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## Update march 2014

31st of March 2014

Dear Euro-Peristat scientific committee members and data providers,

We are arriving at the end of our current project grant, which runs from the 1<sup>st</sup> of May 2011 to the 30<sup>th</sup> of April 2014. The main goal of this project was to produce another report (accomplished successfully!) and to put together plans for a sustainable system for perinatal health reporting in Europe. On this last point, we have made progress, but the institutional context regarding health reporting in Europe is very unclear, with plans changing constantly. Many other projects are in the same administrative limbo.

As far as the coordination at Inserm is concerned, we aim to support the Euro-Peristat network and its mission, whether the project is incorporated into a larger European health information system or through alternative sources of financing).

Given our current low-level of funds and the confusion over the plans for a future ERIC or another DG-SANCO sponsored project, we have decided to postpone our next meeting. We had hoped to be able to meet in Florence in June of this year as part of the European Congress of Perinatal Medicine, but we would only be able to support travel for a handful of participants. Instead, we propose organizing a meeting in Glasgow in November as part of the EUPHA annual meeting. We realize that Glasgow in November may not have as much appeal as Florence in June ③, but the timing will be better for deciding on our next steps. The theme at the conference, which is from the 19th to the 22nd, is "Mind the gap: Reducing inequalities in health and health care" and this fits well with our priorities. The European Perinatal Epidemiology Network (EPEN) will also be organizing a meeting at this conference. So, please mark your calendars. The deadline for abstract submission is the 1st of May. This also gives us additional time to find financing for this meeting; we encourage everyone to see if they can find funds to support their attendance.

However, between now and November, there is still much work to do. The following update describes what we have accomplished in the past few months and what is left to do. If you have any comments or questions on the points presented in this document, please let us know and we can arrange a phone meeting.

With very best wishes, Jennifer, Marie and Ashna

### Attached documents:

- Stakeholder web evaluation of EPHR II Draft report
- Update on writing groups

### 1. Putting detailed output tables on the internet

You will be receiving these between the 15<sup>th</sup> and 25<sup>th</sup> of April for final checks and endorsement. The delay is due to some happy events (Ashna was married in February!) and some technical problems with the data files at TNO. We will be asking you for a quick response.

As we decided in our meeting in Dublin, these tables will be made freely available on the internet before the end of the project. However, in order to access the tables, people will have to provide a name, email and the reason that they are downloading the tables. This will allow us to:

- Document the use of these data
- 7Have knowledge about on-going projects

We are designing the website so that there will be a pop-up box that needs to be filled in before the tables can be downloaded. If you have any comments, please let us know.

### 2. Additional copies of EPHR

We are ordering 50 additional copies of the report (we no longer have any in Paris). If you could use a few extra reports, please let us know. This version will include updates that are in the current pdf file on the website. In order to organize the shipping, please get back to us by the 5<sup>th</sup> of April AT THE LATEST.

### 3. Report on a European health information systems

We are finalising the report on WP4 (leader: Mika Gissler) which will be circulated for comment soon. This report describes the possible avenues for integrating Euro-Peristat into current and planned EU health information systems.

There have been discussions to establish a Public Health Monitoring and Reporting Centre or enlarge the ECDC mandate for public health. Currently, these do not get enough support in the contemporary economic and political situation in Europe. Therefore, other options have to be found out. The most likely option is to join the proposed ERIC Health Information (European Research Infrastructure Consortium).

The Health Information Unit at DG Health and Consumers has proposed an ERIC Health Information. It 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 funded by the participant countries. Preparatory phase funding from DG RTD will be applied this year for further planning. Monitoring of perinatal and child health is mentioned as one of the main activities in ERIC. Currently, eleven countries and several previously funded EU projects (including Euro-Peristat) are involved in the planning to apply for funding for study design project from Horizon 2020 in order to build up an ERIC HI. DG Health and Consumers may also fund health monitoring activities before ERIC Health Information is running. There will be a call for such activities before this summer.

We had a productive meeting with Eurostat in Luxembourg on the 13<sup>th</sup> of March which confirmed our decision that Euro-Peristat indicators could not be collected by Eurostat, but provided some ideas about new ways to collaborate.

### 4. A Mission Statement for the Euro-Peristat project

We are going to put a Mission statement up on our website. This document is based on the Sustainable Action Plan which we prepared in our last project and will describe our mission and our aims (even if our funding structure for the future is as yet unclear). We will be sending out a proposal for this document and will ask you all for comments.

### 5. Project Evaluation

We have written up the results of our stakeholder evaluation. Thank you to all who reached out to stakeholders in their country. We had 104 respondents, which is wonderful. The draft report is attached, describing the major results and including a comparison with our evaluation of the 1<sup>st</sup> EPHR. We would be interested in your comments and reactions for the final version.

Sophie Alexander and her team are also involved in evaluating the project with external experts. They have put together a prestigious group of experts who will comment on our output and project. This report will be circulated at a later date.

### 6. Writing groups

Good progress has been made by all writing groups and discussions of preliminary results are currently underway. WG will be circulating preliminary drafts shortly. At our last EB meeting we updated the list of writing groups. Due to overlap in the research questions of some of our priority articles and some new ideas, we made the following modifications:

- "Are trends in mortality associated with trends in preterm birth and low birthweight"
  - Now: "Trends in gestational age distribution associated with trends in preterm birth"
     WG coordinators: Marie Delnord, Ashna Mohangoo, Jennifer Zeitlin
- "Trends in methods of delivery, induction and episiotomy"
  - With Alison's and Marie's articles on methods of delivery, it was not felt that there was enough material for doing a full article. We decided to contact Eugene Declerq from the US who is interesting in doing an article on VBAC (Vaginal birth after caesarean.
- A new writing group was added: "Trends in episiotomy and obstetric, anal sphincter injuries". WG coordinators: Sophie Alexander, Béatrice Blondel
- Another collaboration with the US is on-going on infant mortality rates with Marian MacDorman at the CEC. Coordinators: Jennifer Zeitlin, Ashna Mohangoo.
- Finally, we have been contacted by Lucy Smith at the University of Leicester. She has a
  project on-going about registration of births/deaths at the limits of viability and would like to
  work with the Euro-Peristat group. If you are interested in this topic, please get in touch
  with us and we will constitute a new writing group.

The full list of writing groups and members of these groups is available in the Annex.

If you would like to participate in one of the new groups or wish to change groups, please let us know as soon as possible. If you haven't yet received information on your group from the coordinators,

### you should be getting it very soon!

If you would like to propose a topic, please contact Jennifer/Marie/Ashna and we will circulate the information to the group

### 7. Finalised list of Euro-Peristat group for publications

In our last update, we asked for confirmation of the "Euro-Peristat group" for publications. Below is the list of SC members. We have not heard from everybody; please let us know if modifications are necessary:

Gerald Haidinger (*Austria*), Sophie Alexander (*Belgium*), Pavlos Pavlou (*Cyprus*), Petr Velebil (*Czech Republic*), Jens Langhoff Roos (*Denmark*), Luule Sakkeus (*Estonia*), Mika Gissler (*Finland*), Béatrice Blondel (*France*), Nicholas Lack (*Germany*), Aris Antsaklis (*Greece*), István Berbik (*Hungary*), Helga Sól Ólafsdóttir (*Iceland*), Sheelagh Bonham (*Ireland*), Marina Cuttini (*Italy*), Janis Misins (*Latvia*), Jone Jaselioniene (*Lithuania*), Yolande Wagener (*Luxembourg*), Miriam Gatt (*Malta*), Jan Nijhuis (*Netherlands*), Kari Klungsoyr (*Norway*), Katarzyna Szamotulska (*Poland*), Henrique Barros (*Portugal*), Mihai Horga (*Romania*), Jan Cap (*Slovakia*), Živa Novak-Antolic (*Slovenia*), Francisco Bolúmar (*Spain*), Karin Gottvall (*Sweden*), Sylvie Berrut (*Switzerland*), Alison Macfarlane (*United Kingdom*).

Project coordination: Jennifer Zeitlin, Marie Delnord, Ashna Mohangoo.

- Data providers and supporting institutions will be included in acknowledgements as follows: (see Annex)

## 8. Alternative sources of financing: Project proposals

We have participated in several bids in order to find funding for future Euro-Peristat activities, including a COST project, submitted by Professor Soo Downe University of Central Lancashire "Building Intrapartum Research Through Health (BIRTH): An interdisciplinary whole system approach to understanding and contextualising physiological labour" . COST projects pay for meetings, but don't cover salaries, just travel and accommodation costs and subsistence. We also participated in a Horizon2020 project submitted by the same team (with Soo Downe as coordinator) called TRANSFORMing Relationships: A New, Sustainable model For ORganising Maternity service improvement. This is a revision of the BirthCOMPASS project that we participated in last year (and which made it through the first round). The Euro-Peristat participation would be to study the impact of national policies, financing systems and health care organization on use of intrapartum interventions.

We are also continuing our collaboration with PREBIC to use Euro-Peristat data to study international differences in preterm birth. Other collaborators in the PREBIC project (Canada, US and Japan) will fill in our data sheets for C1 to C5 so that they can be included in country-level analyses. Marie will take the lead on the analysis for this project (see project proposed for writing group, above).

The collaboration with ROAM is also continuing, although we did not put together a Horizon bid this year. The theme of migrant health is one that continues to be a priority and we hope to find funding to pursue this work.

### 9. To do list and calendar

- 1. By 5<sup>th</sup> of April
- Let us know if you would like (a few) additional copies of the report.
- Provide comments on the Web Evaluation report
- ➤ Comment on the writing group updates especially new or modified groups.
- Comment on the Euro-Peristat group author for publications
- Let us know if there are changes to your country teams so that we can update the website (see... <a href="http://www.europeristat.com/our-network/country-teams.html">http://www.europeristat.com/our-network/country-teams.html</a>)
- 2. April 15<sup>th</sup> to April 25<sup>th</sup>
  - Make time in your busy schedules to check and approve data tables
- 3. By 1<sup>st</sup> of May
  - Deadline for abstracts for EUPHA
- 4. <u>18<sup>th</sup> 20<sup>th</sup> of November</u> EUPHA Meeting in Glasgow Pre-congress meeting on the 18<sup>th</sup>. Please reserve these dates on your calendar.

### **ANNEX**

## Acknowledgements

The authors acknowledge the following contributors to the European Perinatal Health Report: Health and Care of Pregnant Women and Babies in Europe in 2010

Austria, Gerald Haidinger, The Medical University of Vienna, Department of Epidemiology, Centre of Public Health; Jeannette Klimont, Statistics Austria; Belgium, Sophie Alexander, Wei-Hong Zhang, Michèle Dramaix-Wilmet, Mélissa Van Humbeeck, Université Libre de Bruxelles, School of Public Health, Epidemiology, Biostatistics and Clinical Research Centre; Charlotte Leroy, Anne-Frédérique Minsart, Virginie van Leeuw, Centre d'Epidémiologie Périnatale (Cepip); Evelyne Martens, SPE (Study Center for Perinatal Epidemiology); Myriam De Spiegelaere, Brussels Health and Social Observatory, Freddy Verkruyssen, Michel Willems, FPS Economy, SMEs, Self-employed and Energy; Willem Aelvoet, The Federal Public Service (FPS) Health, Food Chain Safety and Environment; Jean Tafforeau, Francoise Renard, Denise Walckiers, Focal Point for the data collection on national health statistics for Eurostat, OECD and WHO; Deborah Cuignet, Philippe Demoulin, French Community of Belgium; Heidi Cloots, Erik Hendrickx, Anne Kongs, Flemish Agency for Care and Health;

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## Update June 2014

Dear Euro-Peristat SC members,

This update concerns 4 points of business. The items to be addressed are listed below in "TO DO".

#### (1) FINALISING TABLES FOR CORE INDICATORS

Please find attached the web tables for the core indicators. These have been checked against the report and any updates should be included (this has been a bigger job than we thought, which is why this has been delayed).

Please look through them and let us know if there is a problem. We would like to put the tables on the website at the end of the month. These are the same tables as those included in our 2008 report appendix. The recommended indicators will follow next week.

NOTE: the table on the cohort neonatal deaths will NOT be put up on the web, but we are including it for your information.

ALSO: As we decided at our last meeting, we will have a system where people will have to register with an email to download the data. This will allow us to keep track of the use of these tables.

#### (2) EURO-PERISTAT MEETING IN GLASGOW IN NOVEMBER 2014

We are moving forward with plans for a meeting in Glasgow as a precongress meeting of the European Perinatal Epidemiology Network at EUPHA in November. Also the workshop proposed by the Euro-Peristat project has been accepted for the main conference. The pre-congress meeting will take place the on Wednesday 19 November 2014. I have been able to find limited funds to cover the costs of the meeting room and of travel for some participants (about 7000 euros in total for travel).

The aim of the pre-congress meeting would be to present on-going analyses and strategize about future proposals to fund the Euro-Peristat work.

Could you let us know if

- 1. you are interested in attending and
- 2. if you are able to cover your own travel costs.

I will then be able to calculate how to distribute available funds.

### (3) A ROAD MAP FOR EURO-PERISTAT

We have revised the Action Plan for Sustainable Health Reporting that we produced after our last project phase. This revision has taken into consideration your comments at the meeting in Dublin in May, the conclusions of our discussions with Eurostat (showing that integrating our indicators into Eurostat is not feasible for the moment – this report was sent out to you last month) and the discussions with DG-SANCO about next steps (ie the idea to set up a European Research Infrastructure Consortium on Health Information). Attached is a \*\* DRAFT\*\* of this document. Please comment by this FRIDAY 27 JUNE.

### (4) NEW PUBLIC HEALTH PROGRAMME CALL

As some of you may know, DG-SANCO has published their public health programme and there is a call to support the development of a health information system, most probably by preparing an ERIC. Euro-Peristat is in discussions about what our place in this project will be with the people who are coordinating the proposal. We will be sending an update shortly to get your feedback on these plans.

Best	rega	ırds.

Jennifer

Ashna

Marie

#### To do

- 1. look through the tables and OK them by sending an email to Marie with Jennifer and Ashna in copy
- 2. Comment on the road map (by this Friday 27 June, if possible if you need more time, please let me know)
- 3. Tell us if you would like to come to a Euro-Peristat meeting in Glasgow in November and if you have some financing for this.

## **Update October 2014**

7<sup>th</sup> of October 2014

Dear Euro-Peristat Scientific Committee members and data providers,

We hope you have had a good summer. We have some good news for this new academic year, in particular, being included in the Bridge-Health proposal submitted to DG-SANCO along with other health information projects (point 3).

Also, the detailed EPHR 2010 tables are now up on the website (point 1).

Last, the meeting in Glasgow on the 19<sup>th</sup> of November is coming up shortly and we are hoping to see many of you there (point 2). For those who are not able to come, if the new DG-SANCO project is successful, the budget includes a fully-funded Euro-Peristat meeting in late 2015 or 2016.

Please note also point 7 about updates to the website. Your ideas for the site would also be appreciated.

With very best wishes,

Jennifer, Marie and Ashna

## 10.EPHR2010 Data tables by subgroups on the internet

The data tables are now on the internet! They are accessible in two ways: through the "Perinatal Health Indicators" tab and also from the page where the report is downloaded (in "Publications").

As you will see, to access the data, it is necessary to sign up once for each session. Please try downloading (we have done several tests) and let us know if you have any suggestions for improvement.

The core tables are those that you approved in the spring. The recommended tables are those published in the report.

We are able to track use of these tables and will provide feedback in our next update.

## 11. Meeting in Glasgow on the 19th of November, 2014

Euro-Peristat meeting will take place as part of the European Perinatal Epidemiology Network (EPEN) meeting which is organized as a pre-congress event at EUPHA. A preliminary programme is available on the EUPHA site (<a href="http://www.ephconference.org/pre-conferences-123">http://www.ephconference.org/pre-conferences-123</a>).

A Euro-Peristat workshop will also be held on the last day of the conference (21<sup>st</sup> November). You can access the workshop abstracts from this link: http://www.europeristat.com/images/Abstract\_for\_workshop\_Eupha\_Glasgowv2.pdf

So far, we have 20 Euro-Peristat people signed up to attend the EUPHA conference. If you have not yet responded, please let us know quickly; if you require financial support, we may be able to help with airfare.

We will be sending around an updated programme for the meeting shortly.

## 12.BRIDGE-Health project for DG-SANCO call

DG-SANCO issued a call for a new project to support health information projects to put together an ERIC (European Research Infrastructure Consortium). As we have told you in previous updates, ERICs are member state financed collaborations around a common theme. There was also a plan to submit a bid to design an ERIC (called ERIC-HI) to Horizon2020 in which Euro-Peristat would participate but this has fallen through for the moment. Nonetheless, we participated in the DG-SANCO BRIDGE-Health project. The call aims "to prepare the transition towards a sustainable and integrated EU health information system for both public health and research purposes while the potential of a comprehensive European health information research infrastructure consortium as a tool will be explored." Only one project will be financed. The proposal is being coordinated by Herman van Oyen from the Belgian Scientific Institute of Public Health and was submitted last week.

Perinatal and Child health are mentioned as one of 9 priorities for this call. The WP on perinatal and child health is being led by Norway (Frederik Froen at the Norwegian Institute of Public Health). The reason is that Norway had shown interest in financially supporting perinatal and child health in a future ERIC. Euro-Peristat is leading the work on perinatal health in this work package. Other applicants are CREAL who manage the CHICOS birth cohort project and DCU in Dublin who coordinated the RICHE project on child health. The Euro-Peristat component involves (1) maintaining and reinforcing our network, including reaching out to the 2 MS who are not members of Euro-Peristat (Bulgaria and Croatia), supporting the network activities by having a meeting and continued analysis of our data (2) improving data collection and transmission (through linkage, data transmission (by thinking about a microdata repository) and outreach to stakeholders and (3) collaborating with the other health information projects (like the ECHI project, etc.) to share information and to harmonize approaches and methods.

The call:

http://ec.europa.eu/research/participants/portal/desktop/en/opportunities/3hp/topics/hp-pj-06-2014.html)

### 13.On-going Analyses and writing groups

The multiple writing groups are continuing.

The following paper based on the Euro-Peristat Preterm Birth Study (data from 2008) has been published: Marie Delnord, Béatrice Blondel, Nicolas Drewniak, Kari Klungsøyr, Francisco Bolumar, Ashna Mohangoo, Mika Gissler, Katarzyna Szamotulska, Nicholas Lack, Jan Nijhuis, Petr Velebil, Luule Sakkeus, James Chalmers and Jennifer Zeitlin. Varying gestational age patterns in cesarean delivery: an international comparison. BMC Pregnancy and Childbirth 2014, 14:321 doi:10.1186/1471-2393-14-321. The article can be downloaded from our website.

We encourage all writing group leaders to send out an update on their papers! If you have questions, please do not hesitate to contact the writing group leader.

The list of SC members and the acknowledgements are included as an Annex to this email. Please let us know if any changes are required.

## 14. Working with other projects and organisations

We have been trying to get the Euro-Peristat project involved in other collaborations, including **Prebic**, the WHO sponsored initiative on preterm birth. You will remember Siobhan Dolan who came to our meeting in London in January of 2012. The Prebic epidemiology working group is now jointly coordinated by Siobhan and Michael Kramer. We met this month with the working group in Geneva to discuss possibilities of collaboration. While there is not an immediate possibility of funding, there was great interest at WHO in the Euro-Peristat approach. Marie will be doing her PhD thesis looking at preterm birth as part of Euro-Peristat and Prebic. We are currently collecting some Euro-peristat indicators from the US, Canada and Japan as part of this project. Our next update will include information on these analyses - of course, those who are interested in joining will be very welcome! The **Cost BIRTH project** represents another possibility for continuing work within the Euro-Peristat network. This project is called: "Building Intrapartum Research Through Health - an interdisciplinary whole system approach to understanding and contextualising physiological labour and birth (BIRTH)" and is managed by Soo Downe. It includes a work package on the organisational and contextual factors which may affect the rates of intrapartum intervention. You can get the proposal and more information at: http://www.cost.eu/domains\_actions/isch/Actions/IS1405. The first meeting will be on the 10th of December. Jennifer will be going and will report back about possibilities for collaboration on this topic. Soo Downe will be coming to our meeting in Glasgow to talk about this project. For those who cannot make it to Glasgow, we will summarize the presentations. If you are interested in this theme, please let us know.

We have also been working with other organisations and countries. We collaborated with Marion MacDorman at the <u>CDC</u> on a data brief that compared the US infant mortality rate and related factors with Europe's (such as they did when our last report came out). This report can be accessed at: <a href="http://www.cdc.gov/nchs/data/nvsr/nvsr63/nvsr63">http://www.cdc.gov/nchs/data/nvsr/nvsr63/nvsr63</a> 05.pdf

We have also been sharing our experiences with the OECD which is reflecting on whether there should be lower gestational age limits for reporting infant mortality statistics. Mika Gissler will be representing Euro-Peristat and making a presentation about our analyses comparing Euro-Peristat and Eurostat data at the annual OECD meeting in October in Paris.

## 15. Expanding the Euro-Peristat Network

We have been contacted by Dr. Tamar Khomasuridze, SRH Programme Advisor at UNFPA's EECA Regional Office about expanding Euro-Peristat data collection to Eastern and Central European countries. Are any of you involved with these countries and interested in helping decide what is the best way forward?

We also aim to expand our project with countries from the Caribbean and Latin/South America where the majority of countries have higher perinatal death rates than European countries. Ashna and Jenny will have a meeting with professor Maureen Lichtveld from the Tulane University in October to discuss feasibility and collaboration.

## 16. Updating the website

Please take a moment and look over the website. In particular:

- Make sure the information about your country team is correct.
- > If you have a link in the national reports section, please let us know if it should be updated.
- If you have any ideas for making the website more lively or dynamic or if there are other links we should add, PLEASE LET US KNOW.

### ANNEX

In our last update, we asked for confirmation of the "Euro-Peristat group" for publications. Below is the list of SC members. We have not heard from everybody; please let us know if modifications are necessary:

Gerald Haidinger (*Austria*), Sophie Alexander (*Belgium*), Pavlos Pavlou (*Cyprus*), Petr Velebil (*Czech Republic*), Jens Langhoff Roos (*Denmark*), Luule Sakkeus (*Estonia*), Mika Gissler (*Finland*), Béatrice Blondel (*France*), Nicholas Lack (*Germany*), Aris Antsaklis (*Greece*), István Berbik (*Hungary*), Helga Sól Ólafsdóttir (*Iceland*), Sheelagh Bonham (*Ireland*), Marina Cuttini (*Italy*), Janis Misins (*Latvia*), Jone Jaselioniene (*Lithuania*), Yolande Wagener (*Luxembourg*), Miriam Gatt (*Malta*), Jan Nijhuis (*Netherlands*), Kari Klungsoyr (*Norway*), Katarzyna Szamotulska (*Poland*), Henrique Barros (*Portugal*), Mihai Horga (*Romania*), Jan Cap (*Slovakia*), Živa Novak-Antolic (*Slovenia*), Francisco Bolúmar (*Spain*), Karin Gottvall (*Sweden*), Sylvie Berrut (*Switzerland*), Alison Macfarlane (*United Kingdom*).

Project coordination: Jennifer Zeitlin (INSERM France), Marie Delnord (INSERM France), Ashna Mohangoo (TNO Netherlands).

- Data providers and supporting institutions will be included in acknowledgements as follows: (see Annex)

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# Glasgow Nov 2014: EPEN-EuroPeristat Meeting

Pre-congress meeting of the 7th European Public Health Conference - EUPHA WEDNESDAY, 19 November 2014

Scottish Exhibition Conference Centre, Glasgow

Summary and decisions

Thanks to all the Euro-Peristat members who were able to come to the meeting in Glasgow. It was a productive meeting, but we missed many of you. As there are several possibilities for obtaining continued funding for meetings, we hope that the next meeting (late 2015/early 2016) will include the complete consortium.

We were able to welcome a new member, Dr. Rachael Wood, from the Information Services Division, NHS National Services Scotland. Rachel is replacing Jim Chalmers who retired last year.

The following summary describes what we discussed at the meeting. If you have any questions or would like more detail about any of the points, please don't hesitate to get in touch. About 30 people attended the meeting, including 18 participants associated with the Euro-Peristat project and other researchers interested in the topic who signed up for the

pre-conference (see participant list below). To make the document easier to read through, **action points** are in **bold orange**.

The following lists the presentations during the day.

You can access all presentations on the members only section of the website (numbered as below). Please do not share these presentations outside of our group as many are based on unpublished data (login/psswd=member/!Peristat).

### Improving routine statistics on perinatal and infant mortality

- Recording of periviable births and impact on perinatal mortality rates, Lucy
   Smith (presentation 1.1)
- Lower limits for reporting infant deaths: an OECD-Euro-Peristat collaboration,
   Mika Gissler (1.2)
- Stillbirth reporting in Europe: a comparison between Euro-Peristat and Eurostat data – Marie Delnord (1.3)
- The impact of recording and reporting of terminations of pregnancy on rates of stillbirths in Europe, Béatrice Blondel (1.4)

### The Euro-Peristat project: past and future

- o Project overview, Jennifer Zeitlin (Presentation 2.1)
- Some national perspectives on Euro-Peristat: The Netherlands (Jan Nijhuis) –
   2.2, France (Béatrice Blondel)- 2.3, Poland (K. Szamotulska)

### European research in perinatal health

- Building Intrapartum Research Through Health an interdisciplinary whole system approach to understanding and contextualising physiological labour and birth (BIRTH), Soo Downe (3.1)
- Ways and means of reducing caesarean deliveries, Sophie Alexander (3.2)
- The impact of implementing the IRIS cause of death coding system on stillbirth and neonatal death data for England and Wales, Claudia Wells (3.3)
- Birthweight distributions by gestational age for South Asian babies born in England, Nirupa Dattani (3.4)
- Using routine data to estimate number of women with female genital mutilation /cutting in European countries, Alison Macfarlane (3.5)

In addition to the presentations, we had a closed meeting to discuss items related to the Euro-Peristat project (4.1 and 4.2).

### **BridgeHEALTH**

Jennifer described the Bridgehealth (BRidging Information and Data Generation for Evidence based HEALTH Policy and Research) project which aims to create European health information (EU-HI) and data generation networks covering major EU health policy areas based on the past experience of European project on indicators (see presentation 4.1 for list of objectives and main partners). Euro-Peristat is participating in this project and we will have the results in January 2015.

The project includes 30 partners that have participated in health monitoring projects. One of the work packages is on: Reproductive, maternal, neonatal health. Inserm is a participant on this WP along with the Norwegian Institute of Public Health (Frederik Froen), CREAL in Barcelona (Martine Vrijheid,) and Dublin City University (Anthony Stains). Herman van Oyen from the Institut scientifique de santé publique (ISP) in Belgium is the coordinator of the whole project.

The objectives of the WP on Reproductive, maternal, newborn, child and adolescent health are: 1. Under the systems framework of this proposal, to develop a blueprint for health information on RMNCH to be sustainably integrated in a European health information system for health care, public health surveillance, research and policy making. 2. Optimize the sustainability, timeliness, comprehensiveness, quality and use of perinatal health information from routine systems as specified in the Euro-Peristat roadmap. Under the systems framework of this proposal, to optimize the synergies of a joint platform and roadmap of the EU funded research initiatives CHICOS, RICHE and ENRIECO towards and European observatory of health information for RMNCH research to make the lives of women and children in Europe more visible.

Euro-Peristat is primarily concerned with the second objective. The tasks planned if the project is funded are:

- Support sustainable perinatal health reporting from routine health information systems in Europe by maintaining the existing Euro-Peristat network of 29 countries and expand it with the joint RMNCH network
- 2. Reinforce capacity and reduce inequalities in data production, transfer, sharing, analysis and use of perinatal health indicators from routine data systems on the national and European levels by implementing cross-cutting health surveillance and research actions identified in the Euro-Peristat project
- 3. Under the systems framework of this proposal, harmonize and integrate Euro-Peristat health indicators, methods and tools within an EU health information system

We discussed several of the ideas which are to pursue our work on linkage, to reflect on how the collection of micro-data on a minimum dataset could facilitate reporting and enrich the research possibilities of the network. The possibility of collaborating with Eurostat to develop an experimental protocol was discussed, since Eurostat has the legal authority to collect microdata from member states. If the project is funded, it would also provide an opportunity to expand our network to include Bulgaria and Croatia and perhaps other countries.

> You can find a part of the proposal presenting the partners and objectives on the members only section of the website (numbered as below). Please do not share this document (login/psswd=member/!Peristat).

### **PREBIC**

We discussed our last meeting with PREBIC's Epidemiology Working Group (EWG) at WHO, Geneva. PREBIC is a multinational collaborative of clinicians and research scientists who aim

to improve pregnancy and birth outcomes, optimising infant health and long term development. PREBIC's preterm birth prevention programmes include workshops for scientists, clinicians and other health care professionals, development and coordination of research expertise nodes and the organisation of annual scientific meetings at the World Health Organization, Geneva, Switzerland. The EWG is co-led by S.Dolan and M.Kramer.

### PREBIC EWG has prioritized work in two areas:

- (1) the extent to which obstetric interventions affect rates and trends of singleton late preterm birth and (2) how international differences in rates of very preterm birth are affected by registration of births and deaths at the limits of viability and the inclusion or stillbirths. EuroPeristat will contribute the European data which we already have and use data from Japan, US, and Canada as part of M.Delnord's doctoral work. At the PREBIC meeting we presented our project, highlighting the results from EPHR2010:
- Evolutions in fetal and neonatal mortality by gestational age in Europe: Ashna Mohangoo, Jennifer Zeitlin
- Varying gestational age patterns in cesarean delivery: an international comparison,
   Marie Delnord
- How are early preterm birth rates affected by inclusion of stillbirths: Jennifer Zeitlin, Ashna Mohangoo
- Patterns and evolutions of the gestational distribution over time in Europe, Canada,
   Japan and the US and impacts on the moderate preterm birth rate: Jennifer Zeitlin

After the meeting in Geneva, Josh Vogel from WHO expressed interest in moving forward with a "global Euro-Peristat." There are some other leads to extend our project beyond Europe. Jennifer was contacted by UNFPA to include Eastern European countries and Ashna about expanding Euro-Peristat to Caribbean countries.

We will be soliciting members of Euro-Peristat to see if they would like to participate in a working group on expanding the project outside of Europe. If you are interested, please contact us.

### The CROWN intiative

Sophie Alexander presented the CROWN project and ideas for collaboration with Euro-Peristat. The Core Outcomes in Women's health (CROWN) initiative is an international initiative, led by obstetrics and gynecology journal editors (UK-driven), to harmonise outcome reporting in women's health research, especially for trials.

Euro-Peristat can provide a lot of experience and this would increase our visibility with clinicians. Although our indicators are developed from routine data sources and might be less relevant for trials, it always useful to situate a study population with respect to the general population.

We discussed writing an editorial for a journal on this (BJOG or Paediatric and Perinatal Epidemiology). If anyone is interested in participating in this editorial, please contact Jennifer and Sophie. <u>COST collaboration</u> - Building Intrapartum Research Through Health - an interdisciplinary whole system approach to understanding and contextualising physiological labour and birth (BIRTH)

Soo Downe presented the COST collaboration BIRTH. Cost is a mechanism for funding networks of researchers on an innovative topic. It can support workshops and conferences on specific themes, if this is agreed upon by the group. This project focuses on the following areas:

1. Biomedicine (epigenetics and the hygiene hypothesis); 2. Biomechanics (maternal and fetal movement); 3. Socio-cultural perspectives (social expectations and experiences, including marginalised and migrant populations); 4. Organizational perspectives (the effect of organizational contexts and cultures on variation in rates of childbirth interventions) 5. Neuro-psycho-social perspectives (how inter-personal actions and behaviours affect physiological processes). Jennifer is participating in WP4 (on organizational perspectives) with the aim of creating links between this network and the Euro-Peristat project. The first meeting is in December and Jennifer is planning to attend. We will give more information on this in our next update.

### **Periviable births**

We have started a collaboration with Lucy Smith who is an epidemiologist at the University of Leicester is working on the topic of periviable births and the impact on mortality rates. Babies born at the limits of viability at 22-23 weeks gestation are very rare – around 1 in a 1000 births. However their mortality is extremely poor and consequently they have a large impact on infant mortality rates accounting for up to a fifth of deaths. There is large variation in whether these babies are recorded as live born or still born at both the hospital-level, regional level and internationally. Furthermore of those that are recorded as fetal deaths, there is variation at which birth-weight or gestational age, these births are officially reported as national stillbirths.

In order to compare mortality rates across Europe with Euro-Peristat it is vital that we understand the variation in practices that determine whether these babies are registered as live born, stillborn or fetal deaths at these very early gestations. Furthermore these differences in reporting may have a large impact on parents in terms of whether they receive birth or death certificates, their eligibility for maternity and paternity leave, and benefits, and also who must pay for the burial. By collecting additional data from all countries across Europe, we aim to understand differences in practice so that we can more accurately compare neonatal mortality and stillbirth rates across Europe and assess where differences are due to variations in the quality of care received rather than artefactual differences in recording practices. We welcome your help in completing this very short questionnaire:

### https://www.surveymonkey.com/r/EURO-PERISTAT

Please complete Lucy's questionnaire (link above). If you are interested in this topic, please contact Lucy (also in copy to this message) and let us know. Please see writing group list.

### Writing groups

We reviewed the writing groups and their current status. The attached list includes these updates – including 2 accepted papers! –

We have also made some changes that we need you to review. In particular for the 3 first papers – you will note that the paper on mortality has become 2 papers one on 2010 and one on the evolution from 2004 to 2010 – we included only one person per paper and tried to balance this choice from a country perspective (i.e. if 2 people from one country, we selected one from each...).

We are also adding a few new topics, please add yourself to the group if you are interested! (send an email to Marie who is managing the list). You may also join a group if the analysis is still on-going (see last column of this list). To do this, contact us as well as the group leader.

Please see the attached updated list.

- Review updated writing list, check that you are where you want to be and see whether you are interested in participating in new groups.
- Writing group coordinators, please send an update to your groups before the end of the month.

# **Euro-Peristat (orange) and non Euro-Peristat Participants**

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Anna	Heino	National Institute for Health and Welfare (THL)	Helsinki	Finland
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