Annual report of the activities of the EUPHA section Public Health Monitoring and Reporting

2013

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1. Formation of a section Steering Committee

As agreed during the section annual meeting in 2012, a Steering Committee for the section was formed, soon after the Malta conference (for more details on the procedure, see point 6. Annual meeting). In November 2013, the Steering Committee consists of:

- Claudia Stein, Director of Information, Evidence and Research at the WHO European office in Copenhagen
- Hans van Oers, Chief Science Officer at the Institute for Public Health and the Environment and Professor at Tilburg University, the Netherlands
- Magnus Stenbeck, Karolinska Institute, Sweden
- Pieter Kramers, external consultant for the Institute for Public Health and the Environment, the Netherlands

Elke van Hoof, Free University Brussels, Belgium, was a Steering Committee member until September 2013, but had to withdraw due to lack of time.

The following tasks were envisaged for the Steering Committee members:

1. Advise the section President and vice-President about issues such as strategy and activities of the section, collaboration with external partners, and the role/position of the section within (developments in) EUPHA
2. Support the section President and vice-President with the execution of section related tasks, such as consulting section members on specific topics, preparing the section's annual meeting, and writing news updates for e.g. the EUPHA Newsletter
3. Contribute to articles, (position) papers etc. on behalf of the section, at the request of or in consultation with the section President and vice-President
4. Represent the section/EUPHA at conferences and other events, at the request of or in consultation with the section President and vice-President and/or the EUPHA office
5. Supporting the section in preparation of research grants

6. Promoting the section's public health areas of interest

Steering Committee members do not necessarily need to engage in all these tasks, engaging in a selection of tasks is possible as well. So far, the Steering Committee members mainly contributed to activities 1 and 6. The Steering Committee had regular contacts through e-mail in 2013 and a short face-to-face meeting during the EPH conference in Brussels.

2. Preconference during the EPH conference 2013 in Brussels

During the EPH in Brussels a full day preconference was organized by the section together with the EUPHA sections on Public Mental Health and Urban Public Health. The topic of the preconference was: the burden of mental health in Europe: future needs for monitoring and research. The specific objectives of this pre-conference were:
1. To provide an overview of the state of the art of monitoring mental health,
2. Give examples from research in the field of Public Mental Health, paying special attention to data throughout the life course and to data at urban level;
3. To bring together knowledge of the members of the three sections and enhance collaboration between the three sections and;
4. Jointly develop a roadmap for research and monitoring.

There were about 20 participants. For the programme of the preconference please see the annex to this annual report. Unfortunately Dr. Barros had to cancel his presentation at the last moment. The main points that were discussed during the group work and the plenary discussion were:

1. Monitoring mental health

*   Should we move from monitoring mental health outcomes to mental health risk factors? A large body of knowledge exists on risk and protective factors, but there is not much focus on monitoring these factors as yet.
*   A lot of gaps in information regarding mental health monitoring have been identified. Should we data, even if their quality is poor, to stimulate improvement of data collections?
*   We need a good balance between stability (necessary for monitoring trends) and flexibility (necessary for incorporating new scientific insights) in mental health monitoring systems.
*   Even though a lot of data are lacking, there are data - sometimes of a more indirect nature - which can be used. These include data on topics which are correlated with mental health, such as data from the economic, social security or labor market sector. Also modeled data could be used more.

➔ The feedback loop between mental health monitoring and mental health research and vice versa is inadequate: gaps in information identified during monitoring do not end up on the research agenda and new research findings, e.g. on risk factors, are not being taken up in monitoring practice. We need to strengthen the links between mental health monitoring and research.

2. Communication about mental health

- How can we engage policy makers at the local level, how can we convince them of the magnitude of the problem and which effective interventions at the community level can we offer them?
- Communication with policy makers/advocacy: we need to focus on solutions more, we need to focus on the quantification of the impacts of mental health and the quantification of the effects of interventions; we need to make economic arguments, as these are important in the current time of financial crises; and we need to focus on story telling rather than on presenting a lot of data.
- We need to make sure we speak the same language. In different settings different, partly overlapping terms are being used now: mental health, mental disease, and well-being.

➔ We need more translational research. There is an explicit focus in Horizon 2020 on translational research; this provides opportunities. A focus on translation into policy/practice is needed throughout the entire research process, starting with the formulation of the research question. A focus in the dissemination phase is not enough.

The presentations and the summary of the discussions will be published at the section specific web pages of the EUPHA site. Possibly the outcomes of the discussions will be elaborated into a position paper or an article.

3. **Workshops during the EPH conference 2013 in Brussels**

Round table: European Health Information System: Steps from idea to reality
Joint workshop by the EUPHA section Public Health Monitoring and Reporting (PHMR), the EUPHA section on Urban Public Health and Maastricht University

Approximately 50 participants attended the workshop. This workshop was a follow up of the letter EUPHA and the section PHMR had sent to EU Health Commissioner Borg regarding the lack of sustainability of health information activities at EU level (see the section's annual progress report 2012 for more information about this letter).

The session started with three introductory presentations, providing concrete inputs and possible elements for a future single European Health Information System:
- An overview on health information strategies (Nick Fahy. Nick Fahy Consulting)
- What do practitioners think is important or are the quality criteria for an EU health information system (Nicole Rosenkoetter, Maastricht University)
- Why consider the urban perspective for a European Health Information System/Strategy? (Arpana Verma, President of the EUPHA section on Urban Public Health and EURO-URHIS)

After the introductory session, the panel discussion started, moderated by Prof. Helmut Brand from Maastricht University. The following panellists took part in the discussion:
- Claudia Stein, WHO Regional Office for Europe

- Stefan Schreck, DG SANCO
- Gaetan Lafortune, OECD
- Martin McKee, EUPHA
- (Hartmut Buchow, Eurostat, had to cancel at the last moment)

Summary of the reflections by the panellists and the discussions:
- According to Claudia Stein, the mandate from Member States for such a system is strong – it has even been reiterated in a recent resolution adopted by 53 European Member States at the Regional Committee for Europe in connection with Health 2020 indicators. As first concrete steps towards a common Health Information System we need: a common set of indicators; further harmonization of data collections; a common platform for sharing data and information; and equal access and ownership.
- Martin McKee stated that such a system has been long overdue; we should focus on the EU first, for if we cannot even sustain a system within the EU, we certainly cannot sustain a system in the wider European region.
- Stefan Schreck explained that due to the subsidiarity principle and the text of the Treaty, in the field of Health Information the EU can only complement what Member States (MS) are doing. As appears from the presentation by Nick Fahy, there is no consensus among MS about the aim of health information. This also complicates the establishment of a European Health Information System. The added European value lies in harmonizing data collections to increase comparability and quality. But if MS are not interested in international comparisons, they will also not support a European Health Information System. The notion that the EU is not able to operate outside the strict textual borders of the Treaty was challenged by the audience and Martin McKee.
- Gaetan Lafortune focused on the joint WHO-Eurostat-OECD data collections that are taking place already. These could be a good starting point for expanding the joint work. He emphasized that though more and more data are being collected together, the three organisations still use different indicators, e.g. they all use different standard populations in the computations of indicators.
- The new General Data Protection Regulation (GDPR) poses great threats for public health monitoring and research. The panellists felt that the public health community to great extents is unaware of this.
- Some participants argued that governments and politicians often do not want to know about the data, they rather perform fact-free politics. It was suggested that to overcome this, we should focus more on economic argumentations, for politicians do listen to those.
- It seems that to a large extent the fact that until now it has been so hard to establish a European Health Information System comes down to (a lack of) political will. So maybe the public health community should focus on policy aspects rather than on technical aspects when trying to make a case for a single system. The panellists strongly advised to use the governance structures of the international organisations to enforce concrete actions towards the single European system.

The outcomes of the discussions and potential follow up actions were discussed during the section's annual meeting at the EPH (see point 6).

Skills building seminar: A scenario building exercise for the future burden of disease in Europe
Joint workshop by the EUPHA sections Public Health Monitoring and Reporting (PHMR) and Health Impact Assessment

Approximately 20 participants attended the workshop.

Abstract of the workshop: to support public health policy making, providing insights into future social, economic and environmental trends is essential. However, these trends are uncertain. The impact scheme of even one policy implies large amount of uncertainty as experienced in the practice of health impact assessment, not to talk about the combined effects of several policies and of poorly controlled social and natural processes. To deal with these uncertainties, a scenario methodology can be applied. Such a scenario methodology consists of various steps in order to have a consistent and systematic description of possible images of the future of public health. The Netherlands Institute for public health and the Environment (RIVM) uses a scenario methodology in the upcoming Public Health Forecasting (VTV2014) to explore possible developments of disease burden, prevalence of health determinants, health care costs, and availability of health care staff. In this workshop, the experience of the VTV2014 will be used as a starting point applying this scenario methodology to explore possible futures for public health in Europe. What are the main drivers of public health, how will these drivers influence health outcomes, what are the main uncertainties, etc. The objective of the workshop is to develop different, consistent public health scenarios for Europe. The participants will be introduced in methods to develop a scenario, apply this to the public health situation in Europe and (qualitatively) describe different scenarios, including messages for policy makers.

Workshop: Pampers or pamper? Should we celebrate an ageing population or fear it?
Workshop organized by EUPHA together with the EUPHA sections Chronic Diseases, Injury Prevention and Safety Promotion, Health Services Research, Health Promotion, Ethics in Public Health and Public Health Monitoring and Reporting (PHMR)

Jean-Marie Robine presented the demographic challenge in Europe on behalf of the section PHMR.

4. Revision of the EU Data Protection Directive: General Data Protection Regulation (GDPR)

An on-going activity of the section is to keep track of the development of the new EU General Data Protection Regulation (GDPR). This revision could have (very) negative consequences for public health monitoring and research. It is therefore of utmost importance to follow this development, and whenever possible provide input in order to try to ensure a favourable outcome for public health monitoring and research. The section Presidency regularly sends updates on the development process to the section members. The issue was on the agenda of the section's annual meeting (see point 6).

5. EUPHActs 'Health information'

In the summer of 2013 the EUPHA section Public Health Monitoring and Reporting drafted a so-called EUPHActs (= EUPHA fact sheet) on health information. The EUPHActs currently is under review with the EUPHA Executive Council. Once the definitive version will have been established, it will be published at the EUPHA website.

6. Annual meeting

The following issues were discussed during the section's annual meeting in November 2013 in Brussels:
1. Administrative and governance update: Presidency, formation of the Steering Group, activity report of the section 2013
2. Short summary of main outcomes preconference on mental health monitoring and research and round table on the single European health information system, focusing specifically on concrete follow-up activities
3. State of affairs new Data Protection Regulation: anything our section could/should do at this stage?
4. Development of European Research Infrastructure Consortia (ERICs) in the field of Health Information: role of our section in these developments?
5. Consequences of the Eurostat Revision of the European Standard Population
6. Gathering ideas for section activities, including ideas for workshops etc. for the 2014 conference

It was discussed and agreed that:

1. Presidency: the 3 year term of the section President and vice-President will end in one year (term lasts until EPH conference 2014). Both the President and the vice-President announced that they will not opt for a second term. **Candidates for both functions were asked to express their interest.**

   Steering Committee: after the EPH conference in 2012, a Steering Committee was formed. Most members were found after a call for expressions of interest through the mailman system. Several reactions were received, which were assessed by the President and the vice-President in terms of public health monitoring and reporting experience and knowledge of/experience with the European health information field. One Steering Committee member was approached directly by the President and vice-President.

   Annual activity report: a draft report was distributed prior to the annual meeting. **The annual activity report will be finalized in November/December** by adding reports of all the section activities during the conference. The final report will be distributed among the section members and published at the section specific web pages of the EUPHA site.

2. Preconference mental health monitoring and research: the main points of discussion (see point 2 of this report) were shared with the participants of the meeting. The participants were informed that **a short report on the outcomes of the preconference will be written.**

Round table single European Health Information System: one of the main outcomes of the panel discussion was that the panellist strongly suggested using the governing bodies of the international organisations to enforce concrete actions towards the single European system. Action can only be taken if this is explicitly moved forward by the Member States. While discussing this during the section's annual meeting, the following follow up points for the section were agreed upon:

- To support public health experts in contacting their national counterparts in the governing bodies of the international organisations, **a standard letter arguing why a single European Health Information System is a necessity will be drafted** by the section.
- **A short publication for the EJPH will be written** by the section, using the Round Table discussions as a starting point.

3. The topic came up in different sessions during the conference. The general feeling was that many public health experts are unaware of the development of the new General Data Protection Directive (GDPR) and its potential consequences. The European Parliament has approved a large number of amendments in October last. Though some sharp edges of the original Albrecht report had been removed in the proposal that was accepted in October, several articles could still have immense consequences. These include: the (restrictive) conditions under which personal health data can be used for public health purposes without informed consent; the (restrictive) definition of explicit, informed and specific consent; defining pseudonymized data in such a way that they become personal data (and hence will fall under the Regulation); and the right of the data subject to be forgotten. During the annual meeting it was discussed that we should assume that several of the EP amendments will remain standing during the further discussions on the GDPR. Therefore we should better focus on trying to influence the definition or interpretation of certain concepts in such a way that they will work for public health (e.g. "high public interest', the right to be forgotten). It was agreed that **the section will make a one page factsheet** to inform the section and EUPHA members about the current situation. The President and vice-President will put the issue on the agenda of the EUPHA Section Council Meeting, which will take place after the ending of the conference.

4. Jean-Marie Robine and Mika Gissler gave an update on the ERIC developments. The European Commission is steering towards a single Health Information ERIC, which should accommodate the work of many former EU-funded projects, such as ECHI, EHLEIS, EHES and IDB. It is not yet clear how this would function.

5. It was agreed that **the section will develop a factsheet** to inform policy makers and public health researchers about the consequences of the introduction of the new European Standard Population by Eurostat.

6. Newsletter: the newsletter of the ECHI Transition Network, which was also distributed among the section members, will cease to exist. As the section members really appreciated the newsletter, it was agreed that **the ECHI newsletter will continue as a section PHMR newsletter**. It will be checked whether students of the master European Public Health in Maastricht can help with compiling information to ensure sustainability of the newsletter.

Ideas for workshops for the 2014 Glasgow EPH conference:
- The effects of the economic crisis on monitoring systems (together with the section on Public Health Economics)
- First results of the Eurostat Morbidity Statistics (there already has been contact with Eurostat about this)
- Data visualisations. Section members were asked to share inspiring examples
- The (quantified) relationship between health inequalities and health information inequalities.

(The agenda and the minutes will be available as well at the section specific web pages at the EUPHA site: http://www.eupha.org/site/section_page.php?section_page=34)

7. Communication

- Website

The section's annual activity report 2012 was placed at the website, as was information about the members of the section's Steering Group. For the section web pages at the EUPHA website, see:
http://www.eupha.org/site/section_page.php?section_ref=S_FOR

- Twitter account

The section has a Twitter account, **@PHMRsection**. The section President is managing this account. On December 1st 2013 the Twitter account had 59 followers, and 246 tweets had been sent.

- Mailman system

The section used the mailman system on several occasions to inform the section members on issues such as conferences, interesting reports, newsletters and section related information (e.g. twitter account, section workshops and preconference in Brussels, agenda for the annual meeting, updates on the development of the EU General Data Protection Directive).

- Presentation on section at 'Holland Fuse Conference'

An abstract on the section PHMR was selected for presentation as an 'elevator pitch' during the 2nd Holland Fuse Conference in April 2013. The aim of this conference is to explore the approaches, opportunities, and challenges involved in the use and sharing of knowledge and evidence across professionals, researchers and policymakers in the public health and wellbeing community.

Annex: programme of the preconference on mental health monitoring and research

Time	Topic	Presenter(s)
9.15 – 9.30	Welcome and introduction	Jutta Lindert, Arpana Verma, Marieke Verschuuren
Part 1: Examples from research on Public Mental Health		
9.30 – 10.00	Urban level data on children, adults and elderly people	Arpana Verma
10.00-10.30	*Coffee break*	
10.30 – 11.00	Mental health in adults – review of research results	Henrique Barros
11.00 -11.30	Risk factors for mental health – challenges for monitoring and research	Jutta Lindert
Part 2: State of the art of mental health monitoring in Europe		
11.30 – 12.00	Monitoring mental health in Europe	Marieke Verschuuren
12.00 -13.00	*Lunch break*	
13.00 – 13:30	Possibilities and limitations of using registry data for public mental health monitoring	Peter Allebeck (Stockholm County Council and Karolinska Institute, Sweden)
Part 3: The European mental health policy and monitoring framework: the way forward		
13:30 - 13:50	Mental health monitoring - WHO-Regional Office`s perspective	Ivo Rakovac (WHO Regional Office for Europe)
13:50 – 14.10	The Joint Action on Mental health and Well-being under the EU-Health Programme: Towards better services with more prevention and health promotion	Jürgen Schefftlein (DG SANCO)
14.10 - 14:30	Mental health monitoring and research - DG Research's perspective	Caroline Attard (DG Research)
Part 4: Group work and panel discussion		
14.30 – 15.30	The way forward – group discussions	
15:30 - 16:00	*Coffee break*	
16.00 – 16.15	Summarizing outcomes group work as input for the panel discussion	
16.15 – 17.15	Moderated panel discussion	Jutta Lindert, Marieke Verschuuren, Arpana Varma, Jürgen Schefftlein, Caroline Attard, Ivo Rakovac, Peter Allebeck
17.15 – 17.30	Wrapping up: main conclusions and agreements, short feedback round	Jutta Lindert, Arpana Verma, Marieke Verschuuren
17.30 -	Dinner (optional)	