EURO-PERISTAT: REPORT ON THE EVALUATION / INTERVIEWS BY THE EXTERNAL ADVISORY BOARD

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By Sophie Alexander and Lilas Weber

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Abbreviations

EAB:	External Advisory Board
EPHR-2010	European Perinatal Report 2010
LMIC	Low and middle income countries
MNCH	Maternal neonatal and child
OECD	Organisation for economic co-operation and development
ULB	Université Libre de Bruxelles
ULB-ESP	School of Public Health at ULB
WHO	World Health Organisation

I. Context and introduction

The content of this report is external evaluation component of the fourth EURO-Peristat project (2011-2014). The EURO-Peristat has been a collaboration between member states of the European Union and other European countries to provide and analyze indicators of maternal and child health in the perinatal period with a final goal of health improvement.
In this fourth and latest EURO-Peristat project the external evaluation addressed global issues: the process, the deliverables, and sustainability.

The evaluation strategy originally negotiated in the contract was modified in Year 1 of the project. It was deemed preferable to have the External Advisory Board evaluate the project at the end of the third period in order for them to have a more comprehensive view of activities and to give the opportunity to evaluate the main deliverable of our project: the European Perinatal Health Report 2010 (EPHR-2010).

II. Methodology and list of experts for the external advisory board (EAB)

The EAB aimed to identify and discuss areas in which the project achieved its goals and areas in which further work is necessary. Six to ten telephone interviews of key informants were planned, involving individuals who have used the EURO-Peristat data in their work and who are familiar with the project.
These interviewees were all but one "at arm's length" of the project and had no identified source of conflict of interest in answering the interview. The interviewee who is not at "arm's length" is the lead person of the Eurocat project. This was decided on, because it was considered necessary to interview one other person familiar with European perinata data collection, albeit in another context.

Selection of the respondents: Informants were identified collectively during a scientific committee meeting in January 2014. The members of the steering committee suggested people coming from different professional backgrounds as well as from different types of organizations.

- Types of organizations
    - National advisory for policy making
    - National other
    - International (WHO, user association, lobby group)
- Types of stakeholders
    - Academics
    - Clinicians
    - Lobbyists
    - Public Health counsellors
    - Mix of more than one of the above

It was aimed that respondents should come from all continents, but finally only Europe and the US were represented.
The task of selecting the external advisory board was by definition complex, and as always in qualitative research, it is difficult to be certain that the choice was optimal.

Table 1: list of contacted experts

Name of the expert		Country	Occupation
Russel	**Kirby**	USA	Professor and Marrell Endowed Chair at USF (university of south Florida)
Soo	**Downe**	UK	Chairs the UK Royal College of Midwives Campaign for Normal Birth steering committee, member of the UK Medical Research Council College of Experts, professor at the University of central Lancashire
Peter	**Achterberg**	Netherlands	National Institute for Public Health and the Environment
Nicole	**Thiele**	Germany	Vice Chair of the Executive Board of EFCNI (European foundation for the care of new-born infants)
Gunta	**Lazdane**	Danemark	Programme Manager, Sexual and Reproductive Health, WHO Regional Office for Europe, PhD
Albrecht	**Jan**	Germany	Gynecologist, Professor at Institute of Public Health, University of Heidelberg, Head of the research group "Global Health Policies and Systems"
Helen	**Dolk**	Ireland	Professor of Epidemiology & Health Services Research, Institute of Nursing and Health Research, University of Ulster

Two other experts had agreed to be interviewed from Birthchoice UK (consumers), and from Statistics Australia, the University of Sidney, South Wales, but a possible date and time never materialised.

All experts contacted agreed to be interviewed.

Content of the interviews: The interviews focused over 3 topics:

1. The process leading up to the latest European Perinatal Health Report 2010 and the choice of indicators
2. The usefulness of the report for Europe and countries' key perinatal stakeholders
3. The reach, impact and sustainability of the EURO-Peristat process

An outline or canvass for a semi-structured interview was elaborated by the ULB-ESP team. It was then submitted to all the members of the steering committee and revised accordingly (Appended 1)

Process of the interviews: Each of the experts was contacted first directly by a member of the steering committee to ask for his/her interest. They then received a letter from ULB giving detals of the process (individual interview around 60 minutes, with questions sent in advance. The main topics addressed were also outlined. When he/she agreed, the ULB-ESP team took the lead to organize a convenient telephone meeting. Finally, 7 interviews were performed, between the 18th of March and the 20th of June.

These interviews were organized and executed by a team from ULB consisting of Lilas Weber and Sophie Alexander.

The interviews were conducted by phone or through a Skype call; one person (SA) interviewed, two people took notes (SA+LW) and the conversations were recorded. An outline or canvass for the semi-structured interview was sent to the interviewee by email prior to the conversation and they were asked to fill it in if they wished and to send it back before the interview if convenient (appendix a). Anonymity was ensured regarding the answers.

Monitoring Tools were developed for data collection: an Excel spread sheet was used to monitor the contacts with the experts. Dates for sending reminders were recorded, as well as the answers of the experts (available if requested).

The following **problems were encountered** and solved.

- Getting the contact and especially finding a convenient date and time was not always easy. However, once the interviews were occurring, the process was straightforward.
- The busy colleagues who were involved for this consultation process seemed pleased to be interviewed, give their opinion and had obviously thought about the topics it depth.

Data analysis was conducted using a qualitative approach. Therefore, no specific indicators were planned. The initial goal pursued was to achieve the interview of the selected experts and to reach saturation (i.e.: no new information coming up from the last interviews). However, in effect, to the last interview new ideas were still emerging.

An initial analysis was performed by the same team (LW + SA) through a qualitative methodology, based on content analysis and emergence of new ideas. All questionnaires filled by the experts, completed by notes taken during the interview were reviewed and main topics or ideas were recorded for each expert in a summary Excel spread sheet under the various categories of the questionnaire (Available if requested). Emerging ideas or recurrent topics were identified and recorded on another sheet. This report was written, stemming from these two summary spreadsheets.

The process was found to be so rich that, post-hoc, it could be considered of value to add one or two interviews, from other countries and profiles; and to perform a more in depth analysis. In particular, clinicians and consumers may have been under represented.

This project was originally planned for internal use. However, as mentioned above, it could be considered, after full analysis that the results are sufficiently challenging to deserve some form of external dissemination.

III. General considerations and concepts common to all topics

Globally, the experts acknowledged the importance and uniqueness of the EURO-Peristat goals and process, and considered it to be very useful. Their opinions were consensual regarding the overall project, in a very positive way. They consider that EURO-Peristat is an important added value to European and national public health monitoring and the process is regarded as “transparent”.

Four experts mentioned that the process does more than providing data and analysis on perinatal health, because it also allows to strengthen infrastructure, to harmonize data collection and indicator definition.

Four experts wished to comment on the “benchmarking” value of the process. This topic brought on a discussion about indicators for promotion of quality of care, such as third degree lacerations or intra-uterine transfer. However, not all experts shared similar views in relation to the added value of using EURO-Peristat for audit or quality assurance.

Two experts emphasized the necessity of introducing on-going procedures of verification of validity of data. A possible example for this would be systematic assessment of variability. However the interviewing team considers in agreement with the principal of subsidiarity, these aspects probably are the responsibility of each national government.

IV. TOPIC 1: the process leading up to the latest European Perinatal Health Report 2010 and the choice of indicators

Some interviewees were not familiar with the process leading up to the EPHR-2010. They mostly believed that the process was part of a routine European system. Most were knowledgeable about the process, and they mostly saw it as a "normal" or "necessary" activity. They mostly said the chapter relevant to the process in the EPHR-2010 was not an "easy read".

Choice of indicators

Generally, the experts agreed with the choice of indicators. According to them, the EURO-Peristat indicators are "pragmatically adequate" because recorded in most countries, covering health behaviour before and during pregnancy and some social determinants such as education and migration. One person pointed out that indicators need to be revised regularly because goals, conditions and behaviours change over time (e.g.: C-section indications, obesity and pregnancy, use of e-cigarette, foetal surgery, etc.).

Two experts questioned the usefulness of collecting congenital anomalies, when this was more the mandate of the Eurocat.

Missing indicators

Although all the interviewees were satisfied with the choice of indicators, most of them suggested that more are needed and that some could be analyzed more in depth.

The following indicators were suggested:

- income level data (e.g.: income quintiles or use of regional differences as a proxy variable)
- rural / urban
- indicator of normal birth
- follow up of assisted reproductive technology and intensive care units both neonatal and adult
- cost-effectiveness of health planning
- pregnancies (="maternities" in the UK concept)
- limits and conditions for issuing birth certificates
- breastfeeding, milk banks, Baby friendly initiative hospitals
- level III neonatal intensive care units, couplet care
- training and continuous professional development health professionals
- pregnancy books (as the "Mutti-Pass")
- maternal and neonatal screening procedures
- preconceptional folic acid
- maternal disease
- hypoxic-ischemic encephalopathy and its relation to cerebral palsy

One expert wished to move maternal morbidity from recommended to core indicators. According to him, even though it is a difficult parameter to measure, moving it to a core indicator would potentially decrease problems of comparability and improve data quality. He also mentioned the possibility to use the WHO near miss tool for this.

Feasability of data collection and analysis

None of the interviewed experts were directly involved in the data collection of EURO-Peristat.

Three interviewees emphasized that having individual data would be greatly better than having aggregate data to be able to stratify them and make sub group analysis.

The problems related to lack of uniformity of definitions in different countries was also raised (e.g. stillbirth, termination of pregnancy, smoking etc.)

Presentation and layout

The experts were unanimously very positive about the EURO-Peristat reports, the second being considered more useful and detailed than the first one. The following expressions were used:

- "*the quality, presentation and layout of the reports"*
- *"clear, authoritative, helpful, readable and comprehensible"*
- *"so easy to get a good and broad impression"*

According to one of the expert, the first report entered a unique field that was so far totally neglected and the second report contained more useful data.

Another interviewee mentioned that it is invaluable to have on line access to results and analysis. Another suggested having data electronically on DVD – and to distribute only executive summary.

V. TOPIC 2: the usefulness of the report for Europe and countries' key perinatal stakeholders

Usefulness for different actors and different goals

In general, the experts considered that the report were very useful for all stakeholder. The following aspects were mentioned.

- Advocacy and sharing the message

The interviewee said*: "The report serves as source of information in our messaging and for advocacy "*

Two experts mentioned they were using the results of the reports "all-over the world", and more especially in the low and middle-income countries.

Two experts mentioned the interest of following performance development of the countries over successive reports. One said: "*the report presents good interpretation, challenges, warnings, and recommendations and increases the general understanding of the importance for healthy aging. It is essential to have a third report in order to see the trends*"

One expert working in LMICs insisted that it is of interest to show the reports in countries that are still far off from the EURO-Peristat data quality.

The report is considered to have a potential to influence surveillance systems in countries where such systems exist and help to be more critical at your own national data, by seeing other countries results (two interviewees / not in their view as true benchmarking, but rather as a hypothesis generating process, for advocacy).

- Decision-makers and policies

Several experts emphasized the interest of having analysis of data and the usefulness in terms of advocacy, funding and potential for policy.

One said: "*it is an exceptional example of policy relevant outcomes from EU funded projects*". Another expert said: "*The 2010 report is the most used document for policy-makers, there is nothing comparable*"

Another expert considered the report can also be used as a goal to reach, developing regional policies and strategic documents.

- Clinicians

A clinician considered it could contributes to the challenge of orienting clinicians towards a change in paradigm and care more centred on global population health.

- Press and media

In the Netherlands, one interviewee mentioned, every report is widely discussed at national level. Thanks to this policies have changed and outcomes have improved between the first and the last report.

This may however be a unique situation, as 4 out of the 7 interviewed experts mentioned explicitly that the reports had insufficient press coverage and were not widely discussed as they should be.

- Policy prioritization and research agendas for policy makers and funding bodies

It was also mentioned that this report represents a useful tool for prioritization / identification of gaps or weaknesses and development of better instruments and programmes. The report can serve as tool for possible warning mechanisms (e.g. obesity)

- Academic teaching about quality of data

The report was in use to initiate discussion on reliability of data (2 interviewees)

Still to improve

However, a certain number of constructive criticisms and suggestions emerged.

- Unlike the report, the summary is not user friendly for non-scientists and could be improved in order to give clearer key messages (2 interviewees).
- Six out of seven experts regretted that the report did not have a better visibility and dissemination. They found that these were not taken up enough by the press. When trying to disseminate it as much as possible (EU parliament and national meetings) it seemed unknown of many stakeholders of MNCH. Four experts, out of 7 declared in addition that within the need for better dissemination, there should be a better focus on recommendations
- One interviewee suggested carrying out a regular survey to document actions that were taken in countries as a result of the implementation of EURO-PERISTAT recommendations.
- Patient representation may be missing/insufficient
- On a very practical side, one interviewee mentioned that it is a pity that the reader cannot jump to the different chapters in the pdf document, the more so as the pages of the report do not correspond to the pages in the pdf.

VI. TOPIC 3: THE REACH, IMPACT AND SUSTAINABILITY OF THE EURO-PERISTAT PROCESS

Reach and impact: the added value of Euro-Peristat

The respondents were unanimous in declaring that the principal added value of EURO-Peristat compare to other systems such as EUROSTAT, OCDE or WHO is the amount of analysis that are performed. One said: "*when EUROSTAT or WHO present results for each country, it will be tedious and time-consuming to go over the results and draw your own conclusions, while EURO-Peristat provides a direct analysis, figures, interpretation and recommendations*".

This advantage of providing analysis and the intelligibility of the presentation of the reports were the two most recurrent and unanimous items cited by the external advisory board.

Sustainability

Three experts, out of the 7 interviewed, were not aware that the EURO-Peristat process has no security and might not be able to continue. All of them agreed not having it would be a great loss.

Regarding drawbacks and shortfalls, three interviewees considered the end of EURO-Peristat would mean losing an important resource to observe and analyze health status and behaviour of EU citizens, starting at the very beginning. Another expert mentioned the lack of input to the bulk of scientific work in the area of perinatal health that the loss would create. Another expert considered that, for clinicians, information about MNCH epidemiology would be left to international congresses, but that because these are restricted to a given speciality, the link between maternal, newborn and perinatal health would be missing.

Two interviewees emphasized that it would be very problematic not to have EURO-Peristat anymore, all the more so since quality of data collection is actually decreasing in some countries, due to changes in funding (decrease or change in source; UK, USA)

Two interviewees mentioned the role of Marsden Wagner at WHO Copenhagen, in the 1970s, in writing the book "having a baby in Europe", and thus starting the process of comparative European perinatal epidemiology. The same persons reminded the interviewers that WHO had attempted to set up a European system on a voluntary base, the OBSQUID, and that without funding this had been unsustainable.

Possible alternatives to Euro-Peristat

Regarding alternatives to EURO-Peristat, the experts were asked whether they had an opinion concerning two possibilities: a network such as The International Network of Obstetric Survey Systems (INOSS) or regular European surveys. They were also asked if they had any other suggestion.

Networks

The voluntary network did not elicit much enthusiasm. The interviewees mentioned difficulties of scope, aim and power. On the other hand one interviewee considered that a funded network with financial participation both of the member states and the EU was a long term solution. Another interviewee also considered this to be the future, but with a formal remit determined by an advisory board with a national delegate officially nominated by each government.

Surveys

All interviewees agreed that surveys may be better than nothing but are very costly. However they provide an opportunity to look at additional data that are not fully embraced by other data collection methods. For instance about smoking, alcohol, diet, lactational support etc.).

Other alternatives

The interviewees concurred that there is a need for a regular system and sustained system. Routine data are the core for improvement. What is expensive is generating them at national level. Putting them together at European level as in EURO-Peristat is a huge added value. Having a system to report from all EU countries is essential, also in order to continue working on common definitions. One interviewee mentioned that having valid data for action is part of the European mandate for equity.
Some practical suggestions were made:

- *"Why not a collaboration of national institutes for MCH? This is what has happened from each of the German regions"*
- *"Set up MNCH dedicated office in EU Commission"*
- *"There should be a little shift in the member states. They cannot wait everything coming from Europe. The member states should also make a commitment and participate. A sustainable solution would be to be networking facilities, capacity building. And networks can ask money from Horizon 2020 or these funds. It is very important that EURO-Peristat is sustained / "It would be interesting if a perinatal risk model could be distilled from the huge amount of data collected, with the aim to present differentiated national policy options and possible priorities." / essential that participating countries will not just wait for subsidies from the EU to continue the work, but commit part of their regular work to it on their own costs. It should be essential basic awareness from all participants that monitoring their own national perinatal health will always benefit from putting it in an international perspective.*
- *Ethical and legal aspects should be harmonized to enable more data sharing and difficult collaboration – e.g. harmonization of legislation determining data sharing and consent wording*
- *We could try to use the post 2015 process to include donor countries as well to have a global post 2015 agenda / it is possible to link perinatal health to the broader non communicable diseases topic that are big on the agenda*

VII. NEW IDEAS GENERATED BY THE INTERVIEWS

Most of the interviewees had themselves a broad experience of collecting, analyzing and sharing perinatal data, which probably means that this topic was one about which they had already given thought. The following ideas emerged:

- The problem of whether the goal is research or providing recommendations
- Routine data are at the core of improvement in health care
- Ethical and legal aspects should be harmonized to enable more data sharing – e.g. harmonization of legislation determining data sharing and consent

VIII. CONCLUSIONS AND RECOMMENDATIONS

The EAB process showed, beyond doubt, that the Euro-Peristat process and in particular the reports generate enthusiasm and admiration in the relevant community. The choice of indicators needs to be regularly updated but is considered appropriate for the moment. It is the analysis component which is the main outstanding

feature in Euro-Peristat, which cannot be found in other available perinatal data bases. There is consensus that dissemination and visibility are the weakest part of the project. The double orientation towards research and policy recommendations is not always an easy balance to achieve, however the process is considered to be of great value. Quoting one of the expert: "*What needs to be thought about is a sustainable funding mechanism, in order to institutionalize the process in the long run*"

Appendix A: interview canvass

EURO-PERISTAT External Advisory Board: semi-structured interview with external experts

A/ Expert details

1. Interviewed colleague
    a. Name, attribution and country
    b. Personal experience in perinatal issues and indicators

B/ Regarding the EURO-PERISTAT projects and reports achievement

1. What do you think of the EURO-PERISTAT process of collection, analysis and dissemination of perinatal data in Europe[1]?

2. The EURO-PERISTAT has elaborated and recommended some core indicators :
    a. Do you have comments on the chosen indicators?
    b. Are there any specific major missing indicators? And why?
    c. Would you like to comment on feasibility of data collection and data sharing in the context of your personal experience?

3. The EURO-PERISTAT project has produced 2 reports (data from 2004 and 2010) :
    a. Would you give a global comment on those reports?
    b. What is the usefulness of our reports for perinatal stakeholders in your country (for clinicians, policy makers, researchers, consumers, media, other)
    c. Any other comment

[1] EURO-PERISTAT was constituted of a series of 4 projects supported by the EU DG SANCO. The first (2000-2004) was initiated within the broader framework of the EU health monitoring program. The EURO-PERISTAT group included clinicians, people working in statistic offices and public health specialists. In the first project, a list of indicators has been elaborated through a Delphi process. A European report has been elaborated for each of the 4 projects, including all indicators in all EU countries. Other activities were conducted which are less relevant to this interview but can be found on the website: : http://www.europeristat.com

4. In your country, in addition to national data collection, is there a process for analysis and utilization of perinatal data?

5. Do you have additional comment on the reach and impact of the EURO-PERISTAT project?

C/ Referring to further improvement in the field of Perinatal Health

1. According to you, what are the comparative benefits of the EURO-PERISTAT projects compare to data collection settings such as EUROSTAT, WHO or OECD?

2. Did you know that the EURO-PERISTAT initiative has no security and may not be renewed?

3. What do you think would be the drawbacks or shortfall in terms of public health if there was no more EURO-PERISTAT?

4. Do you face similar threats on the sustainability of your data collection system in your own country?

5. If EURO-PERISTAT did not exist anymore, do you have any suggestion as a replacement?

    a. What do you think about possible collaborations between countries with performing network systems such as The International Network of Obstetric Survey Systems (INOSS)[2]?
    b. What do you think of the method of collecting routine data like in EURO-PERISTAT versus performing regular European Perinatal Survey?

6. Do you have any ideas or suggestions for the future of the monitoring of perinatal health in Europe?

7. Is there any other issue that you would like to highlight?

The EURO-PERISTAT members thank you for your kind contribution

[2] The International Network of Obstetric Survey Systems (INOSS) is a multi-country collaboration formed to facilitate studies of uncommon and severe complications of pregnancy and childbirth. (Knight M, The International Network of Obstetric Survey Systems (INOSS): benefits of multi-country studies of severe and uncommon maternal morbidities, Acta Obstet Gynecol Scand. 93 (2014) 127–131

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