Euro-Peristat Scientific Committee Meeting Summary

Abdij Rolduc Abbey, Kerkrade, the Netherlands

April 9-10, 2018

The following document summarizes the principal decisions made in each session of our meeting and lists the follow-up activities. If we have forgotten anything or anyone please let us know and we will modify the document.

PDF versions of all presentations (and photographs from the meeting) are available on the members' only page of the website[1]

PLEASE NOTE THAT THESE PRESENTATIONS ARE FOR YOUR PERSONAL USE ONLY – THEY ARE <u>NOT</u> TO BE SHARED OUTSIDE OF THE GROUP BECAUSE THE DATA ARE NOT FINALIZED AND CONTAIN MISTAKES.

Points of action and other decisions made during the meeting by the group are framed in the text.

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[1] Login="member" and password="!Peristat" Link: "http://www.europeristat.com/members.html

I.   Welcome and update

The meeting started with Dr. Jan Nijhuis Head dept. Obstetrics & Gynaecology at the Maastricht University Medical Center and SC member from the Netherlands welcoming us at the Rolduc Abbey. His greetings were followed by a round of introductions for old and new SC members.

Jennifer Zeitlin, Project leader, opened the discussion by presenting the aims of the meeting:

  ➢ Review the data collected on core and two recommended indicators and develop plans for a report : *The strength and innovation of Euro-Peristat is not just collecting data, but collectively analysing data*
  ➢ Present and plan for the Joint Action on health information (InfAct), following up on BRIDGE Health: *Aim is to ensure sustainability for Euro-Peristat's work within a European health information system*

There was also a short update on our work since the last Scientific Committee meeting in Paris in April 2016.

As part of our contribution to the BRIDGE Health project, Euro-Peristat has:

  1. Identified health information gaps in maternal and newborn health in Europe.
  2. Expanded the network by including two new participating countries: Bulgaria represented by SC member Rumiana Kolarova, and Croatia represented by SC member Urelija Rodin.
  3. Invested in new ways to disseminate information via updates to the website (national perinatal health report section) and the introduction of the Euro-Peristat newsletter started in March 2016
  4. Developed new ways to improve data transfer and sharing across EU MS: by exploring the use of data linkage in perinatal health and routine statistics in Europe, and by testing a new pilot data collection protocol for the CORE indicators using multivariate aggregated tables (MVAT).

Since our last meeting, the group has produced 9 scientific publication, 3 letters to the editor, and presented in 6 international conferences. The publications are available from our website: http://www.europeristat.com/reports/scientific-publications.html.

Data checks

Mélanie Durox, Euro-Peristat programme coordinator, gave an update on data validation of the 2015 Euro-Peristat CORE indicators which were collected from 07/2017-01/2018.

Data collection

There were two ways for countries to compile the indicators. Countries could either: a) fill in the standard aggregated data instrument, or b) provide multivariate aggregated tables (12 variables on babies: gestational age, birthweight, type of pregnancy, vital status at birth, neonatal mortality, infant mortality, maternal age, parity, mode of delivery, mode of onset, presentation, previous caesarean section; 3 variables on mothers: maternal age, parity, type of pregnancy). Two STATA programmes were created. One to compute the aggregated tables from the multivariate data, and another to output all data in Excel summary tables.

About half of the countries (16/ 33 countries and regions) that participate in Euro-Peristat were able to provide multivariate tables using the new pilot protocol, the other half used the standard aggregate data collection instrument.

Core indicator data availability was very good across countries (>90%) although not all countries could provide data for all subgroups (by gestational age, birth weight, plurality, vital status and mode of delivery).

Data validation

Data validation (cf. figure below) essentially consisted in identifying: a) entry errors, b) reporting on deliveries vs. births, women vs. babies, or all births vs. live births, c) concordance between the number of births, women and deliveries, d) and if countries could provide information based on the Euro-Peristat reporting criteria: all births 22 weeks+ in each individual week of gestation, and if GA is missing for births 500g+.
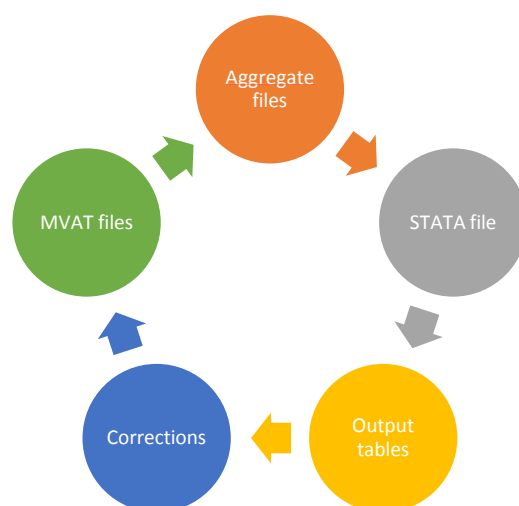
Group discussion

We went over the production of the preliminary Euro-Peristat 2015 Core indicator tables, sent out in the beginning of April. Countries were asked to go over these data and help identify any errors.

These will be corrected in the next round of tables that will be published, and they are listed below:

- For countries providing MVAT data: C2/C3 reported as annual rates instead of cohort
- C2: the column « Live births >= 24 weeks » includes live births unknown for GA
- C4A, C5A: the column « all stated » includes births "not stated"
- C5A: the column « all births » includes TOPS (should be excluded) and « not stated » includes only live births (should also include fetal deaths with unknown GA)
- Incorrect total numbers due to missing data: all stated vs. all births (we used all stated births to compute rates)
- Incorrect total numbers due to discrepant coverage in the data sources for indicators C0- recording of births and deaths vs. C1-fetal mortality and C5-distribution of gestational age (in the summary tables, we based our total population on the number of births reported in C1 and C5 NOT on C0).
- Mismatch between the categories used by countries to create the MVAT files vs. categories requested in the data collection protocol (i.e. "multiples" in bulk vs. "twins", "triplets", "quadruplets" separately) .

SC members also raised the point that in countries using other criteria for births and deaths (i.e. birthweight 500g+ as their main inclusion criteria in official statistics) there may be discrepancies in total number of births provided to Euro-Peristat and national reporting.

We will produce a new output table (either in the next report or on the website) with information on total births in Euro-Peristat vs. total births in official statistics.

This will allow us to explain any discrepancies with national or international data systems and provide more information on how our group produces high-quality comparable information across countries. For instance, this issue relates to the inclusion of late terminations of pregnancy (TOP) in official statistics, and handling of missing data (i.e. births with unknown BW/GA).

We also mentioned the possibility of creating a working group based on SC member's active participation, please contact us if you are interested.

II.   Indicators of perinatal health in Europe in 2015

Next, the Euro-Peristat Executive Board members presented on each of the CORE Euro-Peristat indicators. The presentations focused on:

- The definition and importance of the indicator
- The availability of the indicator in 2015
- Quality issues
- Results in 2015 and trends since 2010

1. Number of total births: comparisons with Eurostat

Jennifer showed that there was a large variability in trends in annual number of births across Europe which is relevant for understanding trends in perinatal health indicators. For instance in Germany, there has been a very big increase in the number of births between 2010-2015. Differences in fertility rates and migrant flows over the past years and across countries could explain these results.

Furthermore, we discussed minor differences between the numbers of births provided to Euro-Peristat compared to Eurostat. In some countries, this could be due to the inclusion/exclusion of births to nationals outside the country. During the discussion, we confirmed that Euro-Peristat does not want data on citizens residing outside of the country.

We agreed it would be good to find out who are the current Eurostat data providers in each country.

If you know who this person is, please email us this information and we will compile a list for the group. We will also request the list from Eurostat.

2. Stillbirths and fetal deaths (C1)

Jennifer showed that there was a good availability of the stillbirth indicator with heterogeneity across countries and over time. Rates varied between 2 to 4.0 per 1000 for births 28 weeks of GA and over, and between 2 to 5.0 per 1000 for births 24 weeks of GA and over.

However, there are also quality issues to consider:

In general, there are issues with registration criteria that vary across countries for births and deaths (TOP legal or not, identified or not), especially at the limits of viability (22-23 weeks). Whereas at 22-23 weeks, the validity of data is weak, at 24/28 weeks+ rates are more stable. In Euro-Peristat, we report stillbirth data on births 24 +weeks to take into consideration countries that use a 500g cut off. Intrauterine growth charts show that babies 24+ weeks are over 500+g. However about one-half of babies at 22 weeks have a weight under 500g.

We also discussed that births vary between 4000 – 800,000 across Europe. In countries with a small number of births each year, there is less precision in the rates and we do not provide CI's. However, we may provide CI for countries with a small number of births to call attention to the possibility for random variation.

A comparison with Eurostat rates of late fetal death were also presented. Although a 1000 gram cutoff is requested by Eurostat for reporting, it appears that countries do not always provide data to Eurostat based on this definition. Therefore these data cannot be used to compare countries.

A final discussion focused on the tradeoffs between stillbirths and early neonatal deaths. We have not focused on perinatal mortality, but this analysis is planned for the 2015 data. At UK level, perinatal mortality is getting reported to get away from artefactual differences in registration between fetal death rates and early neonatal death.

We agreed that as of now, data on births under 24 weeks, should not be used because of the existence of non-comparative BW and GA thresholds. Nonetheless, the ranking of rates based on a 24 weeks vs 22 weeks cutoff is very similar. In the next report we will provide information on fetal mortality for births 24+ weeks as well as 28+ weeks.

We will also take out TOP where this is possible.

We also plan to write a commentary on the differences with Eurostat. Please contact us if you are interested in participating.

3. Neonatal and Infant Mortality (C2-C3)

Alison Macfarlane, UK SC member, presented key findings for both indicators, although data for these are still being checked and changes will be made to the final tables. In particular, as stated above there were problems with annual vs. cohort neonatal mortality rates in the documents circulated before the meeting

Neonatal mortality varies between 0.7 and 3.6 deaths per 1000 live births. Infant mortality varies between 0.2 and 9.2 deaths per 1000 live births. Across Europe, there are low rates in the Nordic countries and higher rates in newer EU countries. There are also differences in relative proportions of neonatal and post-neonatal deaths, of which some could be of babies who have never left neonatal intensive care. Differences in proportions of deaths reported at gestational ages below 24 weeks contribute to overall differences, as well as differences in resuscitation policies.

Producing these indicators within countries is complex as often time multiple sources are used. Moreover, changes over time are difficult to interpret where rates are low and numbers are small.

We agreed that it is preferable to present cohort data in the next European Perinatal Health Report as opposed to annual data since countries who provided MVAT data only gave cohort data. We would also like to encourage all countries to link birth and death records and produce cohort mortality rates.

4. Maternal mortality (C6),

Maternal mortality is a strong indicator of social inequality. Sophie Alexander, SC member for Belgium, presented on what rates in Euro-Peristat countries, and showed that results vary based on the data source. She also discussed ascertainment of maternal deaths across Europe and the existence of routine and enhanced systems.

She showed that there are full Maternal Death Surveillance and Response (MDSR) Systems in the UK, Ireland, France, the Netherlands and the Nordic countries; however the extent to which data are disseminated in scientific publication and for evidence-based recommendations can vary in these countries. Italy has a "quasi running" system, whereas Belgium should start and Germany and Spain have voiced a need. Without fully implemented MDSR, data can be confusing and frustrating. As a group, we also noted that in countries where there are a small number of births (i.e. Iceland, Malta, Luxembourg) rates can soar if they have only 1 or 2 cases in 5 years even.

Given that the presentation was based on preliminary data tables, we will need to check again rates in Latvia, Germany, Netherlands, Portugal, Poland and Luxembourg which seemed out of range.

5. Distribution of gestational age (C5)

Preterm births face higher risks of mortality, morbidity compared to infants born at term (defined as 37 or more weeks of gestation), but there is also a need to benchmark prevention efforts for early term births

(37-38 weeks) in Europe. There is growing evidence that infants born early term births are exposed to higher risks of adverse health outcomes compared to full term infants born at 39+ weeks.

Marie Delnord, Euro-Peristat programme researcher, showed wide differences in the GA distribution of births across countries overall and by sugbgroups. This indicator was widely available across countries. Preterm births varied between 6-12% of all births, live singleton preterm 4-9.0%, live multiple births varied between 38-68% and live early term singleton births varied between 16-45%.

Heterogeneous trends in preterm and early term birth rates raise questions about policies and practices associated with these trends. In countries that provided MVAT, it will be possible to explore the impact of obstetrical interventions and other indicators (maternal age, parity) on rates of early delivery.

> **We agreed to have a broader focus on early term births in the next European Perinatal Health Report since there is a lack of information in Europe. Also, preterm birth rates in some countries with large changes over time should be checked.**

6. Distribution of birthweight (C4)

Birth weight is an indicator of maternal and newborn health during pregnancy. It is widely available across Europe. This indicator depends both on gestational age and fetal growth and among low birth weight (LBW) babies can include babies that are:

- Premature < 37 weeks
- Born at term but small for gestational age
- Born at term and appropriate for gestational age
- Born at term and large for gestational age

Katarzyna Szamotulska, SC member for Poland, showed that the majority of children (90-93%) weigh between 2500-4500 g at birth. The proportion of babies less than 2500 g varies among countries from 4.4 to 10.8% of total births and from 4.4 to 10.8% of live births. The proportion of babies 4500+ g varies from 0.2 to 4.3% of total births and from 0.2 to 4.3% of live births. There is North-South pattern of birthweight which can be observed in 2015 and that seems to persists over time. The change in the proportion of live low birth weight babies between 2010-2015 does not exceed ± 1.5% across countries.

> **As a group, we discussed that an indicator more closely related to fetal growth than LBW is needed. Also for the report, we will consider producing maps for GA & BW to highlight North and South differences in Europe. Henrique Barros may be able to help with the production of maps.**

7. Multiple births (C7)

Babies from multiple births have much higher rates of stillbirth, neonatal mortality, infant mortality, preterm birth, low birth weight, congenital anomalies, and subsequent developmental problems than singletons.

Mika Gissler, SC member for Finland, showed that twin rates vary by country, but the relative differences are larger for triplets and higher order multiples. The total multiple birth rate remained unchanged (+0.5%) between 2010 and 2015: 17.0/1000 in 2010 and 17.1/1000 in 2015. The rate of triplets and higher order multiples decreased by 13%: 0.35/1000 in 2010 and 0.31/1000 in 2015 (-13%).

As a group, we discussed the impact of using deliveries as opposed to births on parity rates, and how to measure parity when there are twins.

> **We will add comments from the European Society of Human Reproduction and Embryology (ESHRE) in the publication.**

8. Maternal age C8

Low maternal age is associated with unplanned pregnancies and unfavorable social conditions. Advanced maternal age is associated with a greater use of fertility treatments, multiple pregnancies, maternal complications, and preterm delivery.

Béatrice Blondel, SC member for France showed that in 2015, there were wide differences in the proportion of mothers less than 20 years old which ranged between <3% in 19 out of 32 countries, and 10% in 2 countries, and mothers 35+ : from 13% to 37%. There was a substantial increase in the proportion of women aged 35+ in most countries, even in those which already had many women in this group with some exceptions. A slight decrease in proportions was observed in Estonia, the Netherlands, Sweden and Germany. She reminded the group of the importance of informing young women and their partners about the consequences of delaying pregnancy and having children late in life.

> **One area for research on our data is to examine shifts in the risk curve for maternal age, as there is evidence that older maternal age may not be such an important determinant of preterm birth or other adverse health outcomes in some European countries.**

9. Parity C9

Parity is associated with many maternal and newborn health outcomes including: higher risks of fetal and neonatal mortality, preterm delivery, caesarean section for primipara and higher risks of preterm delivery, maternal complications for great multipara. This indicator has an impact on many other indicators of perinatal health e.g. impact of primiparae on CS rates (cf. presentation on the Robson Classification).

Béatrice showed that there were wide variations in the proportion of primiparae across Europe: 38 to 53% of births in 2015. Similar international variations of the percentage of primiparous women or women with 3 or more previous births in 2010 and 2015. Lower proportion of parity 0 in 2015 than in 2010 in most countries (slight increase in 7 countries)

However, there were some quality issues which we discussed. There were related to discrepant national classifications used to determine parity vs. gravidity across countries.

> **In the report, there could also be a focus on describing trends in fertility rates to explain the variations in the distribution of parity. We will also provide a comment on the definition of parity (children vs. births vs. pregnancies) which varies across countries.**

10. Cesarean section (C10)

Over the last 20 years, the prevalence of cesarean delivery has increased globally. Delivery by cesarean is a recognized risk factor for mother and child. Mode of delivery data were available in all countries. Henrique Barros showed that there were large C-section variations by country, with an apparent regional distribution. 17 countries increased the frequency of C-section between 2010 and 2015 (see below), keeping in mind that a C-section increases the rate of C-section in a subsequent pregnancy.

2010   **2015**

14,8 - 20,0 20,1 - 25,0 25,1 - 30,0 30,1 - 40,0 40,1 - 56,9
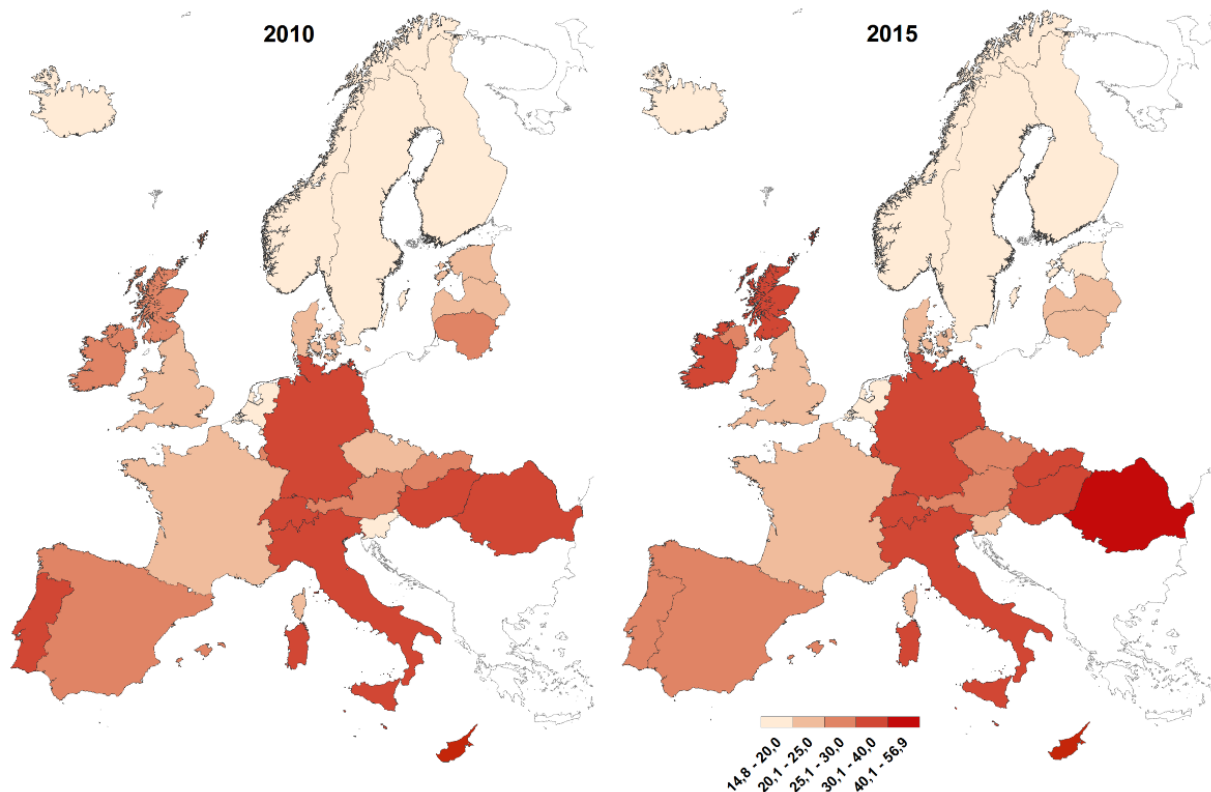
11. New indicator – the Robson classification

Béatrice also presented preliminary results on the Robson classification of CS which is a new data item in the 2015 data collection exercise. The Robson classification was developed in the early 2000's and has been taken up at the national level by several countries. It takes into account some of the factors which may influence the total CS rate such as: Parity, previous CS, number of fetuses, presentation based on mutually exclusive subgroupings and categories. The following countries could provide data based on this classification: Belgium, Denmark, Estonia, France, Italy, Cyprus, Latvia, Luxembourg, Malta, Netherlands, Austria (PARTIAL), Slovenia, Finland, Sweden, UK: England (?), UK: Scotland, UK: Northern Ireland, Iceland, Norway, Switzerland

The 10-Group Classification
1 **Nulliparous** women with a single cephalic pregnancy, ≥37 weeks gestation in spontaneous labour
2 **Nulliparous** women with a single cephalic pregnancy, ≥37 weeks gestation who had labour induced or were delivered by CS before labour
3 **Multiparous women without a previous CS**, with a single cephalic pregnancy, ≥37 weeks gestation in spontaneous labour
4 **Multiparous women without a previous CS**, with a single cephalic pregnancy, ≥37 weeks gestation who had labour induced or were delivered by CS before labour
5 All multiparous women with **at least one previous CS**, with a single cephalic pregnancy, ≥37 weeks gestation
6 All **nulliparous** women with a single **breech** pregnancy
7 All **multiparous** women with a single **breech** pregnancy including women with previous CS(s)
8 All women with **multiple pregnancies** including women with previous CS(s)

9 All women with a single pregnancy with a **transverse or oblique lie**, including women with previous CS(s)
10 All women with a single cephalic pregnancy **< 37 weeks** gestation, including women with previous CS(s)

> **There was some initial confusion due to wording in the Euro-Peristat 2015 data collection instrument on whether the classification was exclusive (correct use) or whether some deliveries could appear in several categories at once (incorrect use). Because these are complex multi-indicator data, we will need time to review and reflect on how to best present this item. We have agreed not to include Robson in the report at this stage.**

12. New approach - Microdata analyses

After going through preliminary results on the Core 2015 indicators, Jennifer reminded us of the importance of the new MVAT pilot protocol. This time, 16 countries/33 countries and regions could provide 12 variables in 2 files (one for mothers/one for babies) in order to compile the indicators. Based on this experience, we have found that this data collection method can improve the quality of data transfer and sharing across countries and supports the sustainability of our data collection activities - statistical programmes to generate the MVAT data are easier to move around than actual individual-level data sets from one country to the next. In looking ahead with where these data could be kept, we could envisage routine transfers to Eurostat of the multivariate data.

Moreover, the MVAT data allow for more impactful research as we will be able to conduct multi-indicator analyses. For example by conducting risk adjustment for maternal characteristics (age, parity) as we evaluate outcomes and use of healthcare services.

However, there are also some limitations. In order to produce the 10 indicators using MVAT data, information constituting the individual-level data set need to be included in one source (or several sources which are already linked).

> **How we can move forward with the MVAT approach will be discussed within the EU Joint Action on health information (InfAct); we will revisit whether partnership with Eurostat could reduce data confidentiality issues for some countries.**

13. Two recommended indicators – Smoking and BMI – J Zeitlin

In the beginning of April 2018 we decided to collect two recommended indicators (%women smoking during pregnancy and distribution of maternal pre-pregnancy BMI) on top of the Core indicator 2015 data collection, in order to provide more contextual information to interpret Core data. The collection of these two indicators is still ongoing as not all countries could provide data by the meeting date.

Smoking during pregnancy:
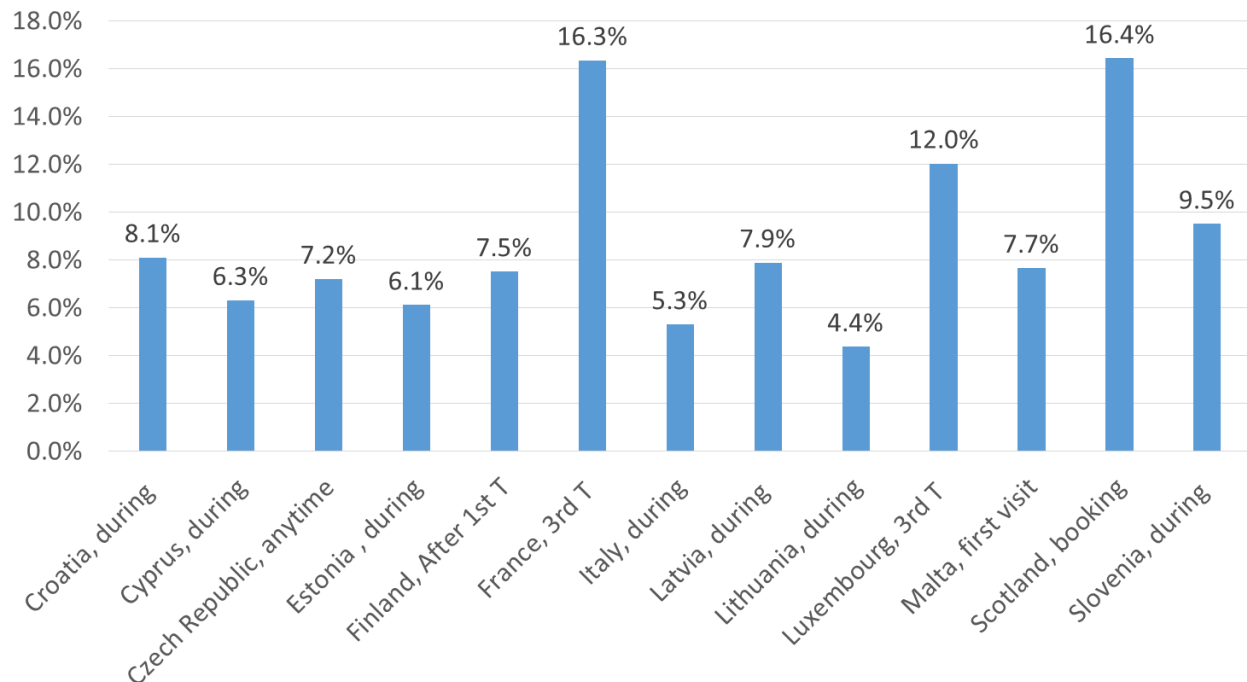
Fewer countries could provide information on BMI (Croatia, Finland, Scotland (height and weight at first visit/booking), Malta, Slovenia (height at 1st visit, weight is self-reported), France (both are self-reported). These data are available in the PowerPoint presentation.

> **Create a list of who is missing vs. who can't provide the data. We agreed to include these 2 indicators in the first report. However, we will need to be able to collect data from all countries by the end of April.**

III.   Producing the report

Next, we discussed the production calendar for the report. We suggested several scenarios:

1. First produce a report on the 10 core indicators and 2 recommended indicators that have been collected
2. Collect the other recommended indicators and issue a separate report
3. Have the data tables on website at a later date

Jennifer asked SC members about their thoughts on what could be a reasonable target date for publication of the report given that resources at Inserm for coordination are limited, and Marie will be leaving in July 2018.

Jennifer also reminded SC members that data were still being collected (Greece will send data by the end of April), checked and cleaned. Then these need to be endorsed by countries before writing groups can be set up for finalizing and writing the report.

Almost everyone was in favor or producing a first report quickly. Perinatal mortality in the Netherlands is an important public and political issue. In order to have impact, we need to move quickly and favor

timeliness. In Germany, stillbirths and neonatal mortality rates have gone up and it is important to put this issue on the table.

Many people will also consider issuing local press releases (8 countries by a show of hands), so we will need to leave some lead time to organize this. In the Netherlands, 2 weeks are needed and less even in the Nordic countries. How do we get HI out and how do we get a change?

We discussed the possibility of truncating the release of the indicators (i.e. mortality indicators first) and some people were in favor. However, the point was made that it is important to keep contextual information in order to interpret these. Also, it involves more work for the coordination team to issue several different reports. Also, we have already cut in half the release of the indicators by focusing first on the Core indicators rather that releasing all core and recommended indicators together.

It was decided to keep the same format as the previous European Perinatal Health Report 2010 but with 10 core and 2 recommended indicators. Marie is in contact with Slickfish who produced the European Perinatal Health Report 2010 for quotes. We are looking into a print on demand option for countries, as Inserm does not have any budget for this publication at the moment.

SC members were asked to think about this over the course of the meeting, and a tentative production calendar was decided on Tuesday – see Section on "Next steps"

IV.   The InfAct Joint Action

This session was moderated by Peter Achterberg. We discussed results of the BRIDGE Health project, and the new European Joint Action on Health Information InfAct. Petronille Bogaert, InfAct project researcher, provided a broad overview of all work packages Next, Nolwenn Regnault presented more specifically on WP9 co-led by Santé Publique France and Public Health Institute of Lithuania. Jennifer presented on the contribution of Euro-Peristat to InfAct and Marie introduced her Marie Slodowska Curie post-doctoral project on measuring the impact of health information on population health.

The main points from this session have been summarized below:

- Setting the stage for an ERIC on Health Information

The BRIDGE health project identified the European Research Infrastructure Consortium (ERIC) as the most feasible solution to support existing international networks which were previously functioning on a project basis. InfACT, the new Joint Action on health information in Europe will ensure the transition to this ERIC by setting up the application process for the ERIC and finalizing the uptake of the ERIC by EU MS. The concept paper for the ERIC on health information is available here: http://www.bridge-health.eu/sites/default/files/Technical%20Report%20WP1_2016_03_Concept%20Paper_final_V2_0.pdf

The ERIC is a MS structure not an European Commission entity, therefore it is Important for individual countries to get in early and ensure full coverage and participation. The countries which are first in the ERIC establish the statutes and determine the terms and conditions. The ERIC is an opportunity to pool budgets to ensure that we are collecting comparable and big data at EU level.

However, there are obstacles to full participation in this ERIC. First, the ERICs are funded principally by ministries of research and this needs to be taken into account. In Finland the ERIC is essentially a scientific infrastructure to push innovations forward more so than routine projects. We also have to realize that in

the UK, there are separate health information systems that run in parallel and this makes it difficult to have a meaningful contribution to the ERIC at UK-level. At the same time, investments to get it set up have to be kept at the national level.

We know that In Europe there is heterogeneity in the level and nature of evidence that are available to decision-makers and key stakeholders. As part of her Marie Curie fellowship at Sciensano (Belgian Federal Research Public Health Institute – coordinator of InfAct), M Delnord will explore associations between health information (HI) capacity and the population burden of disease. The aims will be to identify a core set of HI criteria "*HI standards for better outco*mes" that reflect uptake of information into policy and care overall and in specific health areas, including maternal and child health. The Euro-Peristat network will be asked to provide input into this project, and to identify impactful perinatal health indicators.

- The role of EURO-PERISTAT within the Joint Action.

We will participate in WP7, WP8 and WP9. Tasks involve:

- Supporting the conceptualization of domain specific nodes within a future sustainable health information system (WP7)
- Transferring information about indicators, data transfer protocols, quality control and reporting from the Euro-Peristat network (WP8)
- Analysis to develop new indicators of maternal and child health using routine administrative databases (WP9)
- Work to promote sustainable indicators including work to integrate indicators within Eurostat (WP9)
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The goals of WP9 as presented by Nolwenn are to: 1) Identify more efficient ways of generating comparable, relevant, reliable, updated and sustainable health information across Europe by using data collected for other purposes.2) Assess the potential use of these new data sets for public health policy purposes

- In order to achieve these tasks, coordination of the Euro-Peristat network of 31 member countries will be undertaken (all WP)

- The role of EURO- PERISTAT within the ERIC and sustainability of the project: discussion points

DG Santé does not have funding streams available anymore to fund the Euro-Peristat projects. We need to ensure sustainability in terms of how data are transferred, shared and stored. We need an ongoing recurrent system to have data available for experts. However, even with the ERIC, there may be competition as to which health information activities will be invested in.

The issue is to get funding in and the ERIC which could help channel funding from external partners as well (i.e. professional societies). Also, InfAct is represented by governmental authorities, but we need to ensure that there is room for research as part of the ERIC activities. It is important to realize that sustainability is ensured by promoting human resources and the participation of experts.

Peter Achterberg reminded us the importance of the Euro-Peristat network within the ERIC: full EU coverage, expertise in indicator development and providing high-quality comparable data, capacity building, capacity to influence national policy and strong research outputs.

Many of the Euro-Peristat members were not sure how the ERIC would work in their countries and there was some confusion about the distinction between the ERIC and the Joint Action.

There are also other possible alternatives that can be explored to sustain Euro-Peristat including: using EUROSTAT as a data repository, integrating the Joint research Center (like EUROCAT did), or by participating in targeted big research plateformes (i.e. RECAP for very preterm births https://recap-preterm.eu/). This JRC was not proposed by the Commission as an option for Euro-Peristat.

> **We will get the contact points for all countries in the JA in order to make links between our network and these national representatives.**
>
> **We also discussed the need to reconsider the possibilities with Eurostat or other routine ways to get our data transferred.**

V.   Workshop on registration of births and deaths

This workshop led by Lucy Smith, Prof. at the University of Leicester (MMBRACE collaboration) and Béatrice Blondel investigated persisting differences across Europe in the registration of deaths and births that should be considered when comparing perinatal mortality rates. Ideally we would like to use a fetus at risk approach based on a cohort of pregnant women starting even before our cutoff of 22 weeks, but this is not feasible in most countries. We need to rely on data collected using current methods and differences across units/regions/countries can impact on mortality rates.

To explore these questions, a survey was sent to country representatives on key questions before the meeting (registration limits, practices for recording terminations of pregnancy, definition of date of death for stillbirths, etc.) (cf. in ANNEX). During the meeting, we broke into 3 groups to discuss country responses with reference to specific situations using a series of vignettes (available in the ANNEX). We then reconvened to hear about the discussions in these groups. Lucy, Béatrice and Jennifer took detailed notes and will compile these to be circulated. The key areas of discussion were:

There is great heterogeneity across countries, not only in the rules, but in the interpretation of rules and other factors relating to maternity and other social benefits, funerals and medical practices related to active management of extremely preterm births. These differences are most acute at 22 and 23 weeks of gestation, especially in countries where registration guidelines for stillbirths and live births are different and where these are later than 22 weeks (i.e. 24 weeks, 26 weeks). The situation in countries where birthweight is the primary criteria for registration of stillbirth also contributes to this heterogeneity.

In some countries, these registration issues are more or less important because data come from hospital registers as opposed to civil registration, which may not be linked to medical birth data. In some countries, there are separate registries for stillbirths (one for spontaneous stillbirths and one for abortions) and thus it is possible to get a complete count of all births, even though there is often less data on abortions.

We also discussed parental wishes regarding the registration of stillbirths and how this is taken into consideration. Registration makes it possible to recognize their loss. In some countries, parents are offered a "special certificate" which is not reported to an official statistical system. Whether clinicians take into consideration parents' wishes for registration is not generally known. Some clinicians may feel that it is less of a burden for parents if they don't have to go through the administrative process of registering their child.

Overall, the workshop underlined the fact that practices are not similar across European countries for periviable births. It is important to make these births visible, to account for the burden of mortality at 22-23 weeks, and to find ways to construct common indicators despite differences in official practices across countries. This is a difficult political subject and therefore it is difficult to modify official policies.

We will aim to write up the main points emerging from the workshop as a commentary to the BJOG.

VI.   Next steps

Finally, we discussed the calendar for reporting on the indicators, writing groups on core indicators, new ways to improve indicators of maternal and neonatal morbidity, as well and the importance of using IPD/micro data in future.

1. Calendar for reporting on CORE and 2 RECOMMENDED indicators:

Now to end April: Make corrections of output tables, receive remaining corrections and integrate new data files (Greek data) and other new data files (Norway, UK 2015 mortality data), Review issues on total births.

- 1st to 8th of May – Review & sign-off on tables from SC members
- 8 May – Executive board members provide preliminary drafts texts - these are updates to the texts in the report.
- 8-25 May-Review by reading groups, verification of statistics in tables/figures – Inserm (2015/2010)
- Writing the executive summary – Inserm and writing the introduction/data source sections
- Between 25-31 May: First draft available for review to the group and typesetting.
- By May 20 decide on publication date (either June before the 15th and September?).

If it is not possible to issue the report before the summer, we will provide countries that wish to discuss results with policy makers or other people outside of the group, anonymized, finalized tables where other countries names are not disclosed. We can customize these table to focus on themes or on formats that are most useful.

If decision is to issue the report in September, we will contact BJOG about issuing a summary article. Executive board members agree to revise text from the report and provide a preliminary text and tables/figures. We will set up reading groups for texts for each indicator (a SurveyMonkey survey will be sent out to SC members)

2. Tentative RECOMMENDED calendar (to be confirmed):

We will need to update the 2010 instrument, and make decisions about changes for the maternal morbidity indicator. These changes will be based on the SAAM study (EUROpean NETwork on Severe Acute Maternal Morbidity) led by Anne Chantry at Inserm. 13 countries participate in the project with the aim to develop a valid, reliable, comparable and feasible indicator of SAMM in Europe. 10 different algorithms for the morbidity indicator were developed and analyses are on-going

- July – October 2018: data collection

- December 2018: Report for end of year- This will likely be an on-line report, only.

3. Writing groups

We have been very successful in exploiting results from the 2010 data collection in scientific publications. These articles are available from our website. Now that we have collected 2015 data, we discussed new topics that we can address:

- Comparison of EUROSTAT and Euro-Peristat data
- Perinatal mortality – investigation of the tradeoffs in the trends of stillbirth and neonatal mortality
- Obstetrical interventions and the gestational age distribution across Europe
- Post-term pregnancies: an update on prevalence and association with mortality
- Maternal age, parity and perinatal outcomes in Europe: preterm birth, mortality & low birthweight
- Developing Robson classifications in Europe using routine data
- Comparison of gestation specific mortality for multiples and singletons in Europe
- Birthweight curves and growth restriction
- Changes in the survival infants in Europe: perhaps several analyses that could focus on specific gestational age groups (extremely preterm, moderate preterm, term…)
- Health monitoring using a multi-dimensional indicator of perinatal health
- Commentary on the absence of smoking and BMI data in Europe

We follow BMJ guidelines for authorship and contributorship (http://www.bmj.com/about-bmj/resources-authors/article-submission/authorship-contributorship). Also, always list the Euro-Peristat group author in publications and send manuscript to all co-authors 2 weeks prior to submission. We decided, however, to expand the group author which is now the Scientific Committee Representative (Euro-Peristat Scientific Committee) to include all contributors. Because it is complicated to define who "contributes" we discussed a definition including all people who regularly contributing expertise and data and who attend Euro-Peristat meetings.

We will be sending out the themes so that everyone can express interest in writing groups.

We will also send out the publication guidelines so that these can be endorsed by the new group.

We will be contacting you about finalizing the group author list (Euro-Peristat Research Group)

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4. Use of data by stakeholders

Johanna Walz from the European Foundation for the Care of Newborn Infants (EFNCI) told us more about the importance of the Euro-Peristat data for their network. EFCNI (http://www.efcni.org/) is a parental organization that focuses on promoting active collaboration between different stakeholders from policy, industry, academia, healthcare, and civil society. The goal of this organization is to promote high quality care and services for infants and their families. Euro-Peristat provides crucial data that are used to push for evidence-based recommendations into policy and practice. They have been taken up in several EFCNI publications (White paper, benchmark reports, press releases) and for communications promoting World Prematurity Day (November 17th). The organization has developed European Standards of Care for Newborn Health that will be launched on 28 November, 2018. Data for Euro-Peristat have been used for the creation of the toolkit and include: nicely designed infographics for parents, healthcare providers and politicians.

SC members agreed to be contact points about Euro-Peristat data for EFCNI members and parents. We discussed whether it might be possible to work with EFCNI to develop infographics on our results which are could convey key messages in plain language and images.

Conclusion:

To close the meeting, Jennifer reminded us that for networks to be sustainable, they need leadership and continued funding. One of the items to discuss in the next few years is how to organize governance within our network. We would like to get more contribution from the members and setup a committee with roles that members could fulfill for a limited period. Creating more formal agreements between participating country teams should also be explored. The JA explicitly addresses the questions of how to make domain-specific nodes, like ours, function within a European health system and Euro-Peristat is one of their "proof of concept" projects. Thus we can benefit from suggestions from this group about how to move forward. It gives us the opportunity to reflect on a strategic vision for the future and on how to ensure sustainability as well as visibility and relevance for our work in health policy making. A lot of Euro-Peristat operates on goodwill, but structured agreements at the national level will benefit the network on the long run.

We also discussed that pushing for the uptake of the Euro-Peristat indicators into existing and sustainable data collection systems could also be a way forward (i.e. Healthy Life Years indicator that were integrated to EUROSTAT). If this option is pursued, we also need to make sure that these data are analyzed and collected in the correct manner which requires both medical advice and data management know-how; it's not just about " getting the data out"

It is an opportunity that Euro-Peristat was selected as one of the projects to be a proof of concept for the JA. This shows that we have been able to illustrate the importance of having high quality indicators on maternal and newborn health, based on definitions that are verified and discussed at EU level, for both research and policy making.

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VIII. ANNEX

Available on the website in the members section.

Login="member" and password="!Peristat" Link: "http://www.europeristat.com/members.html