

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

2014

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1. Letter to the editor of the EJPH on the need for a single European Health Information System

In follow up of the ‘Round table on European Health Information System: Steps from idea to reality’, the joint workshop organized during the EPH 2013 by the EUPHA section PHMR, the EUPHA section on Urban Public Health and Maastricht University, the organizers of the workshop submitted a letter to the editor of the European Journal of Public Health. This letter, called ‘The realisation of a European health information system--time to get the politicians involved’, was published in the EJPH in February 2014 (Epub). The main message of this letter is that though some joint activities in the field of health information are taking place, WHO Regional Office for Europe, the European Commission and OECD need to step up in order to realize the single European health information system their Member States are asking for. National authorities need to keep on making a strong plea for international cooperation and harmonization through the governing mechanisms of the three international organizations.

Full reference of the letter to the editor: Rosenkötter N, Brand H, McKee M, Riley N, Verma A, Verschuuren M. The realisation of a European health information system—time

to get the politicians involved. Eur J Public Health. 2014 Apr;24(2):184-5. Doi: 10.1093/eurpub/cku012. Epub 2014 Feb 24. PubMed PMID: 24568753.

2. Activities of the section Steering Committee

- The Steering Committee provided detailed comments on EUPHA's draft Strategy and Work Plan.
- The Steering Committee provided feedback on the meeting materials for the EUPHA Section Council meeting in June 2014, which was attended by the Vice-President.
- In September 2014 the Steering Committee had a 1.5 hour teleconference (see agenda below).

Agenda of the teleconference of the Steering Committee of the section PHMR on September 3rd 2014:

1. Functioning and composition of the Steering Group
2. Annual meeting section during EPH
3. Section workshops during EPH (state of affairs)
4. Section Newsletter
5. Section annual activity report
6. Health assessments (discuss e-mail EUPHA office on this topic)
7. Any other relevant health information developments

3. Workshops during the EPH conference 2014 in Glasgow

Diagnose-based morbidity statistics for the European Union

Joint workshop by the EUPHA section Public Health Monitoring and Reporting, the EUPHA section on Chronic Diseases and Eurostat

This workshop was organized as a back-to-back session with a workshop focusing on the activities of the Joint Research Centre (JRC) in Ispra, Italy, in the field of morbidity. Both sessions were introduced by Stefan Schreck, head of the health information unit at DG SANCO, who placed the issues presented during the workshops in a broader perspective by presenting the state of the art of health information activities by the European Commission. After that Marieke Verschuuren (President section PHMR) and Monica Pace (formerly Eurostat) briefly introduced the need for morbidity statistics from the EUPHA perspective and the Eurostat perspective, respectively. Next, Hartmut Buchow of Eurostat presented the history, current status and future plans of the Eurostat morbidity statistics activities. This was followed by a presentation by Rita Gaidelyte on the results of the Eurostat pilot data collection on morbidity statistics in Lithuania. Lithuania explored the use of the database of the mandatory insurance fund as a new source for calculating the requested ICD10-based incidences and prevalences, and, despite some difficulties, found this to be a usable source. The final presentation was by Grainne Cosgrove from Ireland, and addressed the challenges faced by an EU Member State when having to deal with a (future) request for morbidity statistics from Eurostat. Calculating diagnose-based national best estimates is challenging, as it requires the use and linkage of many different data sources, which makes it a much more demanding task than e.g. providing hospital discharge data. For a country as Ireland, which has been heavily affected by the economic

crises, resulting in a reduction of health information staff, it would be very difficult to comply with a request for regular estimates for 65 diseases. The presenter from Ireland therefore made a plea to the Commission to really work together with the EU Member States and listen to their needs and provide optimal support, and to keep on emphasizing the importance of a high quality data collection on morbidity statistics both at the national and international level. The next step in the developmental process is the voluntary detailed mapping by EU Member States of the potential data sources they have for calculating the requested estimates. Finally, Eurostat envisages the establishment of a Regulation on morbidity statistics by 2020. During the discussions the need for data linkages and the legal problems surrounding this was one of the main points addressed. There seems to be a new momentum for informing the EP about the negative effects for public health research and monitoring of the amendments to the draft General Data Protection Regulation adopted earlier by the (former) EP, as the new MEPs appear to be poorly informed about this dossier.

Adaptation of health information systems following the economic crisis: Risks and opportunities

Joint workshop by the EUPHA section on Public Health Monitoring and Reporting, EUPHA section on Public Health Economics, WHO Regional Office for Europe

Marieke Verschuuren introduced the workshop which aims to identify the effects of the financial crises on health information systems. For not only the health care budgets are being cut, also the funds for health statistics are being cut, with the risk of weaker evidence for policy decisions that have to be made, especially in times of crises.

Mika Gissler, Finland, then pointed out the threats for mental health surveillance. Mental health is often an invisible part of general health: integrating mental health in health information systems with primary care, social workforce and specialized health services, leads to the loss of specific attention for mental health. Moreover, focus has shifted from mental health disorders to also cover positive mental health and well-being. Due to austerity measures, the routine collection of data (routinely collected statistical of register data and surveys) may be discontinued, and health surveys may face shortened and less frequent questionnaires. Due to decreasing quality control measures, the quality of the health information may be deteriorated as well. There may be possibilities too, such as increasing collection of electronic data and the European health interview survey 2014. Mika concluded by stating that mental health surveillance is an important, yet underdeveloped part of public health surveillance and must not be forgotten in times of crises.

Tek-Ang Lim, ECDC, sat in for Julien Beauté (ECDC) who had to cancel due to the work load related to the Ebola crisis, and focused on the impact of the economic crisis on infectious disease surveillance in Europe, based on a qualitative survey. Consequences were numerous: decreased resources, delayed or stopped implementation of new programmes and downscaled nationwide programmes, reduction in the workforce, deterioration of morale, lack of experienced public health scientists, delayed introduction of new vaccines. There is a tension between the obligatory surveillance by ECDC and the cutbacks of the member states responsible for its execution. ECDC already noticed a change in the accuracy of the data. Small public health centres are being joined with

regional public health centres. Staff is less motivated to register, especially for those diseases they find less important.

Marieke Verschuuren, WHO Regional Office for Europe, presented on behalf of her colleague Enrique Loyola the lessons learnt from Greece. The ministry there wanted to monitor the health effects of the economic crisis in Greece, but there was no central health information system (HIS). Therefore, efforts were undertaken to implement an interim indicator database with information from existing data sources, until a permanent long-term HIS would be established in the future. This was done following a structured three-step approach: 1) workshop to select indicators, 2) country visit for assessing potential data sources and the potential host for the interim database, and 3) country visit to take decisions on the actual implementation of the interim database. The appraisal of existing data collection stakeholders showed that every stakeholder had its pros and cons. It was decided that KEELPNO, the Greek centre for disease prevention and control, was the best candidate. It was decided, however, that the interim database would be hosted by the strategic office of the Ministry of Health. The main reasons for this were resource problems at KEELPNO. So far, actual resource allocation for setting up the indicator database has not taken place yet.

Carolien van den Brink, the Netherlands, showed how the lifestyle monitors in the Netherlands are being harmonized, leading to more efficiency and higher quality. Though this initiative did not originate from financial motives, the Dutch experiences suggest that a better data collection could be established with about the same amount of money. Different stakeholders in national data collection, all financed by the Dutch Ministry of Health, had different monitors of lifestyle on different themes using different methods in different frequencies, and leading to different figures on the same topic. Coordinated by the Dutch Institute for Public Health and the Environment (RIVM), a new scheme was established resulting in annual basic figures for each theme and additional modules. All data are collected by Statistics Netherlands based on a representative sample of the Dutch population. Agreements were also made on availability of data for analysis by the partners and publication, and on the financing by the Ministry of Health. One of the benefits for the Ministry is that Lifestyle Monitor now supplies THE national figures on lifestyle.

Tek-Ang Lim concludes the workshop by noting the remarkable discrepancy between the speed with which economic data and health data are being produced. This workshop is the first time the economics section looks into data availability. It is amazing how we are able to present trends in economic data, for example GDP per capita per country, for almost every country. Even though this is a complex indicator, it can be delivered quarterly and quickly (though preliminary). This is a great contrast to health data. Few countries have historical data on health, say before the 70s, while in 2014 (nearly 2015) data availability is the best for the year 2012 (e.g. for hepatitis A).

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), and try to steer the process in a favourable direction where possible. The issue was on the agenda of the section's annual meeting in November 2013, where it was decided that the section would produce a factsheet to raise

awareness of the imminent threats and support the public health community in making the case for a sensible European legal framework. This factsheet was published just before the end of the year at the EUPHA website. The factsheet is available in an annex to this activity report. An update on the legislative process was provided in the first section Newsletter, which was distributed in September 2014 (see under 6). The issue was discussed again during the section's annual meeting in November 2014 (see under 5).

Moreover, the section was invited by the North of England EU Health Partnership (secretariat for the Committee of Regions (CoR) Interregional Group on Health) to give a presentation on the GDPR at a meeting of the CoR Interregional Group on Health in Brussels on 4 December 2014. The meeting coincided with a meeting of the Council of Ministers in which the position of the Council on the GDPR was negotiated.

The section was asked to present

- the relevance of public health monitoring and population-based health research for health policy making,
- the development and status quo of the new General Data Protection Regulation (GDPR),
- the threats for public health monitoring and for health research related to the amendments made by the European Parliament in March 2014, and
- the next steps in the legislative procedure of the GDPR and potential actions that can be taken to express concerns about the EP amendments.

Nicole Rosenkötter followed this invitation and gave a presentation entitled "The importance of health information for public health monitoring and research: the issue with the data protection regulation".

In addition to approx. twenty members of the CoR Interregional Group two representatives of DG SANCO participated in the meeting. Both representatives were closely monitoring the negotiations of the GDPR at the European Parliament and the Council of Ministers. During the meeting the information was disseminated that the provisional opinion (Partial General Approach) of the Council followed rather the research-friendly GDPR proposal of the European Commission than the amendments made by the European Parliament.

The relevance of the topic led to the decision of the CoR Interregional Group on Health to draft a short letter template that can be used by different regions to inform their health ministries and to encourage respective stakeholders to maintain and build on the opinion formulated in the Partial General Approach when writing the final Council agreement and when starting the trilogue between the EP, the EC and the Council. The EUPHA PHMR section was invited to support the drafting of the letter template. The section agreed to this invitation and informed the EUPHA office about it and asked for potential wider EUPHA involvement.

5. Annual meeting

The agenda for the section's annual meeting in November 2014 in Glasgow was as follows:

1. Administrative and governance update:
 - a. Presidency: vote for new President and vice-President,
 - b. Composition of the Steering Group,
 - c. Activity report of the section 2014.

2. Short report of main outcomes of the workshops on morbidity statistics and on the effect of austerity measures on health information systems, and discussing potential concrete follow-up activities.
3. New EU Data Protection Regulation: identification of possible actions by (members of) the section and/or EUPHA.
4. State of play regarding the development of a single Health Information System for Europe.
5. Dealing with the consequences of the Eurostat Revision of the European Standard Population: sharing experiences and good practices.
6. Section Newsletter.
7. Gathering ideas for section activities, including ideas for workshops etc. for the 2015 conference.

Main agreements and points discussed:

Ad 1a) Nicole Rosenkötter and Marja van Bon were elected as the new President and Vice-president, respectively.

Ad 1b) Pieter Kramers has left the Steering Group. New Steering Group members: Marleen Desmedt, Eurostat, and Gaetan Lafortune, OECD. Marieke Verschuuren and Neil Riley, former President and Vice-President, will also remain members of the Steering Group.

Ad 1c) The draft activity report for 2014 was distributed to the section as a background document for the annual meeting. The report will be finalized after the conference, after which it will be sent to the EUPHA office and to the section members for information.

Ad 2) The section has been invited to write some conference proceedings from the viewpoint of the section for a special issue of Eurohealth. This will give us an opportunity to highlight the main issues that were addressed during the workshops. Nicole Rosenkötter will take the lead in writing this paper.

Ad 3) There is a new momentum for informing the (new) European Parliament, as the new MEPs are poorly informed on this dossier. The section President will bring this up during the section council meeting the next day, as the section agreed that it would be preferable if EUPHA would engage in advocacy and action on this topic rather than just the section. A meeting in Brussels on the Data Protection Regulation was mentioned by one of the participants on December 4th; it would be useful if somebody from the section/EUPHA could participate. It was also discussed that sending the factsheet that the section produced after last year's annual meeting to the section once more, and ask the section members for further advocacy, would be a good idea. Nicole Rosenkötter will look into some more detailed materials produced by a consortium of German institutions and organizations on the problems related to the EP amendments to the Regulation, to see whether these could be added to the mail to the section (these materials are partly available in English).

Ad 4) During last year's annual meeting it was decided that the section would write a standard letter on the need for a single European health information system, which section members could use for advocacy with their national representatives in the governing bodies of WHO Regional Office for Europe, the European Commission, and the OECD.

The Presidency had not yet followed up on this action. It was now discussed that one standard letter would be difficult to draft, given the cultural differences in Europe and the fact that the addressees might differ to great extents in terms of (technical) background, familiarity with the issue and hierarchy. Therefore it was decided to write a neutral factsheet instead. The section was informed about the European Health Information Initiative, an initiative that is linked to the development of the single European health information system. This network of countries, institutions, NGOs and international organizations will be instrumental for the development of this system through, among other things, better and more centralized dissemination of (knowledge and expertise on) health information, indicator development and harmonization, and capacity building in the field of health information. The Initiative has been working on an ad hoc basis since 2012. The first Steering Committee meeting is planned for March 2015. During this meeting the Initiative will be formalized (Terms of Reference established), and a strategic vision and work plan will be discussed.

Ad 5) The consequences of this methodological change are considerable, and it is hard to explain to lay people why certain statistics have changed because of this. The Office for National Statistics (ONS) in the UK has produced several papers on the change and its consequences, which can be found at the ONS website. It was discussed that it would be good to share more experiences of how experts are dealing with these changes and communicating with lay people about this. Neil Riley will follow up on this topic and send a call to the section members to share experiences.

Ad 6) Nicole Rosenkötter explained that the aim of the newsletter is not only to inform the section members about relevant European developments, but also to share examples of and experiences with public health monitoring and reporting at the national and regional level. The section members therefore are invited to send their examples and experiences as input for the newsletter. Nicole shared during the meeting a factsheet she had made on a paper (currently under review) about an expert opinion study on essential elements for an EU health information system.

Ad 7) Ideas for workshops:

- Public health reporting and data visualisation
- PHMR good practice on how to monitor and report about health inequalities (linking with social determinants, regional comparisons)?
- The need for health information during the European semester process (opportunities for health care reforms; together with section on Public Health Policy & Practice)
- Data linkage from a political, societal and technical point of view
- PHMR: The relevance and potential of the quantified-self movement (self-tracking of biological, physical, behavioural, etc. information) and big data

6. Communication

- Newsletter

Up to October 2013, five European Community/Core Health Indicators (ECHI) newsletters were produced by the ECHI Transition Network, which were also disseminated within the section PHMR. As decided in the section annual meeting 2013, this newsletter will carry on under the broader umbrella of the EUPHA Section PHRM, to

inform the European PHMR community about recent developments in the field of health information. In September 2014 the [first section PHMR newsletter](#) was published.

- Website

The section's annual activity report 2013 was placed at the [section specific web pages of the EUPHA website](#), as were the Data Protection Factsheet (see under 4 and annex) and the first edition of the section newsletter (see above).

- Twitter account

The section has a Twitter account, [@PHMRsection](#). The section President is managing this account. On December 29th 2014 the Twitter account had 70 followers, and 298 tweets had been sent.

- LinkedIn Group

Marja van Bon-Martens started a [LinkedIn group](#) for the EUPHA Section on Public Health Monitoring and Reporting in December 2014. The LinkedIn group allows members to start discussions and share new publications or job offers.

- Mailman system

The section used the mailman system on several occasions to inform the section members on issues such as interesting conferences and section related matters (e.g. announcement of changing section Presidency, section workshops in Glasgow, agenda and background materials for the annual meeting, section Newsletter).

7. EUPHActs health information

In the summer of 2013 the EUPHA section Public Health Monitoring and Reporting drafted a EUPHActs (= EUPHA fact sheet) on health information. There were some delays in the review process by the EUPHA Executive Council and therefore the EUPHActs was updated in September 2014, after which it was published at the [EUPHA website](#).

Annex. Data protection factsheet

 Factsheet December 2013 Revision of the European Data Protection legislation Potential harmful consequences for public health monitoring and research	
<p>What is the current situation?</p> <p>The current EU Data Protection legislation is under revision and will be replaced by a new General Data Protection Regulation. In 2012 the European Commission published a first proposal. In October 2013 the European Parliament passed several amendments, which could have serious negative effects for public health monitoring and research.</p>	<p>Why do we need personal health data for public health? → EUPHActs</p>
<p>What will the further process be?</p> <ul style="list-style-type: none"> • The Council aims to adopt its amendments in 2015; • After that, the Commission will draft a new compromise proposal, which will be discussed again in the European Parliament and the Council. <p>The process may be delayed due to the European elections next year, as the new Commissioner and rapporteur can decide to draft completely new proposals.</p>	<p>Which amendments potentially have the most serious consequences?</p> <ul style="list-style-type: none"> • Using personal health data for public health monitoring and research (M&R) without informed, explicit consent will only be possible in cases of “high public interest”. What constitutes high public interest may be defined in such a way that using data for public health purposes may be severely restricted. • The definition of informed, explicit consent is not clear. It is therefore questionable whether broad consent, which currently is commonly applied in research, will still be possible. • The definition of pseudonymized data is not clear. It might mean that all pseudonymized data will be considered to be personal data. If this is the case, this will complicate M&R in countries in which currently pseudonymized data are considered anonymous data if specific safeguards are met. • If the right to be forgotten applied to M&R contexts, statistical information about public health threats would become unreliable. <p>These amendments will seriously hamper the possibilities for doing population based research, especially research using register based data and research linking different data sources. Magnitude and quality of M&R will diminish, while costs and time scales for doing M&R will significantly increase.</p>
<p>What can you, as a public health expert, do?</p> <ul style="list-style-type: none"> • Inform your MEPs and counterparts at the Ministries of Justice about the potential devastating effects of the current EP proposal on public health monitoring and research, and hence on the health of European citizens. • Stress that it is necessary and possible to strike the right balance between public and private interests. Citizens want protection of their privacy but they want good health research as well. Good techniques and methods exist that ensure the protection of data subjects in public health monitoring and research. 	
<p>What will EUPHA do? → Inform the decision makers, in liaison with fellow public health and research organizations. → Support its members in their advocacy actions through making an impact assessment for the current EP proposal.</p>	
<p>This factsheet was produced for EUPHA by the EUPHA section on Public Health Monitoring and Reporting, with the help of Evert-Ben van Veen, MedLawconsult</p>	