

## **Closed Euro-Peristat meeting**

9:00-10:30 15:30-17:00

# Agenda

9:00-10:30

- Introductions and update
- BridgeHealth project
- Expanding Euro-Peristat beyond Europe
- The CROWN intiative

15:30-17:00

- Collaboration with the Cost project (which will be presented by Soo Downe during the day)
- More on collaborations (OECD, Prebic)
- Writing groups and on-going analyses

### BRIDGEHealth

### **BRidging Information and Data Generation**

for

**Evidence-based Health Policy and Research** 

### LIST OF APPLICANTS

N	o* Applicant organisation name	Country
1	Institut Scientific de Santé Publique (ISP)	Belgium
2	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICAL (INSERM)	France
3	Robert Koch Institute (RKI)	Germany
4	RIJKSINSTITUTE VOOR VOLKSGEZONDHEID EN MILIEU (RIVM)	Netherlands
5	TERVEYDEN JA HYVINVOINNIN LAITOS (THL)	Finland
6	Beratungsgesellschaft für integrierte Problemlösungen (BiPRO)	Germany
7	Umwelt Bundesamt (UBA)	Germany
8	Fundació Centre de Recerca en Epidemiologia Ambiental (CREAL)	Spain
9	Instituto de Salud Carlos III (ISCIII)	Spain
10	Vlaams Instituut voor Technologische Ontwikkeling (VITO)	Belgium
1	KOBENHAVNS UNIVERSITET (KU)	Denmark
1	Eolkehelseinstituttet (FHI) /Norwegian Institute of Public Health (NIPH)	Norway
1,	Dublin City University (DCU)	Irland
14	ISTITUTO SUPERIORE DI SANITA (ISS)	Italy
1	HUB INTERNATIONZIONALE PER LA RICERCA SANITARIA (HIRS)	Italy
10	SWANSEA UNIVERSITY (SU)	UK
1	EUROPEAN ASSOCIATION FOR INJURY PREVENTION AND SAFETY PROMOTION -EUROSAFE (ES)	Netherlands
1	IIS Aragón Centro de Investigación Biomédica de Aragón (IACS)	Spain
19		Denmark
20	Faculdade de Economia da Universidade Nova de Lisboa (Lisbon Economics Faculty (FE UNL))	- Portugal
2	Nacionalni inštitut za javno zdravje (NIJZ)	Slovenia
2	Semmelweis Egyetem (Semmelweis University (SU))	Hungary
2	Universitetet i Oslo (University of Oslo (UIO))	Norway
2	Karolinska Institutet (KI)	Sweden
2	University Bocconi (UB)	Italy
20	HealthSystemIntelligence (HSI)	Austria
2	Technische universtität Berlin (TUB)	Germany
2	Institut de Recherches et de documentation en Economie de la Santé (IRDES)	France
2	MEDIZINISCHE UNIVERSITAET WIEN (Medical University of Vienna (MUW))	Austria
30	Ecole Pratique des Hautes Etudes, Paris (EPHE)	France

Accordingly the objective of BRIDGE-Health is to work towards an European health information (EU-HI) and data generation networks covering major EU health policy areas by promoting the coordination and convergence of existing key projects in health information. The aim is to work towards a comprehensive, integrated and sustainable EU-HI supporting evidence-based health policy and research for the EU and MSs by providing blueprints and/or concepts of building blocks for a future EU-HI structure such as a European Research Infrastructure Consortium (ERIC-HI). By using the comprehensive experience and integrating existing key EU cross-national initiatives, BRIDGE-Health assures a knowledge transfer from the past health and research frameworks. Throughout the project, BRIDGE-Health aims to work on following generic objectives:

- ensure sustainability of key health information activities that have been run under the past EU-health and research framework programmes and enhance synergy among these activities;
- enhance the transferability of health information and data for policy and improve the utility and use of data and indicators for stakeholders in policy making, public health surveillance and health care;
- reduce health information inequality within the EU and within MSs;
- enhance information on regional variations on indicators, inequalities and specific population groups such as children and the elderly;
- develop a blueprint for a sustainable and integrated EU Health information system by developing common methods for
  - standardizing the collection and exchange of health information (including meta-data, role of different data sources) within and between domains, between MSs, including e/m-health platforms through the development of common tools and mechanisms at EU level to address shortages of resources and to improve health information, and facilitate up-take of innovation in health information at EU and MSs level;
  - o ensuring data quality, including procedures for internal and external validation of health indicators;
  - undertaking priority setting exercises for health information in order to help measure progress towards improving healthy life years (EIP Active Healthy Ageing), focusing on the largest parts of the burden of illhealth such as chronic diseases, mental health, functioning, and accidents and injuries and their causes and
  - addressing ethical and legal issues associated with the collection and use of health data within MSs and the EU.

More specifically, the BRIDGE-Health project

- a) contributes to the conceptual framework for a sustainable health monitoring and reporting system;
- b) evaluates and improves the core set of European Core Health Indicators (ECHI) and ensures its sustainable further development;
- c) strengthens the use of the Healthy Life Years (HLY) indicator, as overarching indicator of population health and outcome measure for health and health inequality improvement efforts, within the EU and MSs in different policy areas;
- ensures that data generated by national health examination surveys conducted in MSs are reliable and comparable over time and between MSs;
- e) maintain and expand work on harmonised European wide Human Biomonitoring (HBM) surveillance in the European population;
- f) improves and strengthens information and data collection on reproductive, maternal, newborn and child health (RMNCH) by bridging efforts for health information in RMNCH and creating a roadmap for further development;
- g) maintains and strengthens the implementation of population based registries for chronic diseases with standardization of methodologies for producing standardized EU-wide indicators taking selected clinical conditions as test cases;
- h) maintains, strengthens and expands the platform for injury surveillance;
- i) maintain, strengthen and expand a platform based on health care administrative data meant to evaluate health care performance;
- j) develops harmonized indicators, methods and to tools to monitor and evaluate health care systems at the national and regional level
- k) develops a blueprint to integrate population health information by creating a roadmap based on mapping barriers and opportunities in MSs with special attention to improving geographic availability of health information and methods for the exchange and use of population health data;
- develops a blueprint to integrate health care information systems using existing data sources administrative data, survey data or registry data, both population or disease-based.

Work package number	7				
Work package title	Reprod	Reproductive, maternal, newborn, child and adolescent health			
Starting month	1	Endir	g month	30	
Leading applicant	NIPH			ł	
Applicants Nr	12	2	8	13	1
Applicants Acronym	NIPH	INSERM	CREAL	DCU	ISP
Person month per applicant	5.2	46.8	16.7	26.6	1.3

### Objectives

- Under the systems framework of this proposal, to develop a blueprint for health information in RMNCH to be sustainably integrated in a European health information system for health care, public health surveillance, research and policy making
- Optimize the sustainability, timeliness, comprehensiveness, quality and use of perinatal health information from routine systems as specified in the Euro-Peristat roadmap
- 3. 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 a European observatory of health information for RMNCH research, to make the lives of women and children in Europe more visible.

#### Description of work

Task 7.1 To develop a blueprint for health information in RMINCH to be sustainably integrated in a European health information system for health care, public health surveillance, research and policy making (NIPH, applicant #12; in collaboration with INSERM, applicant #2, CREAL (applicant #8 and DCU, applicant #13)

- Review and merge existing maps, as well as undertake data collection in the joint network, to map the structure and content of the current European infrastructure of reproductive health registries and other data collections in RMNCH
- Integrate RMINCH data in the overall BRIDGE project's system framework and other health areas, emphasizing
  opportunities to improve the utility and use of data, including use by parents, and young people, reduce
  inequalities, the need to harmonize responses to ethico-legal issues, improving health and care indicators, and the
  increasing use of e- and m-health systems

# Task 7.2 To Optimize the sustainability, timeliness, comprehensiveness, quality and use of perinatal health information from routine systems as specified in the Euro-Peristat roadmap (INSERM in collaboration with NIPH, CREAL, DCU)

- 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
  - Training sessions held with new member countries
  - Meeting of the Euro-Peristat network
  - Report and scientific publications on analysis of Euro-Peristat Health Indicators published
- 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
  - Action research report on extending reporting capacity through data linkage published
  - Protocol for experimental micro-data repository using data on 2015 births published
  - Reporting interface protocol involving policy makers, clinicians, statisticians, users and researchers on a selected theme published
- To harmonize and integrate Euro-Peristat health indicators, methods and tools within an EU health information system
  - Report on synergies between perinatal health information and other health information projects published

Task 7.3 To create a research observatory for reproductive, maternal, newborn and child cohorts and registries. (CREAL, in collaboration with NIPH, INSERM, DCU)

- Maintenance and expansion to new cohorts (see <u>www.birthcohort.net</u>)
  - Report with proposal for improved integration of cohort and registry data sources on RMINC
  - Expert meeting (in conjunction with objective 2A) to develop an infrastructure for research observatory for reproductive, maternal, newborn and child cohorts and registries
  - Guidelines for Europe-wide cohort data harmonization and exchange. List of priority child health areas for data harmonization
- Harmonizing and bridging routine administrative and health data collection systems and indicators with research data collections. (DCU)
  - Review of possible sources of relevant administrative and research data on maternal and child health
  - Report on the extent and value of a range of possible data sources on the lives of children, and adolescents in Europe
  - Workshop, on bringing administrative data into full use for child and maternal health in Europe
- RICHE website maintenance and updating

Deliverables linked to this work package (brief description, month of delivery, reference to the list of deliverables)

- D 7.1 Blueprint for Health Information in RMNCH in Europe; scientific paper :Month 30
- D 7.2 Guidelines for data linkage, transmission using a micro-data repository and mapping priorities among stakeholders.:Month 24
- D 7.3 Report containing describing observatory and including guidelines of data harmonization exchange, prioritization, and bridging within cohorts, and bridging of cohort data with registry data:Month30
- D 7.4 Report on sources of routine data on child and adolescent health across Europe :Month 24
- D 7.5 Ways of making more effective use of routine data to examine the lives of children and adolescents in Europe , scientific paper: Month 30

Specific objective 2.A	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		
Process indicators	Output indicators	Outcome indicators	
Training sessions held with new member countries (yes/no)	Report on test of data collection process in new members using 2010 data published (yes/no)	Aaddition of Bulgaria and Croatia to the network (yes/no)	
Meeting of the Euro-Peristat network attended by at least 80% of member countries	Report on analysis of Euro- Peristat Health Indicators published (yes/no)	Publications in peer reviewed journals on Euro-Peristat data (n=2 )	
Website maintained and enhanced (number of new articles, page visits)	Newsletter published and disseminated to Euro-Peristat stakeholders	Greater involvement of stakeholders .(10 stakeholders to participate in specific objective 2C)	
Euro-Peristat network members attend RMNCH Meetings (yes/no)	Report on Euro-Peristat's members feedback about RMNCH Blueprint published and disseminated to other partners (yes/no)	Countries participating in Euro-Peristat that have endorsed RMNCH Roadmap (number)	

Specific objective 2.B	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		
Process indicators	Output indicators	Outcome indicators	
Meetings of working group on data linkage to improve perinatal health indicators (yes/no)	Action research report on extending reporting capacity through data linkage published (yes/no)	Countries have improved availability of indicators (number)	
Meetings of working group to improve transfer of perinatal health data (yes/no)	Protocol for experimental micro-data repository using data on 2015 births published (yes/no)	Improved quality and cost-effectiveness of data transmission, operationalised in at least 10 countries for 2015.(number)	
Meetings of working group on priority setting for perinatal health indicator reporting (yes/no)	Reporting interface protocol involving policy makers, clinicians, statisticians, users and researchers on a selected theme published. (yes/no)	Consensual list of priorities on selected theme (yes/no)	

Specific objective 2.C	Under the systems framework of this proposal, harmonize and integrate Euro- Peristat health indicators, methods and tools within an EU health information system		
Process indicators	Output indicators	Outcome indicators	
Involvement of Euro-Peristat	Report on synergies between	Modifications to Euro-Peristat's data	
members in Bridge activities relevant to objectives (yes/no)	perinatal health information and other health information projects published (yes/no)	collection and reporting procedures (at least 3 changes). (number)	

## PREBIC





Department of Reproductive Health and Research Family, Women's and Children's Health

### PREBIC/WHO Epidemiology Working Group (EWG) Meeting 16-17 September 2014 M505, Geneva, Switzerland

#### Agenda

#### Day 1, Tuesday, 16 September

9:00 - 9:15	Welcome and introductions	Dr Marleen Temmerman
		Dr Metin Gülmezoglu
		Dr Michael Kramer
9:15 - 9:30	Origins and history of EWG	Dr Michael Kramer, Dr Siobhan Dolan
	PREBIC: summary of March 2014 meeting	Dr Siobhan Dolan
9:30 - 9:45	Overview of HRP/RHR activities in preterm birth	Dr Metin Gülmezoglu
9:45 -10:30	Brief progress report on PREBIC EWG activities	Dr Michael Kramer

11:00-11:30	Goals for WHO/EWG Collaboration	Dr Metin Gülmezoglu
11:30-12:30	WHOMCS EWG projects	Dr Naho Morisaki
12:30-13:30	Lunch	
13:30-14:45	WHOMCS Trainee Projects	Dr Alfred Osoti, Dr Dimuth Peiris
	Group discussion	
14:45-15:00	Algorithm for correcting erroneous gestational ages	Dr Rolv Skjaerven
15:00-15:30	Coffee/tea break	
15:30-17:00	Expanded Euro-Peristat analyses	Dr Jennifer Zeitlin, Dr Ashna Mohangoo,
		Dr Marie Delnord
10.00		· · · ·

### Day 2, Wednesday, 17 September

9:00-10:30	Individual-level HIC analyses	Dr Rolv Skjaerven
	(15 minutes per country)	Dr Mika Gissler
		Dr Sven Cnattingius
		Dr Anne-Marie Nybo Anderson
		Dr Naho Morisaki
		Dr Michael S. Kramer
		Dr Jennifer Richards, Dr Michael R. Kramer
10:30-11:00	Coffee break	1
11:00-12:30	Individual-level HIC analyses	Dr Michael Kramer
	(continued and group discussion)	
12:30-14:30	Lunch	I
13:30-14:15	Management of preterm labour: meeting summary	Dr Olufemi Oladapo
	and future research priorities	
14:15-15:00	EWG and future WHO preterm birth activities	Dr Michael Kramer, Dr Metin Gülmezoglu
15:00-15:30	Coffee/tea break	1
15:30-17:00	EWG-WHO activities (group discussion)	All
	Future analyses, manuscripts, & authorships	
	Timelines & next meeting	

# Euro-Peristat plans

PREBIC EWG 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.
- use country-level indicators to address both study areas using already existing data from 29 European countries participating in Euro-Peristat
- collecting new data on similar country-level indicators provided by the other HICs in the PREBIC project (U.S.A., Canada, and Japan).
- We will also reach out to MIC to see if these indicators are available from routine sources.

Marie Delnord has funding to do a PhD using these data