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Perinatal health monitoring in Europe: results from the EURO-PERISTAT project

Short title: Perinatal health monitoring in Europe

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ABSTRACT

Introduction: Data about deliveries, births, mothers and newborn babies are collected extensively to monitor the health and care of mothers and babies during pregnancy, delivery and the postpartum period, but there is no common approach in Europe. We analysed the problems related to using the European data for international comparisons of perinatal health.

Methods: We made an inventory of relevant data sources in 25 EU member states and Norway, and collected perinatal data using a previously defined indicator list.

Results: The main sources were civil registration based on birth and death certificates, medical birth registers, hospital discharge systems, congenital anomaly registers, confidential enquiries and audits. A few countries provided data from routine perinatal surveys or from aggregated data collection systems. The main methodological problems were related to differences in registration criteria and definitions, coverage of data collection, problems in combining information from different sources, missing data and random variation for rare events.

Conclusion: Collection of European perinatal health information is feasible, but the national health information systems need improvements to fill gaps. To improve international comparisons, stillbirth definitions should be standardised and a short list of causes of fetal and infant deaths should be developed.

Key words: data sources, definitions, health monitoring, health statistics, perinatal health indicators, birth and death registration

INTRODUCTION

Information about deliveries, births, mothers and newborn babies is collected to monitor care during pregnancy, delivery and birth, as well as the health of mothers and babies. Despite significant decreases, there are still inequalities in maternal and perinatal mortality between and within the countries of Europe [1]. Changes in clinical practices and new technologies require continual monitoring and assessment. Differences in the timing of developments and health policies make European comparisons important.

Significant groundwork has now been done to lay foundations for a public health monitoring system for Europe since 1999 [2]. An important component of this work has been to identify the most relevant health indicators and data sources for reliable international comparisons. With finance from the Health Monitoring Programme of Commission of the European Union (EU), perinatal statistics were collected and published for 15 EU member states in 2003 [3, 4]. After the enlargement of the EU, a review of perinatal health indicators and data sources was needed with collection of more recent data from all participating countries. In the second phase of the project, 25 member states which belonged to the EU in 2006 participated along with Norway [5].

Our purpose is to list the existing health data sources relevant to perinatal health and describe the availability of data to construct the key perinatal health indicators in 26 European countries. We use this to identify the problems related to international comparison of the most important perinatal health indicators, and discuss the potential for ongoing compilation of perinatal health data and information in Europe.

MATERIAL AND METHODS

Selection of indicators: The EURO-PERISTAT project developed a list of indicators for monitoring and evaluating perinatal health. This project enlisted the assistance of perinatal health professionals including clinicians, epidemiologists, and statisticians from the participating countries to develop and test a recommended list of perinatal health indicators.

A first set of perinatal health indicators was defined and tested for the 15 states which were EU members before the 2004 enlargement [3-4]. An extensive review of existing perinatal health indicators was followed by a DELPHI consensus process, in which a panel of experts responded to a series of questionnaires with the aim of achieving a consensus on key principles or proposals [3]. The first panel included doctors, epidemiologists, and statisticians and the second exercise involved midwives. After the enlargement of the EU, a third DELPHI process was conducted in 2005-2006 including the ten new member states.

A consensus on a list of core and recommended indicators of perinatal health and care was reached in this process. Core indicators are those considered essential for monitoring perinatal health and recommended indicators are those considered desirable for a more complete picture of perinatal health. Additionally, a list of indicators for further development was developed to measure aspects of perinatal health and care which are important but where further work is required before they can be used.

Data collection: The first aim was to gather population-based data at a national level. If these were not available, regional data were accepted if they covered a geographically defined population. Only data from existing routine data sources - either administrative or health registers or statistical systems or regular surveys - were used.

Aggregated data were collected using an Excel-based system in a format that covered the ten core and eleven recommended indicators. Eight indicators for further development were collected, but only three of them are presented here. We asked for data for 2004 or the latest available year prior to 2004, except for maternal mortality for which data for two years were requested.

Data were examined to ensure their consistency and queries were sent to the participating country, if necessary. The indicators were tabulated and sent to the countries for a first review. At a joint project meeting in Warsaw, Poland in April 2008, the outlying values of all indicators were considered and differences in definitions of the indicators were discussed. All countries endorsed the data tables before they were published [5].

RESULTS

Data sources

Each country decided which data sources to use (Table 1). The number of data sources used for each country ranged from one in Slovak Republic to seven in the Netherlands and 17 in the United Kingdom. All data from Belgium related to regions and most data for the United Kingdom related to constituent countries.

A Register-based data sources

1. Civil registration based on birth and death certificates, including causes-of-death certification

All EU member states have a civil registration system that includes all births and deaths. Civil registration is required by law and data are complete for citizens and permanent residents, but many countries exclude non-residents. Countries derived numbers of live births, stillbirths, infant deaths and maternal deaths from civil registration. Some civil registration systems also record background characteristics, such as mother's age, parity, plurality or babies' birthweight. In most countries, only a limited number of variables related to perinatal health are recorded. In all countries, civil registration includes a compulsory medical certification of causes of death, although some countries process this separately.

Birth and death certificate data were linked together to achieve more complete data in three member states (Austria, Estonia and Ireland), two countries of the UK (England and Wales) and in the Brussels region of Belgium. In Scotland, death registration data were linked to birth data derived from hospital records.

Italy's data pose particular problems. Up to 1998, Italy had a birth registration system but it was then dismantled after implementing new data protection legislation. Data collection was subsequently resumed by establishing a medical birth register, run by the Ministry of Health instead of the National Institute of Statistics [6]. This caused some organisational problems, and the new system covered only 84% of births in 2003. Weighted statistics were calculated to make estimates relating to the total number of births.

2. Medical birth registers and perinatal databases

Seventeen of our study countries and regions have a medical birth register to monitor maternal and perinatal health (Table 2). Data provision is mandatory with the exception of four registers. Medical

birth registers include all births in the registration area irrespective of nationality, citizenship or residence. Midwives, nurses or doctors at local level usually contribute information to the register from the delivery hospitals, either on a separate data collection form or directly from electronic patient record systems. Six registers were exclusively hospital-based, while the remaining registers also included home births. The coverage of medical birth registers was high. Linkage to birth and death data from civil registration can make their coverage nearly complete, and is useful for cross-checking and assessing the completeness of data collection. Linkage to death certificates is essential for obtaining information about deaths after discharging the baby from the hospital.

The medical birth registers contain the data needed to construct most of the core and recommended indicators included in our exercise. These included parents' background, especially the mother's, clinical diagnoses, care and interventions during pregnancy and delivery, and data about babies' health, clinical diagnoses and the care and interventions they received.

Usually, medical birth registers consist of a single register. The Netherlands has three professional-based registers, however, with separate national registers to record the perinatal care given by midwives, general practitioners, obstetricians and neonatologists. All are overseen by the Netherlands Perinatal Registry [7].

Most medical birth registers have been introduced for statistical or health monitoring purposes. In Germany, however, the data collected are used as a basis for benchmarking individual obstetric units on a range of performance indicators. These indicators are compiled on an annual basis and reflect quality of clinical care and obstetric outcome in terms of unit-specific rates. Follow-up measures are taken when national targets are not met [8].

3. Hospital discharge systems

Most European countries have a hospital discharge system to record information about all hospital care, including all hospital births, and 11 countries used these systems to provide perinatal health information. Information about uncomplicated home births is usually not included. In some systems, information about mothers and babies discharged on the day of delivery may be missing, especially if an overnight stay is used as an inclusion criterion. Some countries may exclude hospital care in private institutions, but this causes coverage problems only, if the percentage of childbirths in private institutions is high (Cyprus and Portugal).

Hospital discharge systems usually include information about all hospital births and interventions during hospital stay, such as caesarean sections or instrumental deliveries. They may also include mothers' diagnoses during pregnancy and birth, readmissions after delivery, and interventions. Hospital discharge systems also contain information about babies, including care and diagnoses before they are discharged. The information recorded usually applies only to specialised hospital care, and data about the use of primary and community health care services are not included.

The primary purposes for setting up a hospital discharge system are usually financial, planning or other administrative reasons. The data items may therefore not be standardised for health monitoring and epidemiological surveillance. Financial incentives may also lead to bias for diagnoses and surgical procedures, if more severe conditions will tend to bring a higher remuneration to the hospital.

Hospital data may result in overestimates in incidence and prevalence rates if the discharge information does not have a unique personal identifier, which enables linkage of successive care

episodes of the same person. It can, however, be used for data related to delivery and birth as such records should be included only once. Furthermore, data may not distinguish between confirmed and suspected diagnoses, which can lead to overestimated rates, for example for congenital anomalies.

4. Other registers

Other registers which are used for monitoring perinatal health are congenital anomaly registers (used in five countries and four regions), many of which are included in the European Surveillance of Congenital Anomalies (EUROCAT) [9] and thus have standardised definitions and recording procedures. Information on abortions for congenital anomalies is available from some of these registers. Specific systems for induced abortions exist in some countries, for example in Estonia, Italy and the United Kingdom (excluding Northern Ireland, where the legislation allowing termination of pregnancy does not apply).

B Survey data

1 Perinatal surveys

In our study, three countries used regular surveys to collect perinatal data. In France, surveys of all births in one week were conducted in 1995, 1998 and 2003, and the next one is planned for 2010. Coverage is good, up to 99% [10]. In Spain, a 10% annual sample of all pregnancy summary sheets is collected to supplement the information from civil registration. Since 2000-2001, the Italian statistical authority has annually collected information from a 10% sample of all live births.

The content of perinatal surveys is similar to that of Medical Birth Registers, but compared with routine systems it is easier to add or remove questions. This is also a good method for gathering timely information on perinatal health in the countries and regions where routine data collection is limited. The main limitations are related to response rates, sample size and the inability to monitor rare events, such as death.

2 Confidential enquiries and audits

Confidential enquiries or audits can provide complete case information about specific adverse events, such as stillbirths, maternal or infant deaths or 'near misses'. These use detailed anonymised case information data to assess whether substandard care or other avoidable factors may have contributed to maternal death, stillbirth or infant death. In France and the Netherlands, audits cover maternal deaths and in the Netherlands perinatal deaths. In United Kingdom, the perinatal death enquiries collect information about late fetal deaths at 22 and 23 weeks of gestation, as the legal limit for stillbirth registration is 24 completed weeks of gestation. Confidential Enquiries into Maternal Deaths Confidential Enquiries into Maternal Deaths are also conducted in the United Kingdom.

3 Other routine surveys

The other surveys used in this data collection exercise covered specific health themes, particularly antenatal care and infant feeding and other areas which are not covered by routine data collection systems. For example in the United Kingdom, the Infant feeding survey, which also includes data on other behaviours, e.g. maternal smoking and drinking before or during pregnancy is conducted every five years from a sample of all women who gave birth. In the Netherlands, the Infant feeding

survey has been carried out every year since 2001. The Polish survey collects information on women's experiences of childbirth and opinions of the care provided. This survey also includes questions about parents' socio-demographic characteristics and lifestyles, including smoking during pregnancy.

C Aggregated data sources

Four countries supplied information from systems based on aggregated data. In Estonia and Poland, the Ministries of Health and of Social Affairs, respectively, collect aggregated information from hospitals on morbidity incidences. Similarly, the Czech Society of Perinatal Medicine and the Hungarian Institute for Obstetrics and Gynaecology collect aggregated information from hospitals about care at delivery. Collection in aggregated format can be the fastest method for gathering perinatal health information, but this approach may also be very inflexible as data needs can change after the original data have been collected. In some countries, such as Estonia, aggregated data complement perinatal data based on individual records.

Data availability

All countries provided information for the project. Figure 1 and Appendix (electronic version only) presents the number of countries that provided each of the requested EURO-PERISTAT indicators. In general, availability was good for the core indicators. Approximately 20 out of 29 countries and regions provided the data for the core indicators and three countries provided them either partially or using different methods. Almost all were able to provide information on the distribution of gestational age, birthweight, mother's age, and on the number of multiple births (25-28/29 countries or regions). Data to derive stillbirth rates were available for most countries and regions, although

their inclusion criteria varied. All countries had at least some information on neonatal mortality. Fewer could provide data on infant mortality by gestational age, birthweight and plurality and on maternal mortality by mode of delivery.

The recommended indicators were less widely available. On average 13 out of 29 countries and regions provided data in the form requested and a further seven were able to produce data either partially or in a different form, while nine were unable to provide the data. The majority of countries and regions (17-19/ 29) had data on Apgar score, maternal mortality by cause of death, place of birth and maternal smoking. Fewer countries could provide data on breastfeeding at birth, births after sub-fertility management and mother's maternal education in the form requested.

Information about the indicators for further development was available in the requested form from an average of seven countries and regions and partially or in a different form from a further seven.. Data on episiotomy were available from 12 countries and regions, and data on congenital anomalies as a cause of fetal and neonatal death were available from 11. In total 15 countries and regions had data about at least one of the five aspects of severe maternal morbidity, as defined in the Appendix, but none of them had information about all of them.

Issues complicating international comparisons

1. Registration criteria

In our data collection exercise for 2004, data were requested for all stillbirths and live births at or after 22 completed weeks of gestation, but some countries had different criteria for the registration of stillbirths, and some had different criteria for the registration of live births (Table 3). The WHO

criteria specify that stillbirth statistics should include fetuses with a birthweight of 500 g or, if the information on birthweight is missing, with a gestational age of 22 weeks [11]. The legal limit for registration of stillbirth was at the time of data collection higher than 22 weeks in 8 countries: 24 weeks in Hungary, Portugal and the United Kingdom, 25 weeks and 5 days in Italy, Luxembourg and Spain, and 28 weeks in Greece and Sweden.

In Italy, although the legal limit for registration of stillbirths of 25 weeks + 5 days, fetal deaths below this limit are recorded in a separate spontaneous abortion register, enabling derivation of stillbirth rates in line with WHO recommendations. In Spain, regional data collections may use different criteria. In all four countries of the UK, data on late fetal deaths at 22 and 23 weeks of gestation are reported voluntarily.

In some countries, registration practices may differ from the legal registration criteria. Civil registration data for Greece include stillbirths with a gestational age of less than 28 weeks. In Luxembourg, the limit is 25 weeks and 5 days for civil registration and 28 weeks for the Medical Birth Register, but births at lower gestational ages are often included. Norway and the Netherlands have registration criteria at gestational ages lower than the WHO recommendation, 12 and 16 weeks of gestation, respectively. If the criteria are more inclusive and the recording of gestational age and birthweight is complete, then data complying with WHO can be derived.

In some other countries, the legal limits for civil registration of births can differ from the criteria for inclusion in medical birth registers or other data collection systems. In the Czech Republic, fetal deaths must be registered from 22 weeks of gestational age and these data were provided, but they are only registered as 'births' if the fetus weighs 1000 grams or more. In Ireland, data from the Central Statistics Office include stillbirths at 24 weeks of gestational age or more or with

birthweights of 500 grams or more, whereas the only inclusion criterion in the National Perinatal Reporting System (NPRS) is a birthweight of 500 grams or more.

Another important issue relates to whether late terminations of pregnancy are included in the number of fetal deaths. In some countries terminations of pregnancy are included in their registers of fetal deaths, while in others these are recorded separately. In some countries, the data on late terminations are of low quality, or they are not recorded. Denmark, Germany, Italy, and Norway did not include terminations of pregnancy as fetal deaths and therefore their stillbirth rates were underestimated.

Most countries had no limits for the registration of live births. The Czech Republic and Poland had a 500 gram limit, and France and the Netherlands had a limit of 22 weeks of gestational age or a birthweight of 500 grams, if gestational age is unknown. In Luxembourg, the criterion for the inclusion of birth in the national birth register remains 28 weeks of gestational age, but in practice, babies born at lower gestational ages are registered under this limit, but not systematically. There is no lower limit for live birth registration in Ireland, but the National Perinatal Reporting System (NPRS) has a limit of 500 grams. Finally, Malta has no limit for live birth registration in its National Obstetrics Information System, but a limit of 22 weeks or 500 grams in the National Mortality Register.

2. Coverage of data collection

Civil registration and health registration systems may have different inclusion criteria for non-residents. Civil registration usually includes citizens and permanent residents only, while health registration is likely to include all events in registration area. For example all births will be included

regardless of babies' or their parents' nationality or residence status. This can cause discrepancies even for basic data, such as total number of births. This is particularly likely for countries with large numbers of people without permanent residence status: immigrants, refugees, asylum seekers, visitors and seekers of health care services from other countries. Civil registration may also include information on citizens' births in other countries.

Hospital-based data collection systems may exclude planned births outside hospitals, births without an overnight stay, accidental home births and births on the way to hospital, unless special data collection arrangements. In addition, hospital discharge registration systems may not link data about delivery care given in neonatal units. If data collection is required only for public hospitals, then there may be no data or only incomplete data from private hospitals or practitioners.

3. Data collection using non-standard definitions

Some national data systems could not provide information in line with our recommendations. There were problems in identifying data according to whether they related to women giving birth, deliveries, total births, live births and babies. Some data were available only for live births rather than all births, and some data contained information for all births or babies, but not for singleton and multiple births separately.

Countries differed in their conventions for calculating indicators. For example neonatal and infant mortality rates can be calculated either by birth cohort (infant deaths being tabulated by year of birth and linked to data about birth in a given year data), or alternatively as a death cohort (number of deaths occurring in a given year divided by the number of births occurring in the same year).

Both methods give similar estimates unless the numbers of births or deaths are changing

substantially from year to year. Where countries can use either method, an international recommendation should be established.

Maternal smoking was also recorded using different definitions. Data could be for seven different time periods: before pregnancy, at the start of pregnancy, during the first trimester, after first trimester, during the third trimester, at delivery and throughout the entire pregnancy.

4. Denominators and numerators

In some cases, the denominators and numerators came from different datasets, which led to discrepancies and inaccuracies, for example in gestational age and birthweight-specific mortality rates. In some cases, particularly near the lower limit for reporting and ascertainment, numerators were too low and the rates approached zero. Alternatively the numerators were higher than the denominators and the rates exceeded 1000 per thousand. In these cases, the rates of 1000 per thousand were substituted.

5. Missing data

Ideally, missing data ('not known') should be given as a separate category, but this is not always the case. Where data were stated to be missing in our data exercise, we systematically excluded cases with missing data from calculations of rates and percentages in order to minimise bias.

6. Random variation

The basic aim was to gather national data. France, Germany, Italy and the United Kingdom are the biggest EU member states with more than half a million births per year each. In contrast, there are only about 4000 birth per year in Malta, 5500 in Luxembourg, and 8000 in Cyprus. In addition, Estonia, Slovenia, and Brussels region in Belgium have a relatively small numbers of births each year, ranging between 13 000 and 18 000. Data for three to five years have to be combined to estimate the frequency of rare events or outcomes with any degree of statistical reliability. The same consideration applies to survey data. For example the sample size in the French national surveys is similar to the numbers of births in Estonia and Slovenia. Confidence intervals are therefore recommended to show the statistical variability in the estimates in relation to sample sizes.

DISCUSSION

The strengths of our data collection exercise were the standardised definitions and attempts to compile aggregated data consistently. Most countries were able to contribute national data. All data were carefully checked to optimise the comparability between countries. Most countries were able to provide information for the year 2004 to construct the majority of core and recommended indicators. Mortality data were available for most countries, but many did not have data about morbidity in mothers and babies or about social factors, such as mothers' education. Further data collection would be needed to fill these observed information gaps. This is true for all countries, since none of them were able to provide information on all requested perinatal health indicators.

One limitation was the time it took for compilation and validation of the data. As a results, the data were already becoming out of date when released in 2008 [5]. Furthermore, we had to rely on the knowledge of the project's scientific committee members. They may have missed some relevant data sources, or had better knowledge of their local or regional data collection systems than of their

national data collection systems. In countries governed on a federal basis, data collected routinely at regional level may not be aggregated at the national level. Our project did not seek out data from these regional sources, even though some of them have been used in other EU projects [12]. Our experience suggests that having decentralised data collection systems makes it difficult to obtain data at a national level and thus inhibits public health monitoring in Europe.

It is now over ten years since the work on developing a set of perinatal health indicators was started, and the current list dates from the period after the 2004 enlargement of the EU. Further updating of the indicator list will be needed to reflect factors, such as new policy priorities, emerging evidence and information needs and developments in medical technology. A redefinition of the division between core and recommended indicators may be needed, developments in national data collection systems may provide new data, and the international availability of indicators which are now categorised as indicators for further development has to be investigated. Close links with groups developing other relevant indicator sets should be established. For example, the EU funded REPROSTAT group has proposed and tested a set of 18 indicators, some of which are very relevant to perinatal health [13, 14].

Standardising the definition of stillbirths is still a priority for international comparisons [15]. If national legal criteria and/or data collection practices cannot be harmonised, suitable steps should be taken to collect data in a way which will enable comparable rates to be constructed for international purposes. The current WHO recommendation [11] to include only fetuses weighing at least 1000 grams in international comparisons is no longer relevant for developed countries that have high survival rates for babies born weighing less than 1000 grams. To achieve comparable reporting on mortality, data on birthweight and gestational age should be included in all data collection systems.

A short list of causes or risk factors for fetal and neonatal deaths should be developed for international comparisons [16]. Detailed information about the coding process used to derive the main cause of death for stillbirths and neonatal deaths should be compiled and analysed [17]. There can be differences in the professions which are responsible for completing the certificates, the data checking procedures and post-mortem examination rates, but the biggest differences are in the format used for the medical causes of death and the ways in which these are coded.

We did not systematically collect information about the quality of the data from national and regional sources. For example, previous studies have identified data problems which can make the ascertainment of maternal and pregnancy-related deaths incomplete [18]. Comparison to other published international statistics [1] show the data on total numbers of births and infant deaths were complete and comparable, but data on morbidity and mothers' social and demographic background were incomplete and less comparable. It was also difficult to compare rates of selected congenital anomalies. As well as differences in ascertainment, many countries did not provide these data according to the EUROCAT inclusion criteria [9], which are to include events at or after 20 completed weeks of gestation including terminations of pregnancies. The inconsistencies we have identified point to the need for national and regional perinatal health information systems to review and monitor their data quality. Continuing international collaboration is needed to refine the definitions and data collection methods.

Although it might be expected that national health information systems improve over time, there are a number of examples of setbacks, as shown for Italy [6]. In France, the registration of stillbirths has been incomplete since 2008 as a consequence of a decree on parent's rights. As a result, it is no longer possible to derive accurate stillbirth and perinatal mortality rates [19].

We did not set out to assess which type of data collection system would be best for compiling data about perinatal health and care. There were no signs of any link between the completeness of data collection and whether the data collection system was based on individual records, aggregated reports or sample surveys. Also it did not seem to matter whether the system was statutory or voluntary and whether data collection was centralised or decentralised. Up to 100% coverage can be achieved in voluntary systems with good incentives, such as tailored feedback to hospitals and making data available to hospitals and researchers. On the other hand, our exercise suggested that some statutory systems may have poor coverage and contain unreliable statistical information.

Most of the data used to compile our indicators came from systems which contained individual level data. These included vital registration systems, birth registers and other health registers. Such systems often proved to have data which were of higher quality and wider scope than systems with aggregate data. Collection of data at an individual level requires appropriate legislation about population and health registers since written informed consent can seldom be obtained from all women who give birth. It should be noted that the EU directive on personal data does not preclude this type of data collection, although there are differences in the ways in which this directive has been interpreted [20].

The scope and range of data can be enhanced by linking data from different systems. If the country has a system of unique identifiers and these are attached to all records this facilitates data linkage, but even without personal identifiers, records can be linked using probability matching [21]. Data linkages may be impeded by administrative barriers, costs or data protection regulations. These are problems to be resolved within member states, although it would be useful to discuss the major obstacles at a European level, for example in EUROSTAT or the DG Health and Consumers.

If the number of variables in the civil registration system is limited and no medical birth register or hospital discharge registration system exists then it is useful to do regular population-based surveys of pregnant women and their new babies to fill in the information gaps. This is done regularly in France [10] and less frequently in Greece [22]. Cyprus is currently setting up a survey, but the data were not yet ready at the time our data collection was completed. Regular surveys are more flexible than routine data systems in their capacity to add new questions, but they face same problems as any other surveys, such as the risks of response, research, report and other types of bias.

The European Union does not have a functioning health information or health monitoring system, although the European Community Health Indicator Monitoring (ECHIM) system which aims to collect, analyse and report key indicators from all EU member states is being developed [2].

International organisations, such as EUROSTAT, OECD and WHO, have routine data collection systems, but these include relatively few perinatal health indicators. Collection of these data has been undertaken only for one-off EU-funded projects [5, 17, 23]. Specialised data collection initiatives are key components of perinatal health monitoring. These include the EUROCAT data collection on congenital anomalies which was established in 1979 [9] and the Surveillance of Cerebral Palsy (SCPE) collaboration which was established in 1998 [24]. As with EUROPERISTAT, these activities rely on intermittent funding.

Once the ECHIM system is established, a number of public health sub-themes should be selected for data collection on European level. These sub-themes should include perinatal health, since our project has shown that it is feasible to collect the key perinatal health indicators. Essential questions still remain. These include how and how often to collect such data, and which organisations should be responsible for collecting, analysing and reporting them. Either the Commission of European

Union (DG Health and Consumers or EUROSTAT) or its institutes (e.g. European Centre for Disease Prevention and Control, ECDC) could take responsibility or a new organisation could be launched in the form of a European Perinatal Health Monitoring Centre. The data collection and reporting task could also be commissioned through a tender or grant application with funding from the EU Health Programme. The best solution might be to give this responsibility to a virtual, but permanent, European Perinatal Health Monitoring Centre with national correspondents in each EU member state to ensure continuity, sustainability and high quality.

Health monitoring activities should be complemented by active research networks to analyse the existing perinatal data, to collect more detailed information, for example by approaching medical birth registers for information on more specialised topics and to develop new indicators and data collection methods. At a European level, there are good arguments for collaboration in audits of perinatal and maternal deaths and of rare events or outcomes [25-26].

CONCLUSION

The European Perinatal Health Report was unique. It marked the first time that we have been able to look in depth at comparative statistics on perinatal health in Europe. This exercise is complex because the information systems in European countries differ greatly. It is essential to understand the variety in definitions, inclusion criteria and population coverage and the impact that this can have on indicator values. Improved international comparisons often required updated national health information systems.

Contemporary trends in perinatal health are characterised by dramatic changes in demographic structure paired with declining public resources across all of Europe. These changes as well as the

2007 and future EU enlargement require a flexible information system which can integrate new health priorities and institutional changes. Sustainable ways to collect, analyse and disseminate updated perinatal health information will be essential for policy makers of the future.

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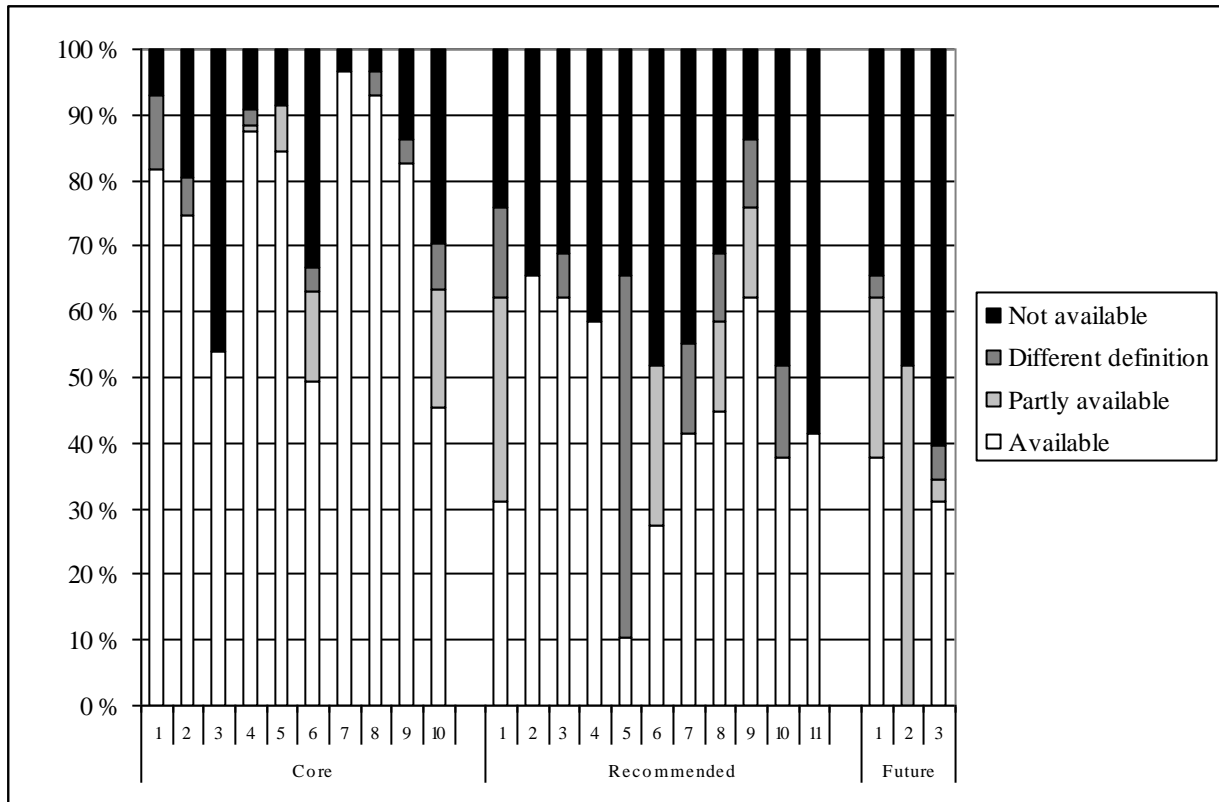
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Figure 1: The availability of European perinatal health indicators, % (for paper version)



Core indicators

- 1 Fetal mortality by gestational age, birthweight and by plurality
- 2 Neonatal mortality by gestational age, birthweight and by plurality
- 3 Infant mortality by gestational age, birthweight and by plurality
- 4 Distribution of birthweight, total and by gestational age
- 5 Distribution of gestational age, total and by plurality
- 6 Maternal mortality, total, by maternal age and by mode of delivery
- 7 Multiple births
- 8 Distribution of maternal age
- 9 Distribution of parity
- 10 Mode of delivery, total and by parity, previous Caesarean section, presentation of fetus and plurality

Recommended indicators

- 1 Prevalence of congenital anomalies
- 2 Distribution of Apgar score at 5 minutes
- 3 Maternal mortality by cause of death
- 4 Women who smoke during pregnancy

- 5 Mother's education
- 6 Births after fertility treatment
- 7 Timing of first antenatal visit
- 8 Mode of onset of labour
- 9 Place of birth
- 10 Breastfeeding at birth
- 11 Very-preterm births by level of care

Further development indicators

- 1 Congenital anomalies as a cause of fetal and neonatal death
- 2 Severe maternal morbidity: Eclampsia, ICU admission, blood transfusion, hysterectomy and embolisation
- 3 Trauma to perineum: episiotomy, vaginal tears

Table 1: Main sources of perinatal health data in 25 EU countries and Norway

Country	Register data				Survey data			Other	
	Number of live births 2004	Civil registration	Medical birth register	Hospital discharge registration system	Congenital anomaly register	Perinatal health survey	Confidential enquiry ¹	Other routine surveys	Aggregated data
Austria	78 934	x		x					
Belgium									
- Brussels	16 200	x							
- Flanders	60 672		x						
- Wallonia	Not available								
Cyprus	8 309	x		x					
Czech Republic	97 664	x	x						x
Denmark	64 521		x	x					
Estonia	13 990	x	x						x
Finland	57 569	x	x	x	x				
France	767 816	x		x	(regional)	x	x		
Germany	705 622	x	x	x					
Greece	104 335	x							
Hungary	95 131	x			x				x
Ireland	62 066	x	x						
Italy	539 066	x	x	x		x			
Latvia	20 355	x	x						
Lithuania	29 480	x	x						
Luxembourg	5 469	x	x						
Malta	3 887	x	x		x				
Netherlands	181 006	x	x		(regional)		x	x	
Poland	356 697	x		x	(regional)			x	x
Portugal	109 356	x		x					
Slovak Republic	52 388		x						
Slovenia	17 846	x	x						

Spain	454 591	x		x		x		
Sweden	100 158	x	x					
United Kingdom								x
- England		x		x	x		x	x
- Wales	639 721	x		x	x		x	x
- Northern Ireland	22 362	x					x	x
- Scotland	52 911	x		x	x		x	x
Norway	57 111		x		x			

1 Covering a) maternal deaths in France, the Netherlands and the four countries of UK b) Perinatal deaths in the Netherlands c) Stillbirths and infant deaths in Scotland and stillbirths in England, Wales and Northern Ireland.

2 Excluding the following register: the Fertility Register of the Danish Fertility Society, the Metabolopathies Register (on metabolic diseases) in Spain, the Neonatal Intensive Care Outcomes Research and Evaluation (NICORE) in Northern Ireland, UK, Child Health System in Wales, UK, and the UK Human Fertilisation and Embryology Authority Register.

Table 2: Medical Birth Registers in the 25 EU countries and Norway

Country (region)	Registration starts	Coverage	Completeness ¹	Type of register	Register keeper
Belgium - Flanders	1987	Hospital-based	100%	Voluntary	Research institution
Czech Republic	1999	Hospital-based	100%	Obligatory	Statistical authority for health information
Denmark	1973	Population-based	More than 97%	Obligatory	Health authority
Estonia	1992	Population-based	Unknown	Obligatory	Public health institution
Finland	1987	Population-based	99.9%	Obligatory	Statistical authority/research institution
Germany	2002	Hospital-based	100%	Obligatory	Non-profit corporation
Ireland	1985	Population-based	100%	Obligatory	Research institution
Italy	2002	Population-based	84%	Obligatory	Health authority
Latvia	1999	Population-based	100%	Obligatory	Statistical authority for health information
Lithuania	1993	Hospital-based	100%	Obligatory	Statistical authority for health information
Luxembourg	1980	Population-based	Excellent	Voluntary	Health authority
Malta	1999	Population-based	100%	Voluntary	Statistical authority for health information
Netherlands	1982	Hospital/population	90-95%	Voluntary	Research institution
Norway	1967	Population-based	100%	Obligatory	Public health institution/University
Slovak Republic	1996	Hospital-based	100%	Obligatory	Statistical authority for health information
Slovenia	1987	Hospital-based	99.9%	Obligatory	Public health institution
Sweden	1973	Population-based	100%	Obligatory	Health authority/statistical authority

¹ Assessment by data provider.

Table 3: Lower limits for registration of stillbirths and live births in 2004

Country/coverage	Lower limits for registration	
	Stillbirths	Live births
Belgium ¹		
Flanders	≥ 500 g	No limit
Brussels	≥ 22 weeks or ≥ 500 g	No limit
Czech Republic	≥ 22 weeks, official registration at 1000g	≥ 500 g or any birthweight surviving first 24 hours
Denmark	≥ 22 weeks	No limit
Germany	≥ 500 g	No limit
Estonia	≥ 22 weeks or ≥ 500 g	No limit
Ireland	≥ 24 weeks or ≥ 500g for civil registration, ≥ 500g for the national perinatal register	No limit for civil registration, ≥ 500 g for the national perinatal register
Greece	≥ 28 weeks	Not available
Spain	180 days (25 weeks + 5 days)	No limit
France	≥ 22 weeks or ≥ 500 g	≥ 22 weeks or ≥ 500 g
Italy	Registered at 180 days (25 weeks + 5 days), but fetal deaths at 22-24 weeks are available in register of spontaneous abortions	No limit
Cyprus	No register of stillbirths	No limit
Latvia	≥ 22 weeks	No limit
Lithuania	≥ 22 weeks or ≥ 500 g	No limit
Luxembourg	Official civil registration at 180 days (25 weeks + 5 days). For birth registry, recommendation is 28 weeks, but many nurses and doctors report babies with lower gestational age	Official civil registration at 180 days (25 weeks + 5 days). For birth registry recommendation is 28 weeks, but many nurses and doctors report babies with lower gestational age
Hungary	≥ 24 weeks	No limit
Malta	≥ 22 weeks or ≥ 500 g	No limit for National Obstetrics Information System, ≥ 22 weeks or ≥ 500 g for National Mortality Register
Netherlands	≥ 22 weeks or ≥ 500 g, if GA is unknown	≥ 22 weeks or ≥ 500 g, if GA is unknown
Austria	≥ 500 g	No limit
Poland	≥ 500 g	≥ 500 g
Portugal	No limit	No limit

Slovenia	≥ 500 g	No limit
Slovak Republic	≥ 22 weeks	No limit
Finland	≥ 22 weeks or ≥ 500 g	No limit
Sweden	≥ 28 weeks	No limit
United Kingdom	≥ 24 weeks is the legal limit, but voluntary notification at 22 and 23 weeks	No limit
Norway	≥ 12 weeks	≥ 12 weeks

1 Information from Wallonia missing.

Appendix: The availability and main data sources of all indicators (electronic version only)

Indicator	Availability in (nr of countries ¹)				Main data sources
	Yes	Partly	Different definition ²	No	
<u>Core Indicators</u>					
1 Fetal mortality by gestational age	25	0	3	1	Medical Birth Register, Death certificate data
Fetal mortality by birthweight	23	0	4	2	
Fetal mortality by plurality	23	0	3	3	
2 Neonatal mortality by gestational age	21	0	2	6	Medical Birth Register, Death certificate data
Neonatal mortality by birthweight	23	0	1	5	
Neonatal mortality by plurality	21	0	2	6	
3 Infant mortality by gestational age	14	0	0	15	Medical Birth Register, Death certificate data
Infant mortality by birthweight	18	0	0	11	
Infant mortality by plurality	15	0	0	14	
4 Distribution of birthweight, all births	24	0	2	3	Medical Birth Register
Distribution of birthweight by gestational age	26	0	0	3	
Distribution of birthweight by plurality, live births	26	1	0	2	
5 Distribution of gestational age, all births	24	2	0	3	Medical Birth Register
Distribution of gestational age, by plurality, live births	25	2	0	2	
6 Maternal mortality	20	4	1	4	Cause-of-death Register, Confidential enquiry
Maternal mortality by maternal age	17	3	1	8	
Maternal mortality by mode of delivery	6	5	1	17	
7 Multiple births	28	0	0	1	Medical Birth Register, Death certificate data
8 Distribution of maternal age	27	0	1	1	Medical Birth Register, Death certificate data
9 Distribution of parity	24	0	1	4	Medical Birth Register, Death certificate data
10 Mode of delivery	15	9	2	3	Medical Birth Register
Mode of delivery by parity	12	6	2	9	
Mode of delivery by previous Caesarean	11	2	2	14	
Mode of delivery by presentation of fetus	13	4	2	10	
Mode of delivery by plurality	15	5	2	7	
<u>Recommended Indicators</u>					
1 Prevalence of congenital anomalies	9	9	4	7	Medical Birth Register, Register on Congenital Anomalies, Hospital Discharge Register
2 Distribution of Apgar score at 5 minutes	19	0	0	10	Medical Birth Register, Death certificate data

3	Maternal mortality by cause of death	18	0	2	9	Cause-of-death Register, Confidential enquiry
4	Women who smoke during pregnancy	17	0	0	12	Medical Birth Register, Death certificate data
5	Mother's education	3	0	16	10	Medical Birth Register, Death certificate data
6	Births after fertility treatment	8	7	0	14	Medical Birth Register, Birth certificate data, ART Register
7	Timing of 1st antenatal visit	12	0	4	13	Medical Birth Register, Death certificate data
8	Mode of onset of labour	13	4	3	9	Medical Birth Register, Death certificate data
9	Place of birth	18	4	3	4	Medical Birth Register, Death certificate data
10	Breastfeeding at birth	11	0	4	14	Medical Birth Register, Separate surveys
11	Very-preterm births by level of care	12	17	Medical Birth Register, Birth certificate data

Further Development Indicators

1	Congenital anomalies as a cause of fetal and neonatal death	11	7	1	10	Cause-of-death Register
2	Severe maternal morbidity (5 causes ³)	0	15	0	14	Medical birth Register, Hospital Discharge Register
3	Trauma to perineum: episiotomy	12	0	2	15	Medical birth Register, Hospital Discharge Register
	Trauma to perineum: vaginal tears	6	2	1	20	

1 Total number of countries = 29. Flanders and Brussels, as well as England and Wales (combined), Scotland and Northern Ireland counted separately.

2 Either available as requested or partly available, but with different definitions.

3 Eclampsia, ICU admission, blood transfusion, hysterectomy and embolisation