Report on the legal and technical basis for integrating Euro-Peristat indicators into Eurostat and ECHIM

Euro-Peristat Action Project (2010 13 01)

Deliverable n°1 for WP4

Legal structure for routine reporting and indicator integration into Eurostat and ECHIM

Report prepared by

Mika Gissler (Work package leader, THL)

Jennifer Zeitlin (Project leader, Inserm)

Marie Delnord (Project Manager, Inserm)

This publication arises from the Euro-Peristat Action project which has received funding from the European Union in the framework of the Health Programme

Co-funded by
the Health Programme
of the European Union

Table of contents

1. Introduction and objectives

This report presents work carried out under Work package 4 which included activities to achieve sustainable perinatal health reporting on the European level and involved two strategies. The first strategy was to explore the integration of Euro-Peristat into routine systems and in particular Eurostat and the European Core Health Indicators (ECHIM). The aim is to ensure sustainability because the indicators would be compiled regularly through routine Member State data reporting and reported in EU websites. The second complementary strategy was to develop a network which could seek sustainable sources of funding from the EU as well as member states. This second component of work package 4 is addressed briefly in this report; a separate report provides more detail on Euro-Peristat's vision for this network, its mission and charter..

The tasks which were proposed within this work package for exploring the possibilities of integrating EURO-PERISTAT indicators into European statistical systems included: (1) Establishing a technical working group including members of the EURO-PERISTAT Scientific Committee, EUROSTAT and members of the ECHIM Joint Action (2) Assessing which EURO-PERISTAT indicators fulfil EUROSTAT legal and technical criteria for inclusion in routine data collection (3) Describing strategies in each MS for integration of EURO-PERISTAT indicators into routine EUROSTAT reporting (4) Detailing the resources needed on the EU level to integrate EURO-PERISTAT indicators into routine data collection and reporting and (5) Develop a written proposal, with a specified time frame and submit it to member states for endorsement. As part of this work package, as well as work package 5: Develop capacity for high quality health reporting, we analysed the concordance between Eurostat and Euro-Peristat indicators in order to assess differences in common indicators.

A technical working group was established at our first SC meeting in London in January of 2012. In addition to Mika Gissler (coordinator of WP), Jennifer Zeitlin (project coordinator) and Ashna Mohangoo (responsible for data collection), other interested members of the SC included Luule Sakkeus (Estonia), Aris Antsaklis (Greece), Maria Chmelovà (Slovak Republic), Christine Cans (France) and Karin van der Pal (The Netherlands).

During the Euro-Peristat Action project, DG-SANCO's plans for ensuring the sustainability of health information projects evolved and, in particular, the possibility of setting up an ERIC for health information. This work package evolved to respond to these new potential strategies and the Euro-Peristat team actively participated in these initiatives. Furthermore, the ECHIM project was discontinued in 2012, and therefore the integration of Euro-Peristat indicators into this project was no longer an option. The following report therefore does not include mention of ECHIM. However, it describes Euro-Peristat work with ERIC and the possibilities for sustainable reporting within this framework.

EURO-PERISTAT also explored the possibilities of establishing a NGO in order to formalise the network and ensure continued collaboration of its members. This was found to be a complicated and expensive solution. The project also contacted EUPHA (European Public Health Association) to create a new section on perinatal health. EUPHA encourages the creation of sections for specific public health themes, which are international and open to all public health experts. The goal is to bring together researchers, policymakers and practitioners working in the same field for knowledge sharing and capacity building. However, the EUPHA executive board did not approve the creation of a new section because of overlaps with the current section "Child and Adolescent Health." To place the collaboration under section on child health was not

seen as sustainable, since all work related to pregnant women and mothers would have been left out in this approach.

During the project period, we held several meeting about this work package (within the group – London in January 2011, Malta in November 2012), with Eurostat (August 2011, March 2012 and March 2014), with DG Health and Consumers (March 2012). Members of the scientific committee reviewed and approved this report.

2. Future of perinatal health monitoring in Europe

The public health monitoring and reporting system in the European Union has been based on projects funded by DG Health and Consumers at the European Commission (Health Monitoring Programme, Public Health Programme and Health Programme). The current message from the European Commission is that permanent functions should not be funded by *ad hoc* projects.

Already in the late 1990s, the working group by Professor Arpo Aromaa proposed the establishment of a Public Health Monitoring and Reporting Centre for EU[1]. This proposal received support from various parties, but it was abandoned after the establishment of ECDC (European Centre for Disease Prevention and Control) in 2005. Some Member States have proposed that the mandate of ECDC should be enlarged to cover public health monitoring and non-communicable diseases, but until now this has not received enough support from the member states.

It has been suggested that the establishment of a Public Health Monitoring and Reporting Centre and/or enlargement of ECDC mandate does not get enough support in the contemporary economic and political situation in Europe. Therefore, other options have to be found:

1. DG Health and Consumers takes responsibility for routine health monitoring and reporting. Data collection would be carried out within the existing routine data collection system of EUROSTAT (demographical statistics, cause-of-death statistics, health care statistics and morbidity statistics), and perinatal health reporting would be supported by an expert group consisting of 5-7 perinatal health experts as well as a virtual network of national perinatal health data providers. The current data collection by EUROSTAT would need to be adjusted in order to be able to gather the recommended perinatal health indicators. Ad hoc data collection would be done every 3-5 years to fill out the data gaps in the current European Statistical System.

2. The Health Information Unit at DG Health and Consumers has proposed an ERIC Health Information. ERIC (European Research Infrastructure Consortium) is a tool designed for high-profile research infrastructures with a European dimension. It is a permanent legal entity with legal personality and full legal capacity, established by Commission Decision and recognised in all EU Member States. According to ERIC principles, its basic internal structure is very flexible, leaving its members to define by way of internal regulations and statutes, on a case by case basis, membership rights and obligations, the

[1] Aromaa A, Achterberg P, Bellach B-M, Gentle P, Salmi S, Sans S: Health monitoring for the European Union. A report of an expert group set up by the commission to advise on the organisation of health monitoring. Helsinki: National Public Health Institute; 2000.

bodies of ERIC and their competences. An ERIC cannot receive a permanent subvention from the EU budget, but preparatory phase funding from DG RTD is possible. ERICs, like any other legal entity, can also apply for other types of EU funding (such as projects through the Research programme and Health programme), contributions from its members, which are at least three Member States (some of these contributions can also be provided in kind) as well as from third parties, such as industry, third countries, or private foundations. ERIC is able to charge fees for its services, as long as these can be considered as limited economic activities closely related to its principal tasks and that these do not jeopardise the achievement thereof.

3. The 2014-2020 Health for Growth programme has been accepted by the Parliament in February 2014. There is a limited amount of funds, which can be allocated to health information-related projects. The possibility to apply these funds for perinatal health reporting should be kept in mind, provided that the annual work plans includes perinatal health and/or European-wide health information system.

The objectives of the planned ERIC on Health Information are:

- to enhance and support the availability and use of health information for European health policy making,

- to enhance the European capacity for health and systems monitoring and health system performance assessment (HSPA),

- to host policy relevant health data and indicators and their meta-data as generated in European projects and Member States,

- to improve health indicator sets for health monitoring, health system assessment and new policy applications, and

- to liaise with international networks and organizations in the health information area.

Tasks of an ERIC on Health Information

The core task of an ERIC is to provide a sustainable research and development infrastructure. This can for instance be achieved by hosting repositories for data, indicators and meta-data and hosting and disseminating meta-information on health data collections. For perinatal health, the work related to repositories for data, indicators and their meta-data and health reporting are the main tasks that Euro-Peristat collaboration could participate. The questionnaire completed by Euro-Peristat for the ERIC white paper on health information is attached as Annex 2.

Hosting projects as well as project data and outcomes would mean that ERIC Health Information could function to support the hosting and dissemination of the outcomes (including data) from relevant health related EU-funded projects that support health monitoring, health system assessment and analyses that assist policy making and evaluation. This would increase the impact, both scientifically and policy-wise of previously funded projects. Incorporating the results and data collection exercises of some well-known EU-funded health information projects will enable synergies with the work on indicator development and improvement of data quality, and will further expertise on health system performance assessment in Europe. Some previously EU-funded and time-limited projects have proven clear ‘sustainability’ value, i.e.

they should be repeated over time, but they are often difficult to finance repeatedly by the Commission. The core business of such projects is liaising with national experts, taking in nationally collected datasets, further developing the evidence base and regular reporting of country comparisons. The ERIC HI could host the continued activities of these projects and joint actions on a more sustainable basis. The Euro-Peristat collaboration has been cited as a good example of such an activity.

The costs for the Euro-Peristat component of ERIC Health Information would be covered by the Member States. To be able to continue the work on perinatal health, enough national funding would need to be allocated to the collaboration or funding would have to be applied from other sources, such as EU or other research funds. Finally, one Member State should take the lead for the coordination for Euro-Peristat activities under the ERIC Health Information, if it is to be established.

Currently, eleven countries and several previously funded EU projects (including Euro-Peristat) are planning to apply for funding for study design project from Horizon 2020 in order to build up a ERIC HI. Monitoring and reporting of perinatal and child health is one of the nine main tasks in the ERIC plan.

3. Integrating Euro-Peristat indicators into Eurostat: technical obstacles

There are several constraints which hamper the integration of Euro-Peristat indicators into Eurostat's routine data collection:

(1) Eurostat has one principal partner in each country, while Euro-Peristat often gets data from several sources.
(2) The contact people for the two systems are not the same in most cases.
(3) To include an indicator in the Eurostat system, agreement is required from all Member States; many of the Euro-Peristat indicators are not available in all countries, and they are not covered by the Regulation (EC) No 1338/2008 of the European Community statistics on public health and health and safety at work.
(4) The negotiation of new regulations is a lengthy process. Eurostat has completed implementation measures for the regulation specifying the rules for collection of data on fetal and neonatal deaths, which, however, does not allow reliable international comparisons on mortality-related perinatal health indicators.

The main problems with the current statistical data on perinatal health at Eurostat are the following:

(1) Data on stillbirths are collected on voluntary basis only. There are no recommendations about whether induced abortions due to fetal anomalies at 22+0 weeks or after should be included as stillbirths. The solution for this has to be found within the technical group of causes of death at Eurostat, where all member states have their representation.
(2) Information on neonatal and infant mortality is available, but not by gestational age and birth weight, as recommended by Euro-Peristat. The solution for this has to be found within the experts on demographic statistics at Eurostat. The proposal to introduce a satellite list for infant deaths by age at death (under 24 hours, 1-6 days, 7-27, and 4 weeks-1 year), by sex and by cause of death is welcomed.

(3) Information on maternal age and parity is available for live births, not by deliveries (mothers), as recommended by Euro-Peristat. The solution for this has to be found within the experts on demographic statistics at Eurostat.
(4) Information on maternal mortality is available at Eurostat for all cases and maternal age, but not published. Data on maternal deaths by mode of delivery remain unavailable. The proposal to reconsider a separate satellite list for maternal deaths with additional data from other sources is welcomed.
(5) Of the core indicators, data on distributions of birth weight and gestational age, multiple births and mode of delivery (excluding Caesarean sections) are not available at Eurostat. A solution for getting these data could be a regular *ad hoc* data collection within the future health information activities at DG Health and Consumers.
(6) Of the recommended indicators, data on congenital anomalies, Apgar scores at 5 minutes, maternal smoking, maternal education, births after fertility treatments, timing of 1st antenatal visit, mode of onset of labour, place of birth, breastfeeding at birth and very-preterm births by level of care are not available at Eurostat. A solution for getting these data could be a regular *ad hoc* data collection within the future health information activities at DG Health and Consumers. The feasibility of using EUROCAT data on congenital anomalies and ESHRE data on fertility treatments should be evaluated.
The recommended list for amenable and preventable mortality list includes all deaths related to complications perinatal period (ICD-10: P00-P96, A33) and deaths from congenital malformations (ICD-10: Q00-Q99) under 75 years. From perinatal health point of view, it is difficult to justify the inclusion of all deaths in ICD-10 chapters P and Q. First, all perinatal deaths are not preventable. Second, deaths from congenital anomalies can be prevented if detected during pregnancy and the pregnancy is terminated due to fetal reasons. This may not be the message to give for public. Perinatal deaths could be restricted to live births (after viability), since deaths due to prematurity and infections are preventable, and deaths from congenital anomalies to congenital cardiovascular anomalies, which in most cases can successfully be treated by surgery. These would give a more precise picture on amenable deaths related to perinatal health (Nolte E, McKee M: Measuring the health of nations: analysis of mortality amenable to health care. BMJ2003;327 and Tobias, M. & L. Yeh (2009), How much does health care contribute to health gain and to health inequality? Trends in amenable mortality in New Zealand 1981-2004, Aust N Z Public Health 33:70-78).

In the meetings with Eurostat the following conclusions were reached:

- For all the reasons described above, the possibilities for integrating Euro-Peristat indicators into Eurostat's routine data collection exercise are limited, but on-going dialogue between perinatal health experts and Eurostat should be maintained.

- It is helpful for Euro-Peristat to have data to cross-check their information with but it is not a sufficient reason for Eurostat to take on the level of detail that Euro-Peristat needs. Also, it is difficult for Eurostat to insist on refining its data from a wider public health perspective when smaller numbers are reported, although these data might be relevant for key subgroups from a perinatal health perspective.

- One solution for the Euro-Peristat project would be to gather a Minimum Dataset to construct the Euro-Peristat indicators. Eurostat could be a depository for such data if countries agree to provide these. They

would need to be piloted for one or two years prior to routine data collection and analysis at Eurostat by Member States.

Annex 1: Requested changes in the EUROSTAT data collection

	Variables	EUROSTAT availability	Problems / Comments	Action
Core 1	Fetal mortality by gestational age	New implementation regulation: yes, but voluntary	No common definition agreed. Induced abortions after 22 gestational weeks not included.	Cause-of-Death Statistics: Improved data quality by more accurate definitions
	Fetal mortality by birthweight	New implementation regulation: yes, but voluntary	No common definition agreed. Induced abortions after 22 gestational weeks not included.	Cause-of-Death Statistics: Improved data quality by more accurate definitions
Core 2	Neonatal mortality by gestational age	Not available	Only total numbers collected.	Cause-of-Death Statistics: Improved data quality by more accurate data collection
	Neonatal mortality by birthweight	Not available	Only total numbers collected.	Cause-of-Death Statistics: Improved data quality by more accurate data collection
Core 3	Infant mortality by gestational age	Not available	Only total numbers collected.	Cause-of-Death Statistics: Improved data quality by more accurate data collection
	Infant mortality by birthweight	Not available	Only total numbers collected.	Cause-of-Death Statistics: Improved data quality by more accurate data collection
Core 4	Distribution of birthweight	Not available		New data collection to be initiated. ERIC Health Information
	Distribution of birthweight by gestational age	Not available		New data collection to be initiated. ERIC Health Information
Core 5	Distribution of gestational age	Not available		New data collection to be initiated. ERIC Health Information
Core 6	Maternal mortality by maternal age	Can be collected from detailed mortality data.	Data quality may vary by country.	Cause-of-Death Statistics: Improved data quality by a new satellite list
	Maternal mortality by mode of delivery	Not available		

Core 7	Multiple births	Not available		New ad hoc data collection to be initiated: ERIC Health Information
Core 8	Distribution of maternal age	Available	Calculated per live births instead of recommended per deliveries.	Current demographic data is used as a proxy. More accurate ad hoc data collection to be initiated: ERIC Health Information
Core 9	Distribution of parity	Available	Calculated per live births instead of recommended per deliveries.	Current demographic data is used as a proxy. More accurate ad hoc data collection to be initiated: ERIC Health Information
Core 10	Mode of delivery	Only section available in hospital procedures		Current data on section is used as a proxy (health care statistics). More accurate data collection to be initiated: ERIC Health Information
	Mode of delivery by parity	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
	Mode of delivery by previous caesarean	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
	Mode of delivery by presentation	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
	Mode of delivery by plurality	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 1	Prevalence of congenital anomalies	Not available	Alternative data source: Joint Research Centre/EUROCAT	Data collection through ERIC Rare Diseases/Joint Research Centre/EUROCAT
Recommended 2	Distribution of Apgar score at 5 minutes	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 3	Maternal mortality by cause of death	Can be collected from detailed mortality data.	Data quality may vary by country.	Cause-of-Death Statistics: Improved quality by a new satellite list
Recommended 4	Women who smoke during pregnancy	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information

Recommended 5	Mother's education	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 6	Births after fertility treatment	Not available	Alternative data source: ESHRE for IVF and IUI	More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 7	Timing of 1st antenatal visit	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 8	Mode of onset of labour	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
	Mode of onset of labour by gestational age	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 9	Place of birth	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 10	Breastfeeding at birth	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information
Recommended 11	Very-preterm births by level of care	Not available		More accurate ad hoc data collection to be initiated: ERIC Health Information

Annex 2: Questionnaire on the Euro-Peristat project for integration into a European Health Information System

I. General description of the project	
1. Title of the project	EURO-PERISTAT Promoting better health for mothers and babies through routine European monitoring of perinatal health and health care
2. Contact details	Project Leader: Jennifer Zeitlin: Jennifer.zeitlin@inserm.fr INSERM U953 Maternité de Port Royal – 6ème étage 53 Avenue de l'Observatoire 75014 Paris Project Manager : Marie Delnord : marie.delnord@inserm.fr INSERM U953 Maternité de Port Royal – 6ème étage 53 Avenue de l'Observatoire 75014 Paris
3. Overall objective of the project	The project's main goal is to improve mothers' and babies' health by building a European perinatal health surveillance system to provide evidence to policy makers, clinicians and users for informed decision-making.
4. The summary the key activities in terms of health information (e.g. area it covers, is it data collection, development of indicators, information system, development of guidelines)	The project began in 1999 as part of the Health Monitoring Programme and has continued into a third and fourth phase, with the ultimate aim of establishing a sustainable system for monitoring perinatal health indicators and producing a routine European Perinatal Health Report . The EURO-PERISTAT project has developed valid and reliable indicators that can be used for monitoring and evaluating perinatal health in the EU. The current project is based on 30 indicators, which were developed with rigorous scientific methods and tested twice (on 2000 and 2004 data)

	The current action has 5 specific objectives: 1. Integrate EURO-PERISTAT perinatal health indicators into European statistical systems 2. Establish a European Perinatal Health Surveillance Network 3. Develop capacity for high quality health reporting 4. Monitor trends and inequalities in perinatal outcomes and care in Europe 5. Expand EURO-PERISTAT's geographical coverage. The specificities of the EURO-PERISTAT project are: - Use of a common data collection protocol with careful attention to cross-country comparability - Collection of data using sub-groups making it possible to analyse indicators in more depth - Creation of a network of specialists who actively participate in analysis of trends and variations
5. Which countries participate(d) and/or which entities from which countries	The EURO-PERISTAT Action project is coordinated in Paris through a partnership between the Institut national de la santé et de la recherche médicale (INSERM) and five other beneficiaries: THL (Finland), TNO (The Netherlands) , CITY U (UK), and NRIMC (Poland) Scientific work is led by an Executive Board that meets regularly and works with representatives from each member state on the Scientific Committee. In Phase I of our project, 15 Member states (2000-2004) participated. In Phase II & III 15 + 10 new Member States + Norway (2005-2010) participated and currently, in Phase IV, 26 EU-Member States, Norway, Switzerland, and Iceland (2011-2014) participate. Please see Annex for a list of the current Scientific Committee members.
6. Was/Is it co-funded by EU Financial Mechanism and if yes which (EU Health Programme, Research Framework Programme,…)	The project is co-funded by the EU Health Programme
7. Total budget	1.012.949,31 € (current project)

EC contribution	See below for previous phases
	59.96%
Total administrative costs	We need further information about what this comprises before we can provide an estimate.
8. Duration of the project (count together with the continuation or follow-up projects)	2011-2014 (current project duration: 36 months) EURO-PERISTAT Action "Promoting better health for mothers and babies through routine European monitoring of perinatal health and health care". 01/04/2011-31/03/2014. EC contribution: 607343 €. 2008-2009 EURO-PERISTAT III " Better Statistics for Better Health for Pregnant Women and Their Babies: European Health Reports" 01/07/2008 - 31/12/2009. EC contribution: 149 987 €. 2004-2007 EURO-PERISTAT II "Comprehensive health information and knowledge system for evaluating and monitoring perinatal health in Europe "15/12/2004 - 15/12/2007. EC contribution: 846 776 €. 1999-2002 EURO-PERISTAT 'Indicators for Monitoring and Evaluating Perinatal Health in Europe' EC contribution: 240 000 €
9. If the project has finished what is the current status of the activity	NA
10. The result of the project (If not yet finished what is the expected result)	The principal outcome is a high quality, innovative, internationally recognised and sustainable European perinatal health information system that compiles and analyses data on a regular basis. While transitioning to this system, the project compiles new data and produces analyses on patterns of perinatal health and care in Europe. The project has produced several reports: a Special Issue in the European Journal of Obstetrics, Gynaecology and Reproductive Biology in 2003, the first *European Perinatal Health Report* in 2008 and *European Perinatal Health Report: Health and care of pregnant women and babies in Europe in 2010.*

	The EURO-PERISTAT network has published more than 20 articles in peer-reviewed journals based on these data (see our website www.euro-peristat.com for a full list of articles). Other researchers have also used the EURO-PERISTAT data – which are made available freely on our website – for research on perinatal health in their own countries.
11. If data collection resulted from the project, what is the quality and comparability of this data, have Eurostat standards been taken into account?	The EURO-PERISTAT indicators are grouped into four themes: fetal, neonatal, and child health, maternal health, population characteristics and risk factors, and health services. The indicators and their definition are available from our website: www.europeristat.com The indicators were developed by a procedure that began with an extensive review of existing perinatal health indicators. The resulting list was used as the basis of a DELPHI consensus process, a formalised method in which a panel of experts responds to a successive series of questionnaires with the aim of achieving a consensus on key principles or proposals. To develop and test a list of perinatal health indicators, EURO-PERISTAT enlisted the assistance of perinatal health professionals (clinicians, epidemiologists, midwives and statisticians) from EU member states and Norway, and consulted with other networks like SCPE, Eurocat, and Euroneonet. A study using data for the year 2000 was conducted to assess the feasibility of the EURO-PERISTAT indicators; the results were published in a special issue of the *European Journal of Obstetrics Gynecology* and Reproductive Biology and used for detailed analyses of health indicators in Europe. The indicators were tested again with 2004 data. In 2012, the EURO-PERISTAT indicators were updated based on our experiences with the first European Perinatal Health Report and the assessments of our Scientific Committee (SC) about the continued relevance of the indicators. A study is on-going as part of our current project comparing EURO-PERISTAT indicators with Eurostat. This report will be finalized in March 2014.

II. The potential for integration of the project with the ERIC on Health Information

1. Is there an interest to integrate long term activities required to maintain the added value of the project in the new ERIC on Health Information?	Our network is committed to continuing to support the perinatal health surveillance of mothers and babies in Europe. The longevity and growth of our network over the past 10 years testifies to the commitment of our participants to improving European health monitoring systems.
2. Describe the societal challenge that can be better addressed with the results of this action	A healthy pregnancy and infancy are a priority in all European countries. Healthy adulthood begins in utero; in Europe, large health inequalities remain between and within countries. The burden of these inequalities falls on young people. Every year, there are about 23,000 stillbirths and 22,000 infant deaths and 40,000 (≈8 per 1,000 births) babies are born with severe impairments, many of perinatal origin. Although, medical advances are being made which allow for increased survival of extremely preterm infants, sub-fertility treatments, or prenatal screening; a key challenge is to benefit from new technology without over-medicalizing pregnancy and childbirth. Data available in the European Perinatal Health Reports can be used as a point of comparison for individual countries. For those indicators for which reliable data exist, countries can benchmark performance in providing effective health services and promoting the health of mothers and their newborn babies. Another aim is to reveal the strengths and weaknesses of perinatal health information systems and to encourage countries to invest in the resources needed to improve the completeness and quality of the data necessary for evidence-based public policy. Data to construct the EURO-PERISTAT core indicators are available in almost all countries, but there are still many gaps. Many countries need to improve the range and quality of the data they collect. Many countries have little or no data on maternal morbidity, care during pregnancy, and the associations between social factors and health outcomes.
3. Describe key aims of the action within the	The ERIC Health Information platform provides the opportunity for a financially

ERIC on Health Information, including prospects over time	sustainable mechanism for the production and use of perinatal health data. The EUROPERISTAT network requires continued financing to collect its set of indicators and routinely report on these indicators, analyse them and disseminate results.
4. Is this action permanent in nature, can it be implemented in different phases, which elements are permanent in nature, which elements can have a defined timeframe to be implemented?	The project began in 1999 as part of the EU's Health Monitoring Programme and has continued into a fourth phase with the ultimate aim of routinely producing data on perinatal health in Europe. Given that data collection and cleaning is a year-long process, releasing a report every 4-6 years would be an acceptable time frame for routine monitoring of perinatal health indicators in Europe. Other elements of the project which would be defined on a yearly basis include: analyses on patterns of perinatal health and care in Europe and dissemination of results within the international scientific community and to health policy planners. Whether this aim of routine reporting is achievable depends mainly on the availability of support at both European and national levels.
5. Will the action include training or educational dimension?	Yes, through methodological seminars and analysis based on data.
6. If data collection will be included, what quality standards will be applied, what will be the level of comparability?	Improving data quality standards is part of EURO-PERISTAT's mission. We have worked on: establishing common definitions to ensure a high level of comparability for all our indicators, promoting linkage, and developing new perinatal health indicators. Our indicator list was selected through several rounds of a DELPHI consensus process in which clinicians, researchers, epidemiologists and midwives participated. The indicators were pretested twice: on 2000 and 2004 data and updated once more in 2012.

	Results from these studies were presented in a Special Issue of the *European Journal of Obstetrics ,Gynaecology and Reproductive Biology*
7. Describe the potential and interest of further research based on the data and services provided	These data make it possible to evaluate public health policies in Europe and produce knowledge to improve maternal and child health. In recent years research has also found connections between perinatal health and chronic diseases of adulthood. Babies born too small as a consequence of fetal growth restriction are more likely than others to develop diabetes and metabolic syndrome as adults. Other implications for adult health of adverse events during pregnancy are currently being explored. These relations make the monitoring of perinatal health outcomes more important than ever
8. How will this action contribute to the overall health evidence framework at EU level?	Promoting healthy pregnancy and safe childbirth is a goal of all European health care systems. EURO-PERISTAT is an internationally recognized high quality surveillance network which brings tenures of collaborative expertise to the overall maternal and child health evidence network at EU level. Data from our reports were widely used by health providers, planners, policy makers, researchers, and users across Europe and beyond. Our first report was downloaded more than 8000 times from our website. Our second report has been downloaded over 3000 times in five months and more than 100 media articles reported its publication. Individual European countries increasing rely on this reference list of indicators to evaluate their policy initiatives and benchmark their performance. The EURO-PERISTAT network has published more than 20 articles in peer-reviewed journals based on these data (see our website www.euro-peristat.com for a full list of articles). Other researchers have also used the EURO-PERISTAT data – which are made

	available freely on our website – for research on perinatal health in their own countries.
9. Is there potential for collaboration with third countries? Which ones?	Our current Member States include 26 EU-Member States, Norway, Iceland and Switzerland. We are currently working on extending our network to Bulgaria and new EU-Member States. The project's main aim is to monitor mothers' and babies' health in Europe but there is great potential for international collaborations on specific research themes based on the knowledge acquired by our members in analysing international data and interpreting population level variations across countries. Euro-Peristat is currently collaborating with: - PREBIC, a multinational collaborative of clinicians and research scientists who aim to improve pregnancy and birth outcomes, optimising infant health and long term development with participation from: Europe, Asia, North America, South America, and Australia - ROAM, The Reproductive Outcomes and Migration: an International Research Collaboration (ROAM) which brings together 33 researchers from 13 countries. Although all aspects of migrant women's reproductive health are of interest to ROAM, the collaboration has begun its work by focusing on perinatal health. - and The PEARL-Peristat Project which has begun to create a regional Reproductive Health Registry in countries of the Gulf Cooperation Council (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and United Arab Emirates).
10. Estimated total budget/year	175 000 Euros per year
Estimated total administrative costs/year	We need further information about what this comprises before we can provide an estimate.