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Selecting an indicator set for monitoring and evaluating perinatal health in Europe: criteria, methods and results from the PERISTAT project

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Abstract

The PERISTAT project was charged with developing an indicator set for monitoring and describing perinatal health in Europe as part of the European Commission's Health Monitoring Programme, run by the Directorate General for Health and Consumer Protection (DG-SANCO), which is working towards the establishment of a comprehensive health monitoring system at the community level. To develop its recommendations, the PERISTAT project carried out an extensive review of existing perinatal health indicators and then implemented a DELPHI consensus process with its scientific advisory committee, a panel composed of clinicians, epidemiologists and statisticians, as well as with a panel of midwives. Consensus was achieved on 10 core and 23 recommended indicators using methods that drew on and consolidated previous work in this field. Twelve of these indicators were targeted for further development and the other 21 for immediate implementation. A feasibility study, reported in the rest of this issue, was put into place to assess these recommendations.

Keywords: PERISTAT; Perinatal health; Indicators; Health information systems; DELPHI process; Europe

1. Introduction

International comparisons of data relating to pregnancy outcome and maternity care date back at least to the mid-nineteenth century [1–3]. In the twentieth century, the drive to produce social indicators to measure and compare populations and health services and the post-war focus on maternal and child health programmes in many countries furthered the development and use of perinatal health indicators. National and international expert groups have convened to define measures of maternal and child health care and outcomes for use in evaluating public health programmes [4,5]. Perinatal epidemiologists, aided by the development of computers, have pursued research on associated demographic, social and behavioural factors that affect maternal and neonatal health and thus provide an empirical basis for efforts to develop indicators. Perinatal health has long been on the European Community's research agenda: a comparative study of antenatal health care took place 20 years ago [6]. Today, perinatal, infant and maternal mortality rates are among the most commonly used indicators of population health status. These rates, derived from civil and medical registers of births and deaths, are published regularly; historical series exist for many countries.

Despite this rich past, good tools are not currently available for monitoring and comparing perinatal health status and perinatal health care in Europe. As perinatal and maternal health have improved, absolute differences in mortality rates between countries have declined. The methodological shortcomings of many indicators have generated skepticism about the data sources, the derivation of the numbers and their usefulness in comparing health status and quality of care [7–9]. Furthermore, European research projects cast doubt on the value of many commonly used indicators as valid measures of quality of care. These projects have consistently documented extensive heterogeneity in health systems and medical practices [10–12]. In these varied settings, relating indicators of health care practices to quality

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of care requires contextual information on the health care system and the policy environment.

The PERISTAT project was charged with developing an indicator set for monitoring and describing perinatal health in Europe. The challenge was to define indicators that cover common concerns and have the same meaning within the different health care systems in the Community. The project's guiding principles were to consolidate existing work on perinatal health indicators and to redress known methodological shortcomings of these indicators.

The PERISTAT project was part of the European Commission's Health Monitoring Programme, run by the Directorate General for Health and Consumer Protection (DG-SANCO), which is working towards the establishment of a comprehensive health monitoring system at the community level. Two parallel projects of this programme considered indicators for other reproductive health issues and child health (the REPROSTAT and CHILD projects). Our focus was thus clearly oriented towards the health issues associated with pregnancy, delivery and the postpartum period, since reproductive health at other points in the life cycle was covered by the REPROSTAT project, and indicators of child health after the perinatal period by the CHILD project.

The PERISTAT project was coordinated by a scientific team at the Epidemiological Research Unit on Perinatal and Women's Health at INSERM (the French National Institute for Health and Medical Research) in collaboration with a steering committee of seven experts in perinatal health and a scientific advisory committee (SAC) composed of a clinician and an epidemiologist or statistician from each of the European member states. The clinicians include obstetricians, paediatricians, and one midwife. There was also one consumer representative. The participants are listed in Appendix 1 to this issue. The project also enlisted the assistance of specialists in the field of congenital anomalies and convened a consultative panel of midwives.

The PERISTAT project included three major components, summarised in Fig. 1: (I) a background review of the scientific literature and existing recommendations on perinatal health indicators, (II) a consensus process by which the PERISTAT scientific advisory committee and a panel of midwives identified a working list of indicators, and (III) a study of the availability of national statistics covering the proposed indicator set to test its feasibility. This article describes the rationale and methods used in the first two components.

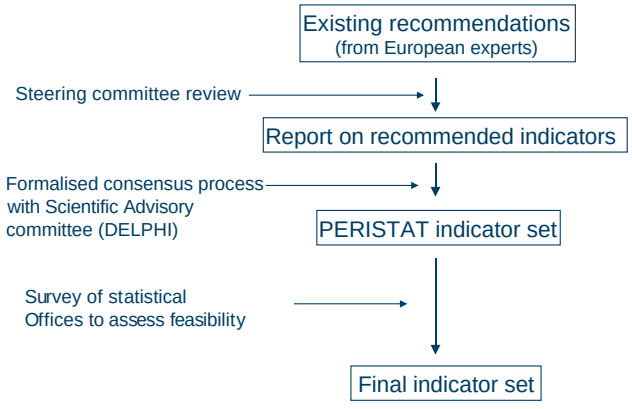

Fig. 1. Methods.

2. 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.

2.1. Review of 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.

Despite this overlap, individual sets are distinct. Table 1 provides examples of recommended perinatal health indicator sets. Health policy as well as the organisation of the health system shape the selection of ''experts'' and the focus of these ''expert groups''. 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 (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. As Table 1 shows, 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.

2.2. Perinatal indicators routinely compiled on perinatal health in Europe

As Table 2 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 7 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 7 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, 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 by MacFarlane et al. in this issue, and the impact that registration practices can have on mortality rates is discussed in more detail by Lack et al, in this issue.

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 1 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.

Table 1
Selected indicators sets

OBSQID Quality indicators for Perinatal Care[a]	Nordic Obstetric and Gynaecological Association[b]	Germany, Hessen and Bavarian Perinatal Quality Assurance Surveys[c]	Victoria's Maternity Services Health Performance Indicators[d]	National Centre for Health Outcomes Development (NCHOD), UK[e]
Maternal 1: Maternal death 2: Number of prenatal visits 3: Eclampsia 4: Previous perinatal death 5: Previous preterm delivery 6: Detection of multiple pregnancies 7: Social class 8: Hysterectomy at delivery	1: Perinatal mortality 2: Preterm birth (<34 weeks) 3: APGAR score <7 4: Small for gestational age 5: Large for gestational age 6: Induction of labour 7: % of vaginal deliveries for breech presentation 8: Caesarean sections (all, planned, other) per 100 deliveries 9: Forceps or ventouse per 100 deliveries 10: Episiotomies per 100 vaginal deliveries 11: Sphincter rupture (III+IV) per 100 vaginal deliveries 12: Epidural analgesia per 100 vaginal deliveries	1: Fetal blood sampling in cases of pathologic fetal heart rate monitoring in singletons. 2: Fetal blood sampling in cases of pathologic fetal heart rate monitoring and secondary caesarean section in singletons 3: Presence of a paediatrician in premature birth 4: Premature birth in an obstetrical department without children's hospital 5: First caesarean section in singletons with cephalic presentation at term 6: Repeated caesarean section in singletons with cephalic presentation at term 7: Estimation of pH in the umbilical artery 8: Acidotic newborns pH Umb. Art. < 7.10 9: Perineal tear III/IV degree 10: Perineal tear III/IV degree with episiotomy 11: Disorders of wound healing with the necessity of a second operation after spontaneous delivery 12: Disorders of wound healing with the necessity of a second operation after vaginal operative delivery 13: Disorders of wound healing with the necessity of a second operation after caesarean.	1: Birth weight-standardised perinatal mortality ratio 2: Rate of term infants transferred or admitted to level 2 or level 3 nursery for reasons other than congenital anomalies 3: Rate of administration of antenatal corticosteroids to women delivered or transferred before 34 weeks' gestation 4: Vaginal birth rate for the birth immediately following a primary caesarean section 5: Selection outcomes for standard primiparae 6: The proportion of women offered appropriate interventions in relation to smoking 7: The provision of appropriate breast-feeding support and advice 8: The proportion of women who receive timely hospital and clinical services 9: The proportion of women from a non-English speaking background without proficiency in English who receive appropriate interpreter services	Fetal 9: Early neonatal mortality 10: Preterm infants (<37 weeks) 11: Caesarean sections 12: Preterm infants (<31 weeks) 13: Perinatal mortality rate 14: Fetal death before admission 15: Instrumental delivery 16: Unattended deliveries 17: Late neonatal mortality rate 18: Neonatal seizures 19: Major congenital malformations 20: Low APGAR score 21: Infants with RDS	1. General health status of mother after delivery 2. Incidence of post-natal depression 3. Smoking among pregnant women 4. Weekly alcohol consumption among pregnant women 5. Illegal drug use among pregnant women 6. Incidence of domestic violence associated with pregnancy and childbirth 7. Incidence & duration of breast-feeding 8: Maternal mortality 9: Stillbirth, neonatal and post-neonatal mortality 10: Incidence of eclampsia 11: Incidence of severe postpartum haemorrhage 12: Perineal trauma and episiotomy rates 13: Pain during labour and delivery 14: Incidence of post-natal urinary incontinence 15: Incidence of post-natal faecal incontinence 16: Gestational age 17: Birth weight 18: Maternal admissions to ICU 19: Use of antenatal corticosteroids to enhance pulmonary maturity 20: Mode of delivery rates 21: Neonatal admission to intensive and special care 22: Emergency post-natal admission of mother 23: Detection and treatment of rhesus iso-immunisation in pregnancy 24: Women's experience of maternity services

[a]OBSQID. European Consensus Conference on Quality Indicators for Perinatal Care. Annex II: The 21 essential indicators and their definitions; November 1994.

[b]Knut Dalaker and Einar J. Berle (Norwegian Society of Obstetrics and Gynecology): Clinical Guidelines in Obstetrics 1999. Oslo: Norwegian Medical Association; 1999.

[c]Geschäftsstelle Qualitätssicherung Hessen(Hrsg.) Qualitätssicherung Geburtshilfe-Neonatologie-Gynäkologie. GQH Eschborn; 2001, p. 42.

[d]Measuring Maternity Services, Victorian Government Publishing Service; 2001.

[e]Troop, P, Goldacre M, Mason A, Cleary R (Eds.) Health Outcome Indicators: Normal Pregnancy and Childbirth. Report of a working group to the Department of Health. Oxford: National Centre for Health Outcomes Development; 1999.

Table 2
Perinatal indicators routinely compiled for European countries

EUROSTAT[a]	WHO health for all database[a]	OECD health database[a]
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
Infant mortality rate	Low birth weight <2500 g	(results from EUROCAT registers)
Prevalence of selected congenital anomalies	Rates of selected infectious diseases	Maternal mortality ratio
(results from EUROCAT registers)	(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	

[a]Extracted from published reports or databases [16–19].

2.3. Conclusions of review

The review helped to define priorities for the European indicator set, and these in turn served as a framework for organising 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 identify 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.

3. Selecting the PERISTAT list of indicators

3.1. 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 indictors, if available.

3.2. Defining an indicator of congenital anomalies

The scientific advisory committee did not feel that it could propose a definition of an indicator of congenital anomalies.

We had two principal questions: can birth data collected on a national level provide a reliable source of information on congenital anomalies? And, if so, what criteria can be used to select several key indicators? To answer these questions, we held discussions with five European specialists, all of whom have long experience in data collection for congenital anomalies on the European (through the EUROCAT network of registers) and international (through the International Clearinghouse on Birth Defects) levels.

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.

3.3. 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 4-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.

3.4. The 10 core indicators

In the second Delphi round, the vast majority of participants agreed on 10 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 3 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.

3.5. 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.

Table 3
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 4
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)
Maternal health					
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
Infant health					
Prevalence of congenital anomalies	10 (37%)	23 (88%)		*	R
Causes of perinatal death (death from congential 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
Population characteristics/risk factors					
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
Health care services					
Mode of onset of labour	14 (52%)	24 (89%)			R
Pregnancy after assisted conception	9 (35%)	25 (93%)			R
Timing of 1st prenatal visit	11 (42%)	21 (78%)			R
Induced abortion rates	9 (35%)	21 (78%)			B
Place of birth (home and 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: 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); and D: more research needed on appropriate indicator, generic indicator included instead.

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 4 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 indicates similarity to others ranked higher; B indicates overlap with other Health Monitoring Programme projects, as with induced abortion, which is one of the indictors in the REPROSTAT list; C indicates 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 is 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 this 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 recognised 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.

3.6. 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 two 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 seven 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 5 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 PERISTAT indicators is presented in Table 6.

Table 5
Midwives' top 10 list

Indicators	Round II votes	%
Perinatal mortality rate[a]	11	100
Maternal mortality ratio (including by cause)	11	100
Mode of delivery	11	100
APGAR scores at 5 min	8	73
Proportion of babies breast-feeding	7	64
Growth restriction[b]	7	64
Births without medical intervention	7	64
Gestational age distribution	6	55
Postpartum depression	6	55
Births attended by midwives	6	55

[a]Included in PERISTAT list as fetal and neonatal mortality rate.
[b]Included in PERISTAT list as birth weight distribution by gestational age.

Table 6
Final list of PERISTAT indicators

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

The PERISTAT indicator set, with definitions for each indicator, is available on: http://europeristat.aphp.fr

4. Conclusion

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. 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 sub-group 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.

Finally, the feasibility study, which is presented in the rest of this issue, provides member states with baseline data with which to evaluate their data collection systems and enables them compare their systems with others in the European Union. The PERISTAT project should thus encourage and assist national and regional efforts to improve the collection of information on the health and care of mothers and babies in the perinatal period. A high quality European information system can only be built on a foundation of good local and national systems.

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