Better statistics for better health for mothers and babies in Europe

A road map for sustainable perinatal health reporting
(Deliverable n° 2)

by the

Euro-Peristat Network

Revised May 2014

Our justification

The burden of mortality and morbidity in the perinatal period – pregnancy, childbirth, and the postpartum – remains a major concern in Europe. Over 5 million women deliver babies in European countries every year. . A healthy pregnancy and infancy confers long-lasting benefits by preventing death, illness and disability in childhood, and reducing risks of adult physical or psychological illnesses and distress, including chronic diseases such as diabetes and hypertension. High quality information is needed to support evidence-based decision-making in order to improve the health of pregnant women and newborns.

A European perinatal health information system is strongly justified from a public health and health care delivery perspective for multiple reasons.

➤ European countries face common challenges and benefit from pooling their experiences. Some risk factors for poor perinatal health, such as older age at childbirth or maternal obesity, are increasing in all countries. Questions about the optimal use of new health technologies are of concern everywhere. Understanding how neighbouring countries structure their healthcare systems and policies to manage these risks provides essential information for the development and evaluation of national and European policies.

➤ Great diversity in cultural, social, and organisational approaches to childbirth and infant care exists within Europe and raises important questions about the best use of healthcare interventions and the quality of care. Care and outcome data are essential benchmarks for assessing the achievements and failings of these diverse models of care and identifying possible gains in efficiency and cost.

➤ European countries face similar economic and demographic pressures and share an interest in monitoring their impact on women and babies. Many European countries are experiencing low fertility rates and investing in young families and children is a priority.

Our Aim

The objective of our Network is to establish a high quality, innovative, internationally recognized and sustainable European perinatal health information system. This system's goal is to produce data and analysis on a regular basis for use by national, European and international stakeholders who make decisions about the health and health care of pregnant women and newborns.

Our scope

- Maternal and infant mortality and morbidity associated with pregnancy, delivery and the post-partum as well as the longer term consequences of perinatal events.
- Risk factors for adverse perinatal health outcomes, including demographic, socio-economic and behavioural characteristics of the population.

- Health services and medical practices for the care of women and babies during pregnancy, delivery and the postpartum period.

Our target groups

Our ultimate target group is the more than 5 million pregnant women and their newborns in Europe every year whose health will benefit from the development of a health information system to support informed decision-making about health practices and policies.

These decisions are made by diverse stakeholders who need reliable information, including clinicians (obstetricians, neonatologists, midwives, and neonatal nurses), policy makers in health ministries, maternal and child protection offices, and insurance and quality assurance agencies as well as pregnant women and their families.

Our Network

Our network includes partners from 29 European countries – 26 within the EU and Iceland, Norway and Switzerland. It includes one official member from each country who serves as the scientific committee (SC) representative. However, most countries have constituted teams with participation from multiple actors – clinicians, epidemiologists and statisticians who provide expertise and data for the project. Members of these teams participate in Network meetings and studies. The list of SC members and the composition of country teams can be accessed on our website: http://www.europeristat.com/our-network/country-teams.html.

Our network welcomes new members and is continually expanding.

Our indicators

Euro-Peristat indicator set includes 10 core and 20 recommended indicators which were developed by a multidisciplinary panel of health professionals from 29 European countries. The indicators are grouped into four themes: fetal, neonatal, and child health, maternal health, population characteristics and risk factors, and health services. Core indicators are those that are essential to monitoring perinatal health, while recommended indicators are considered desirable for a more complete picture of perinatal health across European countries.

The indicators were developed using a series of successive DELPHI consensus procedures after a review of existing perinatal health indicators helped us to develop an initial list of candidate indicators. Euro-Peristat enlisted the assistance of perinatal health professionals (clinicians, epidemiologists, midwives and statisticians) from 29 European countries, and consulted with other networks, notably SCPE (a network of European cerebral palsy registries), ROAM (Reproductive Outcomes and Migration Collaboration), and EUROCAT (a network of European congenital anomaly registries). Euro-Peristat has collected data on these indicators three times (on the years 2000, 2004, 2010) proving their feasibility and sustainability.

Detailed definitions of our indicators are available on our website.

<u>Our vision for sustainable perinatal health reporting</u>

A sustainable perinatal health reporting system should include three core components:

- An active network of clinicians, epidemiologists, statisticians and public health professionals working with routine perinatal data that meets regularly to provide scientific expertise and oversight.

- Collection of data on Euro-Peristat indicators from statistical systems in European member states on a regular basis. The collection process should include data quality checks and internal and external validation.

- Reporting on geographical variations and temporal trends in Euro-Peristat perinatal health indicators and interpreting these variations with input from perinatal and public health professionals and other key stakeholders from participating countries.

Other activities are also essential:

- Providing recommendations about how to collect and present data on perinatal health indicators, including guidelines for collection of data, definitions of items and recommended output tables.

- Updating the Euro-Peristat indicator list and developing new indicators.

- Advocating for better data systems by outreach to governments, European institutions and professional/scientific organisations.

- Carrying out research using the Euro-Peristat indicators and producing scientific publications using the routine data that are collected as part of Euro-Peristat.

- Collaborating with other European and international health and research networks involved in the surveillance and evaluation of perinatal health.

- Developing links with European clinical and public health bodies.

Our network promotes the improvement, expansion and development of perinatal health systems to enable more effective surveillance, evaluation and research. The following are targeted areas for future development:

- Linkage of routine data sources (vital statistics, birth registers, hospital discharge and administrative data) to improve quality and breadth of data available for monitoring and evaluating perinatal health.
- Use of validated hospital discharge data for the surveillance of maternal and child morbidity
- Establishment of a microdata repository to facilitate reporting and enriching research capabilities
- Continued development of indicators on
    - Maternal morbidity
    - Social inequalities in perinatal health outcomes

- Positive outcomes of pregnancy
- Health of high-risk infants

Our Outputs

The system should produce the following outputs:
1. A European perinatal health report
2. Web-based customised tables on perinatal health indicators updated after data are collected with an accompanying summary report
3. Methodological criteria for the collection and production of high quality, comparable indicators
4. Description of the data sources used to produce the indicators
5. Scientific articles based on analysis of the Euro-Peristat indicators

Our deliverables

This systems aims to contribute to:

➢ Better health for mothers and babies. The debate generated by our first two reports has already had effects on health in several countries because of renewed investments in maternal and child health.

➢ Improved reporting on maternal and child health: By producing a perinatal health report on a regular basis (fixed at once every 5 years at present), disseminating it widely and working with its network of stakeholders to promote the use of these data for the evaluation of health policies, we improve the information available about maternal and child health in Europe.

➢ High performing health information systems in EU member states: By defining a set of 10 core and 20 recommended indicators which should be routinely produced, the Euro-Peristat project sets concrete goals for improving health information systems at the national level. Our indicators are feasible, since all of them can be produced by at least a few countries. However, no country can produce all indicators and some countries are highly limited in the number of indicators that are available. Routine reporting at the European level provides incentives (to benchmark rates and trends with neighbouring countries) and pressures (by making the limitations of current data systems visible) to improve information systems.

➢ European networks of excellence and research: Our health information system aims to reinforce European excellence and innovation by strengthening collaboration between data providers, epidemiologists and user associations in a formalised surveillance network. The discussion about the variation in indicators of health and care between countries and over time between groups of stakeholders from different countries and disciplines has already generated new research questions about prevention of diseases and medical conditions and quality of perinatal and newborn care.

➢ Evidence-based health care and policy: We have a high representation of clinicians on our scientific committee because we believe that health information systems need to be clinically relevant to be most useful. Our recommendations were recently integrated into practice guidelines of the European Board and College of Obstetrics and Gynaecology (EBCOG). The Euro-Peristat project routinely publishes in clinical journals to raise awareness about current clinical practice and provide new research hypotheses. We also target political stakeholders and partners concerned by the daily care of pregnant women and babies through our reports, publications in national media and journals as well as our outreach activities.

➢ Tools to strengthen user groups and user involvement: By making data and analysis easily accessible through downloadable reports and tables from our website (www.europeristat.com) and through media dissemination efforts, we aim to empower pregnant women and their families.

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Annex 1: Current operational guidelines

1. Data collection schedule
- Data on the Euro-Peristat indicators should be collected every five years.
- Data collection should begin in early in the year N+2 with the aim of publication in the spring of year N+3. Preparatory work must begin in N+1.

2. Review of indicator list
- The indicator list should be reviewed before every report and updated if necessary.
- Attention should be given to maintaining continuity in order to monitor trends.
- If there is a need to obtain consensus, a formalized Delphi process should be used.
- Modifications should be pretested in a data collection exercise before being officially adopted.

3. Data collection and transmission
- Data collection is based on an excel file developed by TNO which collects aggregate data on each indicator. These data are then transferred into output files. SPSS files with the original data are available for more detailed analyses.
- Only aggregated data are transferred at present using secure internet transfers or by post.

4. Data Quality
- Network meetings include workshops to discuss quality improvement.
- Data providers from each country are involved in assessing data quality and checking statistical tables.
- All submitted data should be checked by the coordinating team (s) and a report with discrepancies returned to the participating country.
- Data should also be checked with previous years and other sources (Eurostat) in order to detect discrepancies and errors.

5. Use of data

- All data tables are checked and then endorsed by SC members before being posted on the Euro-Peristat website or published.
- The Euro-Peristat group fixes a set of analysis priorities and establishes working groups to work on these analyses and produce publications in accordance with the *Euro-Peristat authorship guidelines*.
- To download data from the internet, users are required to register and provide information on their institutional affiliation and their intended use of the data. Information is also given at this time about the importance of verifying data with the coordination team for any updates before publication based on these data.