very preterm babies may have higher neonatal mortality rates than countries where treatment of very preterm babies is more widely practised. In the latter situation, deaths may often be postponed, sometimes to more than one month after the live birth and will thus not contribute to the neonatal death rate. This illustrates the importance of being able to construct fetal and neonatal mortality rates specific by gestational age and birth weight.

Variations in indicators can also result from differences in quality of care. A European audit of perinatal deaths conducted in regions of 10 European countries recently concluded that suboptimal care was present in almost half of all deaths included in the review [18], but their prevalence varied significantly by country. Although systematic audits of deaths on a European level would be an ambitious undertaking for a health information system, a cause of death classification could be developed that would distinguish between groups of deaths likely to be associated with suboptimal factors. This has been identified as an area for further development in PERISTAT. This review showed that cause of death data are available in many countries.

While this overview shows that Europe can produce a variety of indicators for monitoring the health of its

new-borns, some key dimensions of perinatal health cannot now be measured with routine health statistics. For example, growth restriction is associated with higher mortality and with long-term sequels [18], but Europe-wide standards have not yet been developed; these would need to take into account differences in optimal birth weights in each country [19]. Few data are collected routinely about neonatal morbidity and especially about the longer-term morbidity associated with perinatal events. Data on cerebral palsy should be more widely available for all infants born preterm to study the effects of low gestational age on long-term morbidity, handicap and disability. European collaborations of CP registries have made it possible to provide a European approach to this issue; it is not yet clear how surveillance of this key issue can be implemented on a national level [2,20].

## Appendix A

Data sources used for constructing tables.

Member state	Coverage (if not national)	Data source <sup>a</sup>	Year(s) provided	Abbreviation	Total births where relevant
Austria		Statistics Austria	2001	A1-2001	75,707
Belgium		National Institute of Statistics and Scientific Institute of Public Health	1995	B1-1995	116,122
Belgium	Flanders	Studiecentrum voor Perinatale Epidemiologie (SPE)	2000	B2-2000	62,122
Belgium	French community	Office de la Naissance et de l'Enfance (ONE)	2000	B3-2000	44,328
Denmark		Danish perinatal database	2000	DK1-2000	67,337
Finland		Medical birth registry—STAKES	2000	FIN1-2000	56,768
Finland		Cause of death registry—Statistics Finland	2000	FIN2-2000	
Finland		Hospital discharge register—STAKES	2000	FIN3-2000	
Finland		Register of congenital malformations—STAKES	2000	FIN4-2000	
France	Representative Sample	National Perinatal Survey	1998	F1-1998	13,718
France		INSEE	2000	F2-2000	778,341
France		CepiDC neonatal deaths	1999	F3-1999	
France	Paris	Paris registry of congenital anomalies	2000	F6-2000	39,400 (1999)
Germany	Nine Bundesländer <sup>b</sup> representing 72.6% of all births	BAQ—perinatal survey	2000	D1-2000	558,079
Germany		Federal bureau of statistics Wiesbaden	1999	D2-1999	770,744
Greece	Representative sample	Population based perinatal survey undertaken in 1998	1998	EL1-1998	14,659
Ireland		National Perinatal Reporting System	1999	IR1-1999	54,302
Ireland		Birth Registration System	1999	IR2-1999	54,242
Italy		ISTAT, Civil birth and death registration. Discontinued in 1998	1998	I-1998	533,808

**Appendix A. (Continued)**

Member state	Coverage (if not national)	Data source <sup>a</sup>	Year(s) provided	Abbreviation	Total births where relevant
Luxembourg		National Statistics on Cause of Death	2000	L1-2000	n/a
Luxembourg		FIMENA 2000	2000	L2-2000	5,430
The Netherlands		Merged database from professional registers. LVR: data on course of pregnancy and delivery. LNR: diagnoses of the child, duration of hospital stay, treatments	1999	NL1-1999	201,600
Portugal		Estatisticas Demograficas	1999	P1-1999	120,871
Portugal	75% coverage of national births	Estatisticas de Saude, Instituto Nacional de Estatistica (INE)	1999	P2-1999	
Spain		Voluntary national register of congenital malformations	1999	E1-1999	397,632 (live births)
Spain	Madrid, Valencia, Pais Vasco (74% of births)	National Institute for Statistics (INE)	1999	E1-1999	
Spain		Spanish Society of Neonatology	2000	E2-2000	86,656 (live births)
Spain		ECEMC (Spanish Collaborative Study of Congenital Anomalies)	2000	E3-2000	
Sweden		Medical Birth Register	2000	S1-2000	89,722
United Kingdom	England and Wales	Office for National Statistics. Civil registration.	2000	UK1-2000	607,644
United Kingdom	England	Department of Health, Maternity Hospital Episode Statistics	2000/2001	UK4-00/01	
United Kingdom	Wales	National Assembly for Wales, Child Health System	2000	UK5-2000	
United Kingdom	Scotland	Information and Statistics Division, SMR2 Maternity Discharge Sheet	2000	UK6-2000	52,413
United Kingdom	Northern Ireland	Perinatal Information, Northern Ireland, aggregated data from child health systems	2000	UK7-2000	21,794
United Kingdom	England	Confidential Enquiry into Stillbirths and Deaths in Infancy.*	2000	UK8-2000	
United Kingdom	Wales	All Wales Perinatal Survey	2000	UK9-2000	
United Kingdom	Northern Ireland	Confidential Enquiry into Stillbirths and Deaths in Infancy, Northern Ireland	2000	UK10-2000	
United Kingdom	Scotland	Scottish Stillbirth and Infant Death Survey	2000	UK11-2000	
United Kingdom	England and Wales	National Congenital Anomaly System	2000	UK13-2000	
United Kingdom	Scotland	Scottish Congenital Anomalies Database linking data from SMR1 and SMR11 returns and Scottish Stillbirth and Infant Death Survey	1999	UK14-1999	
United Kingdom	England	Hospital Episode Statistics	2000	UK17	

<sup>a</sup> More detail on data sources available in Macfarlane et al. (this issue).

<sup>b</sup> Bayern, Baden-Württemberg, Berlin, Hessen (data from 2001), Niedersachsen & Bremen, Nordrhein, Sachsen, Thüringen and Westfalen-Lippe.

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