

# PERISTAT

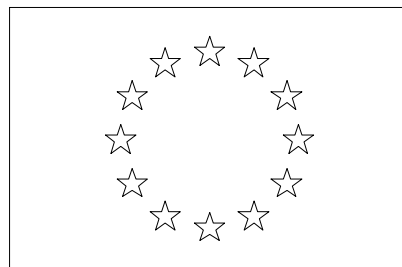
## Indicators for Monitoring and Evaluating Perinatal Health in Europe

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### Scientific final Report

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**Programme d'action communautaire en matière de surveillance de la santé**



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# 1. Overview of objectives and work programme

## 1.1 Objectives

The PERISTAT's overall project aim was to develop valid and reliable indicators for monitoring and evaluating perinatal health in the European Union. Perinatal indicators include measures of maternal, fetal and infant health during pregnancy, delivery and the post-partum period and their determinants.

This general objective consisted of four specific objectives:

1. definition of relevant measures of perinatal health and the determinants of perinatal health ;
2. development of methods, definitions and guidelines for the construction and publication of reliable and comparable indicators ;
3. assessment of the extent to which existing data collection systems could be used to construct reliable perinatal health indicators; and
4. creation of a data base containing perinatal health indicators currently available for EU member states.

## 1.2 Work programme

This project builds on existing work on perinatal health indicators and the expertise of European health professionals who have worked on monitoring and evaluating perinatal health in their countries and on a European level. The work programme for the project, as specified in the contract, is reproduced below.

This project was divided into two principal phases. Phase one responded to specific objectives 1 and 2 while phase two addressed specific objectives 3 and 4.

I. Definition of indicators and guidelines for data collection and publication (12 months)

A. ***Review of existing recommendations, methodological guidelines, legislation, scientific literature and documents from European, national and regional data collection systems:***

The areas covered will be : *health outcomes* : maternal mortality and morbidity, fetal and neonatal mortality, neonatal morbidity and long term measures of perinatal outcome / *clinical practice and the organisation and quality of health care provision* during pregnancy, delivery and the postpartum period / *medical, demographic and social risk factors* which influence perinatal health. This step will include :

1. synthesis of recommendations by official bodies and scientific and professional societies about relevant indicators of perinatal health ;
2. overview of existing definitions and guidelines for compiling and publishing perinatal health indicators and published evaluations of these methods ;
3. review of the scientific literature using population-based indicators of perinatal health;
4. description of perinatal indicators currently collected in European countries as well as on a European level. As part of this step, a list of relevant data collection systems and contact individuals will be compiled.

B. ***Construction of a set of perinatal indicators and endorsement by Scientific Advisory Committee (SAC).*** A proposed list of perinatal indicators will be drawn up by the project

steering committee based on the review in A and then presented to the Scientific Advisory Committee (SAC). The SAC consists of one clinician and one epidemiologist/statistician from each EU member state and will be set up at the beginning of the project. The members of the SAC will act as liaisons with experts in their home countries. The SAC will modify and finalise the list of perinatal indicators and, also, establish a priority level for each indicator based on its usefulness for monitoring and evaluating perinatal health (mandatory, highly recommended, recommended).

## II. Collection of perinatal indicators in Europe (12 months)

In this phase, data will be collected on the set of perinatal indicators and current capacity to produce the indicators according to definition will be assessed. Ways to computerise the data compilation process will be explored.

- A. **Survey to compile the set of perinatal indicators** from institutions that currently collect relevant data using lists established in I.A.4. Additional information will be collected about the data collection process, including completeness, ascertainment, and data quality.
- B. **Analysis of the reliability and comparability of data in Europe** by (a) contrasting data collection practices ; (b) reviewing indicators from participating countries and regions for evident outliers ; (c) comparing indicators with other similar measures from existing national and regional population-based systems and surveys ; and (d) observing trends in the evolution of indicators. Step B includes country visits by the research coordinator to identify the strengths and limitations of the data collection systems in each country.
- C. **Technical aspects of data transmission** : a feasibility study of a computerised network between institutions participating in the perinatal health surveillance system will be undertaken (provisional financing has been requested).
- D. **Establishment of the final set of indicators, definitions and guidelines and current data used to construct these indicators.** The results of the survey will be presented to the SAC which will provide final endorsement of results and the list of indicators. A data base containing current indicators and data used to construct them will be created in a format compatible with those used by the EU. The final report will include definitions, guidelines and notes for each indicator and provide recommendations for improvements in data collection practices, when necessary.

## **2. Summary of tasks accomplished in relation to work plan established in the contract.**

The PERISTAT project was successful in attaining its objectives. After a review and consensus process, the PERISTAT scientific advisory group developed recommendations on 10 core indicators and 23 recommended indicators of perinatal health, of which 12 are targeted for further development. Because of the decision to complete a publication on the results of the PERISTAT project, an extension was requested through the end of July 2003.

Section 3 of this report describes the contribution of the scientific advisory committee and external experts to this process. The scientific process for developing the PERISTAT indicators is described in section 4. Preliminary documents describing tasks A1-A4 are available in the midterm report and will not be repeated here.

To achieve its consensus on indicators and organize the completion of the tasks defined in the work programme, PERISTAT organized the following meetings:

Steering Committee Meeting	4 December 1999
Steering Committee Meeting	19 March 2000
Scientific Advisory Committee	21-22 September 2001
Steering Committee Meeting	19 June 2002
Scientific Advisory Committee	4-5 October 2002
Steering Committee Meeting	31 March 2003

The PERISTAT project also carried out a feasibility study for the collection of its recommended indicators in the member states and constituted a database of the indicators that were available for 2000 (or most recent year) – please see part II of the work plan.

For this survey, funds were provided to member states that needed to undertake additional data preparation to complete the PERISTAT data collection forms. Funds were provided to the following countries: Austria, Finland, Denmark, the UK, Germany, The Netherlands, Belgium and Italy. Some country visits were undertaken during the project to meet with data providers (Spain, Portugal, UK), but most communication was possible via the scientific advisory member to PERISTAT or directly by telephone and email.

Technicians at INSERM U149 developed the data instrument. The instrument (included in Annex 2) was transmitted both as an MS-Word document and as an MS-Excel spreadsheet. Definition of the data fields and the construction of a database was done by INSERM U149. Data entry and analysis was also carried out at INSERM. The files were structured to allow automatic tabulation of each indicator by subgroup using excel spreadsheets. An interface was developed to allow the use of statistical software, in particular STATA 8.

The methods for the survey and the results are described in detail in Section 5 and Annex 3 of this report.

PERISTAT project has placed significant emphasis on the dissemination of indicators and results from the feasibility study, to make the project known both to scientists and policy makers, as presented in the initial project proposal.

The following scientific publications will be forthcoming before the end of 2003. Thirty-five copies of the special issue of the European Journal of Obstetrics, Gynecology and Reproductive Biology will be provided to each member of the SAC for dissemination in their country. Copies will also be sent to the data providers, members of the HMP scientific commission and to the SANCO directorate as well as to the many experts that contributed to the project.

1. ZEITLIN J, WILDMAN K, BREART G, ALEXANDER S, BARROS H, BLONDEL B, BUITENDIJK S, GISSLER M, MACFARLANE A, and the PERISTAT scientific committee. PERISTAT : Indicators for monitoring and evaluating perinatal health in Europe. Eur J Publ Health, 2003 Sep;13(3 Suppl):29-37.
2. BUITENDIJK S, ZEITLIN J, LANGHOFF-ROOS J, CUTTINI M, BOTTU J. Indicators of fetal and infant health outcomes. Eur J Obstet Gynecol Reprod Biol, 2003 (in press).
3. LACK N, ZEITLIN J, KREBS L, ALEXANDER S. Methodological difficulties of comparisons across Europe. . Eur J Obstet Gynecol Reprod Biol, 2003 (in press).

4. MACFARLANE A, GISSLER M, BOLUMAR F, RASMUSSEN S. The availability of perinatal health indicators in Europe. *Eur J Obstet Gynecol Reprod Biol*, 2003 (in press).
5. BRÉART G, BARROS H, WAGENER Y, PRATIS. Characteristics Of The Childbearing Population In Europe. *Eur J Obstet Gynecol Reprod Biol*, 2003 (in press).
6. WILDMAN K, BLONDEL B, NYGUIS J, DEFOORT J, BAKOULA, C. European indicators of health care during pregnancy, delivery, and the postpartum period. *Eur J Obstet Gynecol Reprod Biol*, 2003 (in press).
7. ALEXANDER S, WILDMAN K, ZHANG W, LANGER M, VUTUC C, LINDMARK G. Maternal health outcomes in Europe. *Eur J Obstet Gynecol Reprod Biol*, 2003 (in press).
8. ZEITLIN J, WILDMAN K, BREART G, ALEXANDER S, BARROS H, BLONDEL B, BUITENDIJK S, GISSLER M, MACFARLANE A. Selecting an indicator set for monitoring and evaluating perinatal health in Europe: criteria, methods and results from the PERISTAT project. *Eur J Obstet Gynecol Reprod Biol*, 2003 (in press).

PERISTAT has also presented information on its results at several conferences, including a session at the EUPHA conference on health information systems in Brussels in December 2001, the European Association of Perinatal Medicine congress in Oslo in June of 2002, the 2002 EUROCAT meetings in Lisbon, and the European Perinatal Epidemiology Network in Oxford in October of this year (this congress was not funded by PERISTAT as the project had already been completed).

Other publications based on the data collected in this project are planned over the next year. All members of the SAC can submit proposals for additional analysis to the coordination team. After approval from the group, the data requested will then be made available for analysis.

### **3. Scientific Advisory Committee and participation of external experts**

#### *3.1 Scientific Advisory Committee*

The Scientific Advisory Committee participated in the identification, definition, endorsement and dissemination of the PERISTAT indicators.

The PERISTAT steering committee, at its first meeting in December 2000, defined the objectives of this committee and proposed names of perinatal health professionals. Proposed individuals were contacted by letter and asked if they were able to participate. If they were not able to participate, they were asked to propose the names of other experts to take their place.

#### **Criteria for selection of SAC:**

- Well-established experts in the field of perinatal health.

- Include two representatives from each country: one epidemiologist and one clinician.
- Include mix of clinical specialities (doctors in obstetrics and neonatology as well as representation from a midwife and a user representative).
- Available for the 2 meetings during the project.

### **Objectives of SAC**

- Supply information on national perinatal health indicators and statistical offices.
- Generate ideas for the development of an indicator set for a European health system.
- Establish priorities for the indicator set.
- Provide endorsement of the indicator set, both personal endorsement and assistance with endorsement from national professional societies.

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### *3.2 Participation of External experts*

#### **Defining an indicator for congenital anomalies**

Based on the DELPHI process, PERISTAT had a general consensus among its experts that congenital anomalies needed to be included, but the indicator needed development for inclusion in the feasibility study. PERISTAT collaborated with the EUROCAT project for advice on how to include an indicator of congenital anomalies in PERISTAT. We consulted the following European experts:

- Janine Goujard, France
- Beverly Botting, UK
- Helen Dolk, UK
- Annuka Ritaven, Finland
- Hermien de Walles, the Netherlands

All five agreed that information on some congenital anomalies could be collected in national systems and that this approach was complementary to a register-based approach. All five independently selected two similar criteria for choosing anomalies for inclusion in the PERISTAT indicator. The first was that they be easily diagnosed or readily apparent early in life, since aggregated national-level data are not likely to include any follow-up or anomalies diagnosed after the first few days of life, except where a neonatal or infant death has occurred. The second was that their prevalence be relatively high. Based on these discussions, the following anomalies were selected for inclusion on the PERISTAT indicators questionnaire : trisomy 21, all neural tube defects, anencephaly, and spina bifida. The panel also stressed that, given the range of availability of prenatal testing in the EU, it was crucial to collect information on induced abortions as well live births and fetal deaths. This information is most likely to be collected in specific registers and is essential to interpreting the variability in the prevalence of congenital anomalies at birth.

#### **DELPHI process with a panel of European midwives**

PERISTAT initiated an additional DELPHI consensus process with midwives because members of the SAC commented that this clinical perspective was underrepresented in the SAC DELPHI. The objective was specifically to consult an additional group of experts to assess their consensus on indicators to measure perinatal health.

With the help of our SAC, we identified 15 midwives in 11 member states. We allowed for no more than 2 respondents per member state. Representation included: Austria, Denmark, France, Greece, Ireland, Netherlands, Portugal, and the UK. Missing from the process were: Belgium, Sweden, Germany, Finland, Italy, Spain, Luxembourg. These countries are missing because either no midwife could be identified, or for non-response to the questionnaires.

The results of the DELPHI process with a cohort of European midwives highlight three indicators that were not identified in the PERISTAT SAC DELPHI. At a recent meeting of the project's steering committee, there was unanimous agreement to include these three indicators in the projects working list of indicators. These indicators are:

- Births without medical intervention
- Births attended by midwives
- Post-partum depression

These indicators require further development to implement both their definitions and to identify suitable data sources to construct them at the national level. As shown in Annex 1, they are considered as recommended indicators for further development.

## **4. Definition of indicators and guidelines for data collection and publication**

### *4.1 Background review: development of guiding principles*

The PERISTAT project began its work by seeking information on existing recommendations about perinatal health indicators from a wide range of sources. In some countries, letters were sent to key informants, designated by members of the scientific advisory committee as most likely to have knowledge of experts on perinatal health indicators in that country. Elsewhere, letters went out to a wider group of perinatal health professionals, composed of past participants of European projects on perinatal health and leaders of perinatal health associations. We also collected information on indicators routinely published by EUROSTAT, the WHO Regional Office for Europe and the OECD.

### **Recommendations issued by international and national expert groups**

The review process identified 10 sets of recommendations from international collaborations and 13 sets of national recommendations on perinatal health indicators, from Australia, Canada, Denmark, France, Germany, Italy, Spain, the UK and the USA. These indicator sets contain from 9 to 43 separate indicators. Several of the recommended sets are related more generally to child health; from them we retained only indicators relating to the perinatal period. Other indicator sets are more specific and concern only the care of high-risk babies or the quality of antenatal services. The review also included an analysis of indicators that are compiled regularly by three organisations: EUROSTAT, the OECD and the WHO Regional Office for Europe.

Some of the documents making recommendations described their selection criteria for indicators. Three major types of criteria are mentioned, although the precise terminology differs. The first assesses the importance of the indicators by terms such as: significant, useful and relevant. Importance is determined both in relation to the prevalence of the problem and its amenability to change. The second set of criteria are technical. There is broad agreement on the need for scientifically robust indicators that are valid, reliable, sensitive and specific. Finally, the third criterion for choosing indicators is that they must be practical in relation to the data currently collected in each country. Feasibility and data availability are routinely mentioned. Other less frequently mentioned criteria include ethical indicators and the importance of encompassing all issues or population groups to derive representative and balanced indicators sets.

Many individual measures are common to these indicator sets. Rates of fetal mortality, neonatal mortality, and caesarean delivery and indicators of birth weight and of preterm birth are included in over half of all recommended indicator sets. The maternal mortality ratio is also included in most indicator sets that cover maternal health outcomes.

Because of their reference to local health systems and policies, many of the indicators included in these sets would not be appropriate for comparative European analyses. For

instance, recommendations from Australia and England include indicators based on neonatal admission to intensive and special care. These would be difficult to compile, let alone interpret internationally, in view of the wide differences in the organisation and definition of intensive and special care units (10). Moreover, the availability of on-site care and practices unrelated to the newborn's health status can affect referral decisions (13). Similarly, comparison of indicators based on the number of antenatal visits would require information on national recommendations about the optimal number of these visits, which varies from 5 in Austria and Luxembourg to 13 in the Netherlands and 14 in Belgium (14). Medical practices also affect the feasibility of compiling specific indicators within a European context. For example, Germany uses an indicator of the acidosis level ( $\text{pH} < 7.1$ ) among term infants, but it can be compiled only in countries where pH is routinely measured and recorded. Finally, some indicators are meaningful only when a clear consensus exists among health professionals about specific protocols. For instance, indicator 6 in the state of Victoria's maternity service set is the proportion of women offered appropriate interventions in relation to smoking. Perceptions of 'appropriate' may well differ between countries despite universal acceptance of the benefits of smoking cessation during pregnancy.

The review of recommended indicator sets also brings up the issue of the differences in definition for individual indicators. Different specific indicators can be defined for a common theme, such as mode of delivery. Caesarean sections, for example, may be subdivided into those occurring before the onset of labour and those after labour has begun, and vaginal deliveries into spontaneous and operative. Denominators may be total births, the total number of women delivering a baby, or the total number of vaginal deliveries. Preterm birth provides another example. While WHO publishes internationally agreed definitions, these may be ignored in practice (15). The OBSQID recommendations use two indicators, with cutoff points at 31 and 37 weeks of gestation, while the Nordic indicators use the cutoff point of 34 weeks. To provide an interface with local indicator sets, a European indicator set should use broad definitions of individual indicators and present full distributions.

### **Perinatal indicators routinely compiled on perinatal health in Europe**

As Table 1 shows, databases maintained by EUROSTAT, the WHO Regional Office for Europe and the OECD (16-19) already compile a considerable number of indicators related to perinatal health and care. With the notable exception of preterm birth rates, the indicators most commonly contained in the recommended indicator sets are already regularly compiled.

Research on these indicators, however, shows that improvements are necessary before they can be compared across Europe. The perinatal mortality rate is an important example. In the mid-twentieth century, it was suggested that stillbirths had many features in common with deaths during the first week of life and that they should therefore be combined (20). From the 1950s onward, the perinatal mortality rate, defined as the number of stillbirths plus deaths in the first seven days after live birth, expressed as a rate per thousand total live and stillbirths, was widely used in statistical publications.

This rate is very sensitive to criteria for inclusion of live and stillbirths. According to the WHO, 'the perinatal period commences at 22 completed weeks (154 days) of gestation (when birth weight is normally 500 g) and ends seven completed days after birth' (15). In practice, countries differ in their legal criteria for birth registration and in their inclusion criteria for other data collection systems. For example, in Denmark, Spain and Sweden, only fetal deaths after 28 or more completed weeks of gestation are registrable as stillbirths. Other countries, including Austria, Germany and Portugal, add a minimum birth weight criterion. The absence

of common criteria distorts comparisons between countries (5).

Some countries have explicit criteria for live birth registration, and these too differ. Even in countries with no such criteria, regulations about stillbirth registration can affect decisions about whether an event is a late miscarriage or should be registered as a live birth and neonatal death. Furthermore, under-reporting can be a problem, particularly where data collection systems are not statutory. The lower limits for registration of stillbirths and live births are presented in MacFarlane et al in this volume, and the impact that registration practices can have on mortality rates is discussed in more detail in Lack et al, in this volume.

Indicators of maternal mortality are also extremely sensitive to under-reporting (21, 22). When ascertainment is good, maternal mortality measures not only a key health outcome, but also the quality of obstetrical care, since many direct maternal deaths are associated with substandard care. Ascertainment of maternal deaths, however, requires an effort by governments to ensure that deaths during or within one year after pregnancy are identified on death certificates or by other measures (23, 24). In many cases, very low levels of maternal death reflect poor ascertainment rather than good care. Alexander et al. discuss approaches to ascertainment for maternal mortality.

### **Conclusions of review**

The review helped to define priorities for the European indicator set, and these in turn served as a framework for organizing the selection process. These priorities were (1) to assess maternal and infant mortality and morbidity associated with events in the perinatal period; (2) to describe the factors that may be associated with perinatal health outcomes in the population of childbearing women, including demographic, socio-economic and behavioural characteristics, and the trends in these factors; and (3) to monitor the use and possible consequences of medical intervention in the care of women and babies during pregnancy, delivery and the postpartum period. All the criteria mentioned in the recommendations and discussed above were considered relevant to the selection of indicators for a European health information system. Comparability was added to the list of criteria.

The PERISTAT group placed a high priority on improving indicators already collected routinely. One way to improve quality and facilitate interpretation is to cross-tabulate indicators by other factors to form sub-groups. We thus asked the panel of experts to select individual indicators and also to specify the factors that should be cross-tabulated with them. For example, fetal and neonatal mortality rates can be tabulated by gestational age and by birth weight. The user can then determine the sub-groups for which variation due to reporting bias is greatest, such as the most preterm or lowest birth weight babies, and interpret the findings with appropriate caution. Other methodological principles included presenting indicators as full distributions and including confidence intervals and population sizes.

Finally, despite its strong emphasis on improving existing indicators, the PERISTAT group also set goals for future indicator development. In particular, most recommendations do not include indicators on the longer-term consequences for mothers and their children of events that occur in the perinatal period. The views of new mothers and their families about the care and support they receive from clinicians in the perinatal period constitute another neglected area.

#### *4.2 Selecting the PERISTAT list of indicators*

## **Defining the choice set**

We attempted to constitute a complete inventory of possible indicators of perinatal health, which incorporated previous work as well as the opinions of our scientific committee, before we began the selection process. Its starting point was the report from the background review, which included a master inventory list containing all perinatal health indicators found in existing recommendations with a tally of the number of times each indicator was mentioned. Small working groups discussed this list at the first plenary meeting of the PERISTAT scientific advisory committee, and committee members added indicators that they felt were missing. Indicators were also eliminated from the list, but only if all three working groups agreed. This process left us with a list of 97 indicators sub-divided into four categories: fetal/neonatal health, maternal health, demographic, socio-economic and behavioural factors associated with health outcomes, and health services.

Definitions were proposed for each indicator when they could be found in the documents consulted in the PERISTAT review. Where possible, WHO definitions were applied to individual indicators. If no WHO definition was available for a certain indicator, the steering committee used a definition proposed by previous expert groups on perinatal health indicators, if available.

## **Delphi Consensus process with the Scientific Advisory Committee**

To achieve a consensus for the indicator set, we used a modified Delphi process with the PERISTAT scientific advisory committee. This process is a formalised consensus method in which a panel of people respond to a successive series of questionnaires with the aim of achieving a consensus on key principles or proposals (25, 26). Participants rank items by priority or importance, although they can also give more extensive comments. The benefits of this approach are anonymity, iteration (which allows participants to change their opinions during the process), controlled feedback in which participants are provided with the distribution of the group's previous response to individual questions, and the derivation of summary measures of agreement (27). Moreover, in a European context, where many people are asked to participate in meetings held in languages that are not their native tongue, the Delphi process provides less fluent members additional time to read and respond. Finally, it is useful when it is logistically difficult to bring people together.

Two structured questionnaires were sent out to the scientific advisory committee over the four-month period after our first meeting. Each member was asked to engage in a priority assessment exercise. In round 1, all indicators from the master list were ranked from 0 to 3 (3 = essential; 2 = important; 1 = less important; 0 = not useful). Participants were also asked separately to give their list of 'top 10' indicators and to rank associated analytic variables needed for the cross-tabulation of indicators. The second questionnaire retained all indicators considered essential by 40% of the participants, those with an average priority score of 2 (important) and those included in the top 10 lists of at least two participants. In round 2, participants were asked to select from 10 to 15 essential indicators and 20 recommended indicators. They were also asked whether the indicator could be implemented immediately or was to be developed in the future. Participants could object to the removal of indicators from the shortlist and provide general comments on the results of the first round. Twenty-seven participants responded to both rounds of the Delphi process.

## **The 10 Core indicators**

In the second Delphi round, the vast majority of participants agreed on ten core indicators. This agreement was clear and robust: at least 80% of the participants agreed that the indicators should be in a core indicator set. Table 2 reports the top 10 indicators and the percentage of participants considering them to be core. In contrast, the level of agreement among respondents dropped to 50% for the eleventh ranked indicator, thereby demonstrating a clear demarcation in the consensus around this set of indicators.

### **Recommended indicators**

To arrive at the next tier of recommended indicators, we examined a cross-tabulation of two rankings from the second Delphi questionnaire: (1) indicators selected as core, and (2) those selected as recommended. These two rankings were very similar: only three indicators were in one list but not the other. To shorten the list, overlapping indicators were merged. For instance, deaths from congenital anomalies became a sub-category of an indicator of cause of death. We excluded indicators that had received no core votes or those with at least one core vote but recommended by less than 60% of the group. The list from which the choices were made, including rankings for each indicator, is presented in Table 4, which also includes the percentage of experts responding that further development is needed for those indicators, when this percentage was at least 25%. Finally, the table shows which indicators are on the list of European Community Health Indicators (ECHI) developed by the Health Monitoring Programme. This list includes indicators that have been identified as belonging to a general set of EU indicators by other projects in that programme: we accorded additional priority to them.

The list in Table 3 was refined to obtain a shorter list of 20 recommended indicators, as shown in the last column in the table: **R** indicates that the indicator was included in the recommended list, and **F** that it was included in the recommended list, but targeted for further development. Shaded indicators were eliminated for one of four reasons, specified in the last column: **A** = similarity to others ranked higher; **B**= overlap with other Health Monitoring Programme projects, as with induced abortion, which is one of the indicators in the REPROSTAT list; **C**=only borderline for inclusion in the list (<70% of experts felt it should be recommended, only a few selected it as core) and not on the ECHI list; and, finally, **D**=related to a 'topic' that received considerable support, but no clear indicator for a specific indicator definition.

Severe maternal morbidity, for example; was part of the latter category. Eclampsia had the highest score of indicators of maternal morbidity, but 85% of the experts selected at least one indicator of severe maternal morbidity in addition to eclampsia. This shows that they did not feel that eclampsia should be the only indicator of severe maternal morbidity. No consensus emerged for another indicator, such as severe haemorrhage or transfer to an adult intensive care unit. In this case, we chose a 'generic' indicator that was targeted for further research, but which does not have a specific definition. Three generic indicators were identified at this stage of the analysis: maternal morbidity, care for high-risk infants and an indicator of support for women. The latter was added because of comments made by our panel of respondents during the second DELPHI round. Many participants were unhappy that the shortlist from the Delphi questionnaire did not contain indicators of support for women during pregnancy and the perinatal period, although they recognized that no specific indicator definition was available.

This working list was approved and slightly modified during the final SAC meeting. All members were given the chance to express their opinions about the final list – no member



suggested changes to the selected indicators. Consensus was reached for several of the generic indicators. A discussion at this meeting led by a committee member with relevant expertise developed a definition for an indicator of severe maternal morbidity. We were unable to agree on a definition for an indicator of maternal support, although the group agreed to add an indicator of maternal satisfaction to the list of indicators needing further work. Finally, the committee decided to eliminate the indicator of care for high-risk babies. Many other recommended indicators are cross-tabulated by birth weight and gestational age and can therefore be used to describe the health of high-risk babies.

### **DELPHI process with a panel of midwives**

After the DELPHI process with the PERISTAT scientific committee, members of the scientific advisory committee commented that the clinical perspective of midwives was under-represented. Accordingly, we decided to conduct an additional DELPHI process with a panel of midwives, to assess their consensus on core indicators for measuring perinatal health and, more specifically, to obtain ideas and comments about an indicator of support for pregnant women. We hoped to derive a specific indicator definition for the generic indicator 'support to women' that was selected for inclusion in the PERISTAT list. With the help of the scientific committee, we identified 15 midwives in 11 member states. We allowed no more than 2 respondents per member state. Midwives represented Austria, Denmark, France, Greece, Ireland, Netherlands, Portugal, and the UK. Missing from the process were Belgium, Sweden, Germany, Finland, Italy, Spain, and Luxembourg, because no midwife could be identified or because those identified did not respond to the requests to participate.

The DELPHI process for midwives used the same comprehensive list of indicators as the DELPHI with the SAC, and respondents were requested to select a 'top-10' list to pinpoint the indicators most important for monitoring perinatal health at the European level. In the second round questionnaire, the comprehensive list was reduced to those indicators that received a minimum number of votes ( $\geq 2$ ) in the first round. A second table in that questionnaire consisted of indicators to be dropped, and respondents had the opportunity to vote for them to remain on the list. Each questionnaire also contained certain targeted qualitative questions aimed at improving our understanding of the midwives' perspective on key topics identified in the early DELPHI, and in particular, maternal support. The response rate was 73% (11/15) in the first round and 67% (10/15) in the second. Most respondents replied individually to their questionnaire, although some consulted others from their home country to provide a group response. In the Netherlands, for example, one questionnaire represents 7 midwives. Questionnaires based on group responses were weighted as two questionnaires for the analyses.

The decision rule for inclusion in the final list was agreement by more than half the respondents that a given indicator should be retained. Table 4 presents the resulting list, along with the number and proportion of votes received. Indicators shown in italics are those that do not coincide with the results of the SAC DELPHI, that is, births without medical intervention, births attended by midwives, and postpartum depression. Because these indicators require further development to operationalise their definitions and to identify suitable data sources to construct them at the national level, the committee decided to add these indicators to the list of recommended indicators for further development. The other indicators on the midwives' top-10 list are already included in the PERISTAT indicator list.

### **The final list of indicators**

The final list of PERISTAT indicators includes 10 core indicators and 23 recommended indicators of which 12 are targeted for future development. This final list is presented in Table 5. Definitions of each individual indicator are available on the PERISTAT website (<http://europeristat.aphp.fr>) and reproduced in Annex 1 to this report.

With this list, the PERISTAT project achieved its aim of obtaining an internal consensus on a perinatal health indicator set. The methods used to compile this list drew on and consolidated previous work in the field and the Delphi process successfully identified a strong core set of indicators. To make these core indicators, many already routinely compiled in European countries, effective tools for monitoring health, the SAC defined associated factors for subgroup analyses for the core indicators. This should improve their comparability and interpretation.

In contrast, we did not achieve consensus on specific indicators in areas where uncertainty about appropriate indicators was high. No consensus emerged around specific definitions for the indicators of maternal support or maternal satisfaction, both areas where data are not routinely available. The Delphi method, in tandem with the group meetings of the scientific committee, did make it possible to establish goal posts for indicators that require further development. The set of 12 indicators marked for further development help to orient future research on perinatal health indicators.

## **5. Collection of perinatal indicators in Europe: Assessment of the feasibility of the PERISTAT recommendations**

To fulfil the PERISTAT objectives, we fielded a survey to test the capacity of the member states to provide indicators, particularly those recommended for immediate implementation. Our aim in this study was to collect data about the PERISTAT indicators when they were readily available and to identify gaps in the availability of data and differences in definition and coverage. The study was conducted over a relatively short time period, which did not always give institutions the time to generate new indicators after additional analyses of existing data. Accordingly, the data provided here are illustrative; our mission was not to produce a ‘perinatal statistics yearbook’ for Europe. Instead, we aim to assess the quality of data available for constructing indicators in Europe and to provide examples of how these can be used to monitor and evaluate perinatal health in Europe.

### *5.1 Methods for the PERISTAT survey*

In order to collect the aggregated data required to construct the indicators, the members of the Scientific Advisory Committee were first asked to provide information about the routine data collection systems in their countries, including both routine administrative and clinical systems and periodic sample surveys. For each system, the information provided included the name of the statistical, clinical or other organisation running it and the contact details of a person within the organisation who could be approached to provide the data for PERISTAT.

For each indicator, one or more blank tables were set up to show the layout of the aggregated data required to construct it. Although most of the indicators are expressed in terms of rates and ratios, numbers were requested in order to be able to calculate rates on a common basis. The data collection instrument used to compile the indicators is presented as **Annex 2** to this report.

The members of the Committee then compiled the tables using routine data for their country for the year 2000 or the most recent year. Some members compiled at least some tables themselves using data from published sources in consultation or collaboration with colleagues in the relevant organisations. Often the categories used in the PERISTAT tables differed from those used in routine publications, especially where PERISTAT tables had quite detailed tabulations, to enable common cut-offs to be selected when constructing the indicators. In these and other cases, they asked their contacts within the relevant organisations to compile the data needed to complete the tables. In many cases, this included requests for ad-hoc tabulations which were run especially for PERISTAT.

Participants were asked to provide national data for their country, as far as possible. If data were available for some but not all components of any given table, participants were asked to provide the available data and mark the remaining cells as 'unavailable'. Where data were not available for all parts of a country, but population-based data were available from one or more regions, these data could be provided instead.

The requests were for population-based data. If such data were not available but the relevant data items were collected in hospital-based systems, then data from these sources could be used. Participants were asked to record the names of the data source or sources used to compile each table. They were also asked to complete a questionnaire about each data source used overall.

If it was possible to derive the indicators from more than one source of data, participants were asked to provide data from both. In particular, if some limited national data were available, but better quality or more detailed data were available at a regional level, participants were asked to provide these in addition to the national data.

In cases where it was not possible to provide data in the form requested, because the definition used within a country was different from that used by PERISTAT, participants were asked to provide the data available. They were asked to document clearly the definitions used and how they differed from the definitions used in PERISTAT.

For each of the indicators, preliminary tables were constructed from the data provided. These were sent to all data providers and SAC members to check the data. All countries were anonymous at this stage. Only when the data were checked and approval provided by the data providers were country names documented on the tables.

To carry out analyses, the SAC constructed working groups on specific themes. These working groups defined additional tables and analyses to complete on the indicators and undertook secondary research to place these indicators in a broader context.

To analyse the data collected in the feasibility survey, the scientific advisory committee constructed working groups on specific themes. These working groups defined additional tables and analyses to complete on the indicators and undertook secondary research to place these indicators in a broader context. These analysis groups were responsible for writing a critical analysis of their theme.

## *5.2 Results*

Six working groups were set up to analyse the data from the PERISTAT feasibility survey. These correspond to the articles included in the PERISTAT special issue for the European

Journal of Gynecology, Obstetrics and Reproductive Biology. These articles are reproduced in Annex 3 to this report. Also included is the article by Zeitlin et al on the methods for constructing the indicators.

The first two articles using data from the feasibility study focus on methodological and data issues related to perinatal health indicators. Macfarlane et al discuss the data for perinatal health indicators and report the methods used to survey feasibility. This article describes the large variety of data sources used to construct perinatal health indicators and discusses the strengths and weaknesses of these different approaches. Lack et al discuss the technical qualities of good indicators and the difficulties of choosing optimal indicators in a European context, and they provide concrete examples of the challenges posed by cross-European comparisons.

The last four articles provide data on perinatal health in Europe, assessed with available indicators. The articles are organized by theme, as are the PERISTAT recommendations. No predefined format was established for the presentation of these indicators; instead, data tables presenting indicators were generated and provided to the authors for interpretation. The writing groups are composed of members of the scientific committee with a particular interest in these themes. Each writing group took its own approach to the presentation and discussion of these data.

These chapters consider data availability and quality and provide an overview of the statistical values of the indicators. Bréart et al report on the characteristics of the child-bearing population and their effect on the PERISTAT outcome indicators: they present the data and simulate the impact that observed variations between countries may have on health outcomes. Wildman et al present and discuss available indicators on health care and health services and examine the challenges of comparing these indicators between countries. The discussion includes a review of the empirical justification of the selected indicators and of the context of the relevant policy debates. Buitendijk et al focus on the 10 PERISTAT indicators that measure infant and fetal health and show how the recommendations for the use of the 5 core indicators can improve our understanding of the variation and trends in health outcomes. Finally, Alexander et al address maternal health outcomes. Although most of the available data concern mortality, they also explore the need to develop indicators of morbidity.

This survey shows both the positive and negative aspects of the current situation in Europe. On the optimistic side, European countries can provide many of the PERISTAT indicators and can supply some of them by the sub-groups, such as gestational age, birth weight and plurality, that make their analysis more methodologically sound and more useful for understanding variation and trends between countries and over time. These data, currently available from national statistical offices, are not currently easily accessible to people in other countries. This project can thus conclude that significant improvement in the quality of European-level indicators on perinatal health is possible now.

Unfortunately, many countries cannot provide these indicators. Indeed, most countries will need to improve their data systems before they can provide the complete set of indicators recommended by PERISTAT. The negative corollary of our first conclusion is that a fully operational European-level health information system will require most countries to make significant investments in their data collection systems. Nonetheless, at least 3 or 4 countries – and not always the same ones – can provide data for most of the indicators recommended for immediate implementation; this finding shows that these recommendations are not

unrealistic. We hope that the knowledge that other countries are able to produce these indicators will spur regional and national efforts to improve local systems.

More generally, our hope is that the presentation of the data that we have been able to gather in this project will serve to encourage those interested in setting up European collaborations in the short term and will generate a common interest in improving our surveillance and evaluation tools.

**Figure 1: Methods**

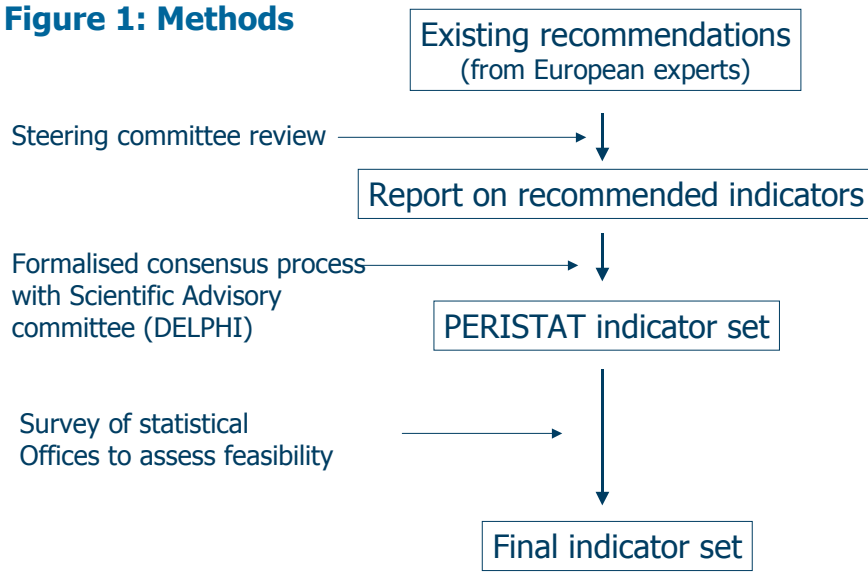


Table 1 Perinatal indicators routinely compiled for European countries

EUROSTAT <sup>1</sup>	WHO Health for All database <sup>1</sup>	OECD Health database <sup>1</sup>
Perinatal mortality rate	Perinatal mortality rate	Perinatal mortality rate
Fetal mortality rate	Fetal death rate	Infant mortality rate
Early neonatal mortality rate	Early neonatal death rate	Low birth weight
Late neonatal mortality rate	Late neonatal death rate	Prevalence of congenital anomalies (results from EUROCAT registers)
Infant mortality rate	Low birth weight <2500 g	Maternal mortality ratio
Prevalence of selected congenital anomalies (results from EUROCAT registers)	Rates of selected infectious diseases (congenital syphilis, rubella, neonatal tetanus)	Fertility rate
Fertility rate	Prevalence of selected congenital anomalies	Caesarean section rate
Distribution of maternal age	% infants breast-fed at 3 and 6 months of age	Expenditures on maternal/child health
Births by birth order	Maternal mortality ratio	Length of hospital stay for childbirth
Births by marital status	Fertility rate	
	Induced abortion	
	% young mothers	
	% older mothers	
	Number of midwives per 100 000 population	

Note 1. extracted from published reports or databases (16-19)

Table 2 Selection of the PERISTAT 10 core indicators

Indicator (associated factors for tabulating indicator)	% participants selecting as core indicator
Fetal mortality rate (gestational age, birth weight, plurality)	96%
Neonatal mortality rate (gestational age, birth weight, plurality)	96%
Maternal mortality ratio	93%
Maternal age	93%
Birth weight distribution (vital status at birth, gestational age, plurality)	89%
Gestational age distribution (vital status at birth, plurality)	89%
Multiple birth rate	85%
Mode of delivery	85%
Parity	81%
Infant mortality rate	78%



Table 3: Selections of recommended indicators (shaded indicators eliminated).

	N of core ratings	N or core, recommended or future ratings	Future > 20% of responses	ECHI indicator	Decision (see notes)
<b>Maternal health</b>					
Maternal mortality by cause	13 (48%)	26 (96%)		(*?)	R
Indicator of severe maternal morbidity					F
Incidence of eclampsia	7 (27%)	22 (81%)			D
Incidence of severe postpartum hemorrhage	6 (22%)	17 (63%)	29%		D
Blood transfusion	<5	17 (63%)			D
Trauma to the perineum (episiotomy)	5 (19%)	20 (74%)	30%/42%		R
Faecal incontinence	< 5	21 (78%)	55%		F
<b>Infant health</b>					
Prevalence of congenital anomalies	10 (37%)	23 (88%)		*	R
Causes of perinatal death (death from congenital anomalies)	10 (37%)	20 (77%)	20%/21%		F
Distribution of APGAR score at 5 min	9 (33%)	18 (69%)			R
Hypoxic-ischemic encephalopathy	6 (22%)	18 (67%)	29%		F
Cerebral palsy	7 (26%)	20 (74%)	37%		F
SGA newborns	5 (19%)	18 (67%)	28%		A
<b>Population characteristics/risk factors</b>					
Smoking	8 (30%)	26 (96%)		*	R
Mother's education	5 (19%)	21 (81%)			R
Mother's country of origin	1	19 (73%)	42%		F
Mother's occupation	1	17 (63%)			A
<b>Health care services</b>					
Mode of onset of labour	14 (52%)	24 (89%)			R
Pregnancy after assisted conception	9 (35%)	25 (93%)			R
Timing of 1 <sup>st</sup> prenatal visit	11 (42%)	21 (78%)			R
Induced abortion rates	9 (35%)	21 (78%)			B
Place of birth (home & size of maternity)	8 (30%)	21 (78%)			R
Number of prenatal visits	5 (19%)	19 (70%)	22%		A
Breast-feeding at birth	4	17 (63%)		*	R
Indicator of maternal-child support					F
Number of ultrasounds	1	18 (67%)	28%		C
Timing of first ultrasound	2	17 (63%)			C
Use of amniocentesis	2	18 (67%)			C
Number of very preterm births delivered in units without NICU	8 (30%)	20 (77%)			R
Indicator of care for high-risk infants					F
Mechanical ventilation/CPAP	6 (22%)	<18	20%		D
Antenatal corticotherapy	6 (22%)	17 (63%)			D
Surfactant	5 (19%)	<18	31%		D

**Notes to table :** R. Recommended indicator. F. Recommended, further development required  
A. A similar indicator, ranked higher, was selected. B. Recommended by REPROSTAT project  
C. Indicator borderline on both criteria (<70% in favour as recommended, few selected as core)  
D. More research needed on appropriate indicator, generic indicator included instead

Table 4: Midwives' Top Ten list

Indicators	Round II votes	%
Perinatal mortality rate <sup>1</sup>	11	100
Maternal mortality ratio (including by cause)	11	100
Mode of delivery	11	100
APGAR scores at 5 minutes	8	73
Proportion of babies breast-feeding	7	64
Growth restriction <sup>2</sup>	7	64
<i>Births without medical intervention</i>	7	64
Gestational age distribution	6	55
<i>Postpartum depression</i>	6	55
<i>Births attended by midwives</i>	6	55

NOTES:

1. included in PERISTAT list as fetal & neonatal mortality rate.
2. included in PERISTAT list as birth weight distribution by gestational age

Table 5 Final list of PERISTAT indicators

**Summary table**

Category	Core	Recommended	Recommended, further development needed
<b>Neonatal health</b>	<p>C1-Fetal mortality rate by gestational age, birth weight, plurality</p> <p>C2-Neonatal mortality rate by gestational age, birth weight, plurality</p> <p>C3-Infant mortality rate by gestational age, birth weight, plurality</p> <p>C4-Birth weight distribution by vital status, gestational age, plurality</p> <p>C5-Gestational age distribution by vital status, plurality</p>	<p>R1-Prevalence of selected congenital anomalies Down syndrome Neural tube defects</p> <p>R2-Distribution of APGAR score at 5 minutes</p>	<p>F1- Causes of perinatal death</p> <p>F2-Prevalence of cerebral palsy</p> <p>F3-Prevalence of hypoxic-ischemic encephalopathy</p>
<b>Maternal health</b>	<p>C6-Maternal mortality ratio by age, mode of delivery</p>	<p>R3-Maternal mortality by cause of death</p>	<p>F4-Prevalence of severe maternal morbidity</p> <p>F5-Prevalence of trauma to the perineum</p> <p>F6-Prevalence of faecal incontinence</p> <p>F7-Postpartum depression</p>
<b>Population characteristics or risk factors</b>	<p>C7- Multiple birth rate by number of fetuses</p> <p>C8-Distribution of maternal age</p> <p>C9-Distribution of parity</p>	<p>R4-Percentage of women who smoke during pregnancy</p> <p>R5-Distribution of mothers' education</p>	<p>F8-Distribution of mothers' country of origin</p>
<b>Health care services</b>	<p>C10-Distribution of births by mode of delivery by parity, plurality, fetal presentation, previous CS</p>	<p>R6-Percentage of all pregnancies following fertility treatment</p> <p>R7-Distribution of timing of 1<sup>st</sup> antenatal visit</p> <p>R8-Distribution of births by mode of onset of labour</p> <p>R9-Distribution of place of birth</p> <p>R10-Percentage of infants breast-feeding at birth</p> <p>R11-Percentage of very preterm births delivered in units without NICU</p>	<p>F9-Indicator of support to women</p> <p>F10-Indicator of maternal satisfaction</p> <p>F11-Births attended by midwives</p> <p>F12 –Births without medical intervention</p>

The PERISTAT indicator set, with definitions for each indicator, is available on:  
[euperistat.aphp.fr](http://euperistat.aphp.fr)

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