

Editorial

Perinatal health indicators for Europe: an introduction to the PERISTAT project

This special issue presents the results of PERISTAT, a project funded by the European Union (EU) to recommend a set of indicators for monitoring perinatal health and health care on the European level. These indicators are intended to be substantively and statistically useful for health professionals, policy-makers, researchers and health service user groups who wish to monitor and evaluate the health of mothers and babies in the European Union.

Europe faces common challenges in perinatal health: to maximise safety for mothers and babies, minimise iatrogenic risks associated with medical technology and decisions, reduce social inequalities in health and access to care, respond to the needs of pregnant women and their families, and use limited resources efficiently. Approaches to perinatal health care differ greatly throughout Europe. Sharing knowledge about this diversity is essential for comparing policies and outcomes between countries, monitoring trends, and developing European health policies.

Perinatal health priorities in Europe

Perinatal and maternal mortality have declined dramatically over the past four decades. In 1960, perinatal mortality rates ranged from 20 to 41 per 1000 total births in the 15 countries that today constitute the EU [1]. By the 1990s, they ranged from 6 to 10 per 1000 births. In 1970, maternal deaths from all causes ranged from 10 to 55 per 100,000 live births, while national statistics for the closing years of the twentieth century report between 3 and 13 maternal deaths per 100,000 live births [2].

The principal determinants of perinatal death in Europe today include congenital anomalies, very preterm births, and stillbirths associated with foetal growth restriction [3–6]. Moreover, preterm birth and low birth weight are important risk factors for morbidity in infancy, and morbidity in the perinatal period can have severe long-term health consequences. Changes in antenatal and delivery care have reduced morbidity from intra partum asphyxia and dystocia among babies born at term. Nonetheless, hypoxic ischaemic

encephalopathy, when it does occur together with fetal distress before or during labour, can result in long-term cerebral motor dysfunction.

Medical science also continues to push back the limits of viability. In many countries, babies born alive at 25 and 26 weeks of gestation now have a 50% chance of survival [7,8], but these extremely preterm babies have higher rates of disabling impairments than babies born at term [9,10]. Very preterm babies have the highest rates of long-term health problems, including cerebral palsy, severe learning disabilities, chronic lung disease, visual and hearing impairments and poor growth. Overall, children born before term are more likely than others to have moderate or minor motor and learning difficulties. The health and other consequences of the decisions made during pregnancy and after birth must be evaluated and monitored.

The causes of maternal death can be separated into those directly attributed to pregnancy, which include thromboembolism, amniotic fluid embolism, haemorrhage, hypertension, infections/sepsis, obstetrical complications, and ‘indirect’ causes, such as cardiac and other maternal conditions aggravated by pregnancy. Committees that audit maternal deaths regularly report that 40–60% of them are associated with substandard care [11–13].

Less information is available about morbidity among mothers. Severe life-threatening morbidity is relatively rare. It is estimated that pregnant women are admitted into intensive care units in about 0.3% of all deliveries [14,15]. Other significant maternal health conditions related to pregnancy and the post-partum period are more common. It has been estimated that between 10 and 20% of women experience depression in the two or three months after pregnancy ends [16,17]. Urinary and faecal incontinence can result from perineal trauma during childbirth and become severely distressing and disabling long-term health conditions.

It is also essential to monitor the use and consequences of medical technology. For most women, pregnancy and childbirth should be a natural process that requires little medical intervention. The challenge in obstetrics is to use and benefit from new medical technology without the concomitant over-medicalisation of pregnancy and childbirth, which results in

additional diagnostic tests after false positive screening tests, unnecessary caesarean deliveries and their attendant maternal morbidity, and always higher levels of parental anxiety. Information is needed on the effective use of medical interventions and about users' views.

Another crucial issue is social inequality of access to health care and of health outcomes. Perinatal mortality and morbidity are higher among women of low socio-economic status than among those in higher social groups [18]. This association is especially notable for mortality, low birth weight and preterm birth. The lasting health impact of poor health status in the perinatal period makes it particularly important to reduce the social and economic health inequalities associated with perinatal outcome. Furthermore, the disabilities associated with perinatal morbidity can impose a significant psychological and financial burden on families.

From research to routine surveillance

Reliable indicators of health care and health outcomes are needed to develop policies to address these health priorities. The indicators currently available provide valuable information, but they are insufficient, both in quality and breadth. The European investment in reproductive health is considerable; research financed by Europe has generated knowledge about health care and outcomes and has promoted connections between researchers and clinicians throughout the continent. This EU investment has not, however, been directed at improving routine health reporting, and much of this knowledge is not widely disseminated to policymakers. PERISTAT built on past work to develop indicators and to achieve a consensus among health professionals on reproductive health indicators in the perinatal period, including key themes for future development.

Developing a consensus on indicators for monitoring perinatal health

The PERISTAT project is not the first to search for appropriate perinatal health indicators. International collaborations on this topic date back to the last century, and numerous groups have been convened more recently. In our background review for the project, we found 28 separate recommendations on perinatal health indicators issued over the past 10 years! Furthermore, the initial discussions of the PERISTAT scientific committee, composed of individuals selected to represent the clinical and research community in Europe, revealed a generalised scepticism about currently published data on indicators and a widespread hesitation to recommend new indicators when existing ones had so many limitations.

In response to these comments and because of the large body of existing work, the PERISTAT project adopted a

pragmatic approach from the outset, aimed at improving current indicators and developing basic comparable indicators of perinatal health and health care for the countries of Europe. The selection process used to develop the PERISTAT indicators began with a comprehensive review of existing indicator sets. Research on the methodological difficulties inherent to European-level comparisons was considered in constructing the PERISTAT recommendations, which include methods for computing and presenting the indicators. For example, an important innovation is the project's recommendation that the indicators be presented by analytic sub-groups, such as gestational age, birth weight, and plurality, in order to make them more comparable and to improve their usefulness. The final PERISTAT indicator set includes 10 core indicators and 11 recommended indicators for immediate implementation (see Zeitlin et al for the full list of indicators).

The PERISTAT project also sought to identify areas requiring further development. Twelve such indicators were identified. They require significant work—either to formulate an appropriate definition or to assess appropriate data sources—before they can be implemented on a European level. They include measures of maternal morbidity, the longer term consequences of perinatal events, and positive reproductive health outcomes and thus represent key but neglected dimensions of perinatal health. Our aim is to orient future research towards these important health issues and their surveillance in routine statistics.

Assessment of the feasibility of perinatal health indicators in Europe

In line with PERISTAT's pragmatic approach, we fielded a survey to test the capacity of the member states to provide indicators, particularly those recommended for immediate implementation. This survey provides the data that are presented in the articles of this special issue. 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 show the data available for constructing indicators in Europe and to provide examples of how these might be used.

This special issue contains seven articles. The first three present the PERISTAT indicators and the methodological and data issues related to perinatal health indicators. Zeitlin et al present the results of the background review and the methods used to achieve consensus within the scientific committee. 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 organised 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 foetal health and show how the recommendations for the use of the five 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 reveals 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 three or four 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 data collection 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.

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