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

#### 2016

# Publications by the section Participation in the WHO-EURO European Health Information Initiative on behalf of EUPHA Activities of the section Steering Committee EPHC pre-conference Workshops during the EPH conference 2016 in Vienna

- 6. Annual meeting
- 7. Communication

Addendum: Section structure

#### I. Publications by the section

#### Health Assessments: status and perspectives

The EUPHA PHMR section is involved in the preparation of a joint publication on the various health assessment approaches. The paper is coordinated by Rainer Fehr supported by the EUPHA sections Public Health Epidemiology, Public Health Monitoring & Reporting, Health Impact Assessment, Health Services Research, Health Technology Assessment, Public Health Practice and Policy, and Public Health Economics.

The paper aims to:

- $\rightarrow$  present a systematic overview of the current situation including basic and advanced assessment approaches;
- → to explore cross-cutting issues including commonalities and differences of assessment types;
- $\rightarrow$  to discuss potential perspectives.

The paper was submitted to the European Journal of Public Health in summer/autumn 2016 by the coordinator Rainer Fehr.

### 2. Participation in the WHO-EURO European Health Information Initiative (EHII) on behalf of EUPHA

More information: <u>http://www.euro.who.int/en/data-and-evidence/european-health-information-initiative-ehii</u>

The European Health Information Initiative (EHII) is a WHO network committed to improving the information that underpins health policies in the European Region. It fosters international cooperation to support the exchange of expertise, build capacity and harmonize processes in data collection and reporting. The EHII has currently 29 members (November 2016). These are mainly individual countries in Europe and

stakeholders such as the European Commission, the ECDC, the Wellcome Trust, The Commonwealth, EuroHealthNet, the OECD, the Institute for Health Metrics and Evaluation and EUPHA. The EHII works in six key areas:

- gathering and analysing information that deepens the understanding of health and well-being, with a focus on indicators;
- enhancing access to and dissemination of health information;
- building capacity;
- strengthening health information networks;
- supporting the development of health information strategies; and
- communication and advocacy.

The PHMR section president participated in 2016 on behalf of EUPHA in three meetings of the EHII Steering Group.

- $\rightarrow$  4<sup>th</sup> meeting in Copenhagen (22. and 23. March 2016),
- $\rightarrow$  5<sup>th</sup> meeting a WebEx meeting on 6. July 2016, and
- $\rightarrow$  6<sup>th</sup> meeting a WebEx meeting on 22 November 2016.

Focus of the meetings was on (1) information exchange on health information activities of WHO-EURO, EU (and EU-co-funded health information projects), OECD and the other members; (2) the definition of a Joint Operational Framework and (3) the formulation of an EHII Action Plan. With regard to the envisaged action plan, the PHMR section president offered to support the communication activities of the EHII. An extensive report on the fourth meeting was published here:

http://www.euro.who.int/en/data-and-evidence/european-health-information-initiative-ehii/european-health-information-initiative-ehii-fourth-meeting-of-the-steering-group

Within the Initiative four networks were established for in-depth exchange of interested members: (1) Evidence-Informed Policy Network (EVIPNet Europe); (2) the Central Asian Republics Information Network (CARINFONET); (3) the Small Countries Health Information Network (SCHIN), and (4) the European Burden of Disease Network. The latter one presented their work to the EUPHA members in the EUPHA PHMR section meeting (Join the Network Meeting) at the EPHC in Vienna.

#### 3. Activities of the section Steering Committee

- $\rightarrow$  The Steering Committee member Magnus Stenbeck, Karolinska Institute, Sweden stepped out of the Steering Committee due to changes of his working field.
- $\rightarrow$  The Steering Committee provided feedback on the meeting materials for the EUPHA Section Council meeting in February 2016, which was attended by the President.
- $\rightarrow$  One Steering Committee member is involved as co-author in the publication on health assessments.
- $\rightarrow$  The Steering Committee provided input for the 3<sup>rd</sup> and 4<sup>th</sup> PHMR section newsletter published in February and November 2016.
- $\rightarrow$  The Steering Committee supported the section president in submitting/ organizing EPHC 2016 workshops and the pre-conference.
- $\rightarrow$  A teleconference was held on 21 October 2016 (10:00-11:30)

#### <u>Agenda</u>

- I. Section activities during the EPHC 2016
- 2. Presidency and vice-presidency of the section, elections at EPHC 2017

- 3. Compilation of the 4<sup>th</sup> EUPHA PHMR newsletter
- 4. Organisation of the Join the Network meeting at the EPHC 2016 (former Annual Section Meeting)
- 5. Draft annual report

#### **Minutes**

All SG members as well as the president and vice-president participated in the teleconference.

- (1) Nicole Rosenkötter informed the Steering Group Members about the Section activities during the EPHC 2016.
- (2) Marja van Bon-Martens decided to step down as vice president in 2017. It was decided to announce the new elections during the Join the Network Meeting at the EPHC 2016.
- (3) The compilation of the 4<sup>th</sup> PHMR section newsletter was discussed and tasks were disseminated among the SG members and the president.
- (4) The content and organisation of the meeting was discussed. It was agreed on having three separate presentations during the section meeting: (1) European Burden of Disease Network (Henk Hilderink, RIVM), (2) Morbidity statistics of Eurostat (someone of Eurostat), FIAT Health → Introduction of the Figure Interpretation and Assessment Tool Health (Reinie Gerrits, Academisch Medisch Centrum Amsterdam). It was planned to publish the presentations on the PHMR section website.
- (5) The Steering Group Members provided feedback on the draft Annual Report that was sent to the EUPHA office end of August 2016. During the teleconference tasks for the finalization of the report were disseminated.

#### 4. EPHC pre-conference

The section organized a pre-conference on "Strengthening health information systems through cross-country learning and collaboration" at the EPHC 2016. The pre-conference was organized in cooperation with the BRIDGE Health project, WHO Regional Office for Europe, and OECD. It was a two half-day conference.

The presentations of the pre-conference can be found on the EUPHA PHMR section website (workshops/conferences).

#### Brief reflection on the pre-conference

#### Day I

The pre-conference started with a presentation of the European Health Information Initiative by Claudia Stein (WHO EUR). Under the auspices of the European Health Information Initiative (EHII), the World Health Organization Regional Office for Europe (WHO EUR) has launched a support tool to assess national health information systems and to develop a health information strategy. This tool covers all the phases related to health information strategy development – from assessment of the current state of health information systems, through strategy development and implementation to evaluation. Moreover, it addresses all the different elements of health information systems, such as governance, databases and resources. During Day I the Support Tool was introduced by Tina Dannemann Purnat (WHO EUR) and Marieke Verschuuren (RIVM, The Netherlands). Neville Calleja (MoH, Malta) shared common experiences from the national pilot tests of the Support Tool. The following experiences were made during these assessments:

- $\rightarrow$  Common understanding is lacking: What is a health information system?
- $\rightarrow$  Miscommunication between health information agencies and policy makers
- $\rightarrow$  Commonalities in the pilot regions:

- Strength: Promising e-health developments, functioning data collection systems, dedicated HIS personnel, Understanding of the policy makers on the need for sound evidence for decision making
- Challenges: Lack of a HIS strategy, missing or poorly functioning central multisectoral coordination mechanism, sustainability of e-health (donor funding), limited analytical capacity, data quality issues, unclear role and responsibilities for data exchange, limited use of health information for decision making

In general, the assessment of the health information system was perceived as golden opportunity to engage with policy makers and other stakeholders and to trigger a reflection on the role of health information in the overall health strategy.

At the end of Day I participants had the possibility to discuss within moderated working groups strength and weaknesses of their health information systems. It was focussed on the elements: resources, health indicator sets, data sources (population-based/health services-based), data management, health reporting, dissemination and use.

Moreover, participants had the possibility to gather remarks and responses for the international health information actors who were invited as speakers at Day 2 of the preconference. The following remarks were established:

- $\rightarrow\,$  Reduce the use of diverging terminologies and streamline the language across international health information stakeholders
  - What does harmonization mean?
  - Which indicators are relevant?
  - Harmonize metadata
- $\rightarrow$  **Provide support for member states and regions** 
  - o support national stakeholder to ensure quality of health information
  - provide a platform for communication and exchange across member states (e.g. with regard to the national implementation of the GDPR)
- → Recognize diversity in member states and diverging needs of member states
  Request: involve member states
- $\rightarrow\,$  (EU) Establish a strong regulatory framework for health information. Support ECHI.
- $\rightarrow$  EU, OECD, WHO EURO  $\rightarrow$  Cooperate more.
- $\rightarrow\,$  International organizations should streamline their investments according to the results identified by the Health Information System

#### Day 2

On Day 2 representatives from the EC, OECD and WHO EUR were invited to present their health information systems, current activities and government tools. Representatives from the BRIDGE Health project introduced the problems and needs of an EU health information system and presented a road map for the operationalization of an EU health information system in form of an ERIC (European Research Infrastructure Consortium). The title of the proposed ERIC is: Health Information for Research and Evidence-based Policy (HIREP-ERIC).

These representatives also acted as panellists for the discussion of strength and weaknesses of health information activities in Europe, possibilities for cooperation, and to react on the remarks collected by the pre-conference participants on Day 1.

The following questions and remarks were discussed on the panel:

 $\rightarrow\,$  How do we get political commitment for an EU health information system from the member states?

EU Expert Group on Health Information could act as supporters of the ERIC on national level, WHO can support discussion on national level (links to the Action plan to strengthen the use of evidence, information and research for policy-making in the WHO

European Region), explain how member states will benefit from the system and ensure cooperation with member states.

## $\rightarrow$ What is the primary function of a health information ERIC: research, liasing, monitoring?

Its primary function is to conduct research to develop standards for data collection and calculation of indicators and to assess the acceptability of indicators (engaging with member states is relevant), to improve the understanding of the needs for continuous data collection, and to develop PHMR methodologies. The ERIC can also support public health research. An ERIC is not the unique answer for EU health information, but one of the relevant tools.

## $\rightarrow\,$ What is in summary the business case for the ERIC? What is the problem, what is the elevator pitch?

It is relevant for bringing health onto the economic agenda, e.g. by supporting decisions on age of retirement, on how to invest in health.

What doesn't get measured doesn't get done – it can support policy makers to get things done.

There is probably also a new seriousness in the use of health information (e.g. European Semester process, EU country-specific recommendations) – thus, one needs to make sure that data are comparable and robust.

ERIC should take actions on e-health into account and ERIC should use e-health networks

 $\rightarrow\,$  International organisations could help European countries to exchange experience and to o common capacity building.

It was discussed that this issue can be followed within the EHII meetings.

#### 5. Workshops during the EPH conference 2016 in Vienna

## Workshop: Round table: The impact of new and emerging technologies on population health, 10 November 2016 (13:50-14:50)

Organizers: the National Institute for Public Health and the Environment (RIVM), the Netherlands, and the EUPHA section on Public Health Monitoring and Reporting. Chair: Henk Hilderink, RIVM.

Panelists:

- Roza Adany, Dean of the Faculty of Public Health of the University of Debrecen, Head of the Department of Preventive Medicine, leader of the Public Health Research Group, Hungary and among other activities president of the EUPHA section on Public Health Genomics.
- Clayton Hamilton Unit Leader, E-health & Innovation, Division of Information, Evidence, Research and Innovation, WHO Regional Office for Europe, Denmark
- Nick Guldemond, Associate Professor Integrated Care & Technology Institute of Health Policy & Management, The Netherlands
- Hans van Oers, Professor of Public Health at Tilburg University's Tranzo Scientific Center for Care and Welfare and Chief Science Officer of System Assessments for Policy Support at the National Institute for Public Health and the Environment (RIVM), The Netherlands

The workshop was opened by Nicole Rosenkoetter, president of the EUPHA section on Public Health Monitoring and Reporting. Next, Jacqueline Pot of RIVM presented the preliminary outcomes of a technology scan, which RIVM is conducting in the framework of their four-yearly Public Health Foresight Reports. The next PHFR is due in 2018. For this technology scan, potential 'game-changers' have been identified by means of expert sessions, interviews and a literature search. Currently RIVM is in the process of assessing the future impact of these technologies on population health. They use a broad array of outcome measures for this, not only looking at (the absence of) disease, but also at health inequalities, participation, autonomy and costs. Also, they look at systemic barriers for the implementation of new technologies. In the Netherlands, these are e.g. related to a lack of harmonization of IT systems and EHRs, financial hurdles (no remuneration for new forms of health care delivery), and the fact that education for health care professionals is lagging behind. All in all, it is a complex tasks trying to identify and systematically assess all (interrelated) factors that may influence the impact of technologies on population health. After the introductory presentation, there was a panel discussion with active participation

from the audience. The discussion focused on three statements:

- 1. The role of 'new' technologies in healthcare, such as genetic screening, bio-printing and robots, is overestimated.
- 2. The increased application of technology in health care will increase health inequalities.
- 3. Life-sciences based and curative oriented technologies, such as biomarkers, diagnostic techniques and high-tech interventions, tend to increase overall healthcare cost with minor improvements in quality of life in very specific populations. Is this the best way of spending the health care budget?

Related to statement I, the general feeling was that the impact of new technologies was overestimated, rather than the role. The discussion focused on genome-based technologies, and the conclusion was that these technologies have great potential, but we need to be very realistic about their pace of implementation.

Related to statement 2, many participants saw a risk that increased application of technologies may increase health inequalities. However, new technologies also have the potential to decrease health inequalities by improving access to information and health care. Improving digital literacy is key here, as is involving the end-users in the development of new technologies.

Related to statement 3, the panellists agreed that new technologies often lead to increased costs, as they are usually implemented as add-on rather than as a replacement. However, their effects are not only minor; new technologies, such as improved medicines for cancer, can save lives. Thus, the effects can be very substantial!

## Workshop: Skills building seminar: Health information is beautiful: tools and approaches to visualize data and health indicators, 12 November 2016 (11:10-12:40)

This workshop is planned as a workshop series, with additional workshops at the consequent EPH conferences. Potential topics for future seminars

- the design of informative graphs and maps,
- how to generate animated or interactive graphics, and
- the theory behind and the resources required to design infographics, info websites or explainer videos.

The series of skills building seminars on data visualization start with exploring online health information platforms.

Tina Dannemann Purnat from WHO Europe presented the WHO European Health Information Gateway.

The WHO European Health Information Gateway has been conceptualised as a one-stop health information shop for policy-makers, analysts, WHO staff and the public in the WHO European Region catering for different needs and skills. It offers an innovative approach for the presentation of key public health information made available by the WHO Regional Office for Europe.

The demonstration will take a look "under the hood", presenting technical building blocks of the Gateway, how they work, and with examples on how they come together to address the needs of various audiences. Elements that will be presented: (1) the Data Warehouse, its API (application programming interface) and examples of tools data scientists can use to make visualisations on the fly based on the data from the API; (2) the Gateway and it various components for information presentation and use, (3) approaches and examples to interactive infographic designs and data story communication, and (4) design and use of mobile apps for dissemination of health information. The presentation will emphasize a hands-on walk through and opportunity for participants to provide feedback.

The continuous design of all the tools has been influenced by the user research WHO Europe has conducted on its online data presentation tools and the Gateway is being adapted accordingly. The user research was conducted as a web-based audience of visitors to the WHO Europe web site who seek health information (n = 694), 12 follow up interviews with volunteers among survey respondents, as well as in-depth qualitative interviews with 12 stakeholders from strategic collaborators and actors in the health information landscape in Europe. Recommendations of the research were: (a) making WHO data count, proactive engagement in strategic health information roles, development of user-oriented tools, and establishing communication services for health information users.

Heidi Lyshol from the Nowegian Institute of Public Health presented thei health information toolset.

The Public Health Act (2012) obliges the NIPH to supply counties and municipalities with some of the data needed to provide public health services for the population.

This is done through a set of health information tools, available online to the public:

1) Public health profiles for municipalities, counties and city districts. These small booklets give a brief overview of population health and risk factors, specialized articles on a new topic every year, and a public health barometer; a graphic device that shows key indicators for each municipality/county/city district with colour codes and symbols.

2) The two statistics banks NorHealth and the Municipal Data Bank. They make it easy to find and illustrate data for users without statistical knowledge: maps, time lines and bar charts. The banks have more indicators than the public health profiles.

3) Fact sheets: short articles, written in non-medicalese, explaining and describing diseases and risk factors, illustrated with data from the statistics banks, updated in real time.

NorHealth and around 30 fact sheets are available in English.

To improve user-friendliness, contact with potential users is important. In 2014, in-depth interviews were conducted with users from different areas, and an online user survey was done. The users wanted changes in functionality and specified more indicators which led to several changes implemented by the NIPH team. A new survey was done in 2016.

The information tools were primarily made for public health coordinators and advisors. According to the 2014 survey (N= 216), 48 % of respondents belonged to this group. Other users were administrators and planners, and health professionals.

Looking at the NIPH information tools together, one might say that the public health profiles present data from the statistics banks, while fact sheets explain what the data mean.

Eveline van der Wilk and Laurens Zwakhals from the RIVM gave a presentation on visualisations at the RIVM in the Netherlands.

The Dutch National Institute of Public Health and the Environment (RIVM) has been improving its visual presentations on health information websites like VZinfo.nl, Municipality Health Profiles and Atlas Living Environment. This was done by using several types of data visualisation, such as graphs, (interactive) maps, infographics and one pagers.

Within the presentation we will give an overview on the building blocks of the RIVM health and environmental information websites, our capacity building efforts in data visualisation, as well as the applied technical resources.

First part of the presentation will be dedicated to a short demo of these websites. Each of these websites has its own target groups and its own level of interactivity (ability to adjust the visual presentation). Furthermore, each website has its own level of exploration and explanation possibilities. 'Exploring' in this respect means visitors are offered tools for analysing data and build their own interpretation. Explanatory websites and visuals on the other hand tell a story, by means of an infographic, or by providing an explanatory text along with a graph.

Capacity building regarding data visualisation is bundled within the DIVE-project (Data Information Visuals Explored): We share some good practice examples in data visualisation, experiences regarding the production of good, attractive, and interactive data visualizations, highlighting some information on the development of a 'good practice database' for data visualisations as well as a wizard that supports people in producing good data visualizations.

The third part of the presentation has a more technical focus. We work with i.e. High Charts, High Maps, D3 and Geoserver and will explain which choices we have made regarding the applied visualisation tools.

#### 6. Annual meeting

An invitation to the annual meeting as well as preparatory material was forwarded to the PHMR section members via the Mailman System on 7 November 2016.

The Join the Network Meeting took place on 11 November 2016 at the EPHC in Vienna (12:45-13:55). The agenda and the minutes of that meeting can be found on the PHMR section website.

#### 7. Communication

#### Newsletter

In February and November 2016 the third and the fourth issue of the PHMR newsletter were published on the section specific web pages of the EUPHA website. The newsletters were

- forwarded to the PHMR members via the Mailman system
- uploaded at the LinkedIn group of the section
- twittered via the sections Twitter account

The next newsletter issue is planned for spring 2017.

#### Website

The section's annual activity report 2015 was placed at the section specific web pages of the EUPHA website, as were the minutes of the  $6^{th}$  annual EUPHA PHMR section

meeting in Milan 2015 and the third and fourth issue of the PHMR section newsletter (see above).

#### Twitter account



The section has a Twitter account (@PHMRsection). The section president is managing this account. On 28 December 2016 the Twitter account had 159 followers, and 546 tweets had been sent.

#### LinkedIn Group

The LinkedIn group allows members to start discussions and share new publications or job offers. The section President and Vice-President are managing the account. On 28 December 2016 the LinkedIn Group had 48 members.

#### Mailman system

The section used the mailman system on several occasions to inform the section members on issues such as section related matters (e.g. section news and updates, the section workshops in Vienna).

#### ADDENDUM

#### **Section structure**

Members 1198 members (28 December 2016)

#### **Steering Committee**

Marleen Desmedt Gaetan Lafortune Neil Riley Claudia Stein Hans van Oers Marieke Verschuuren Eurostat, Luxembourg OECD, France NHS England, United Kingdom WHO-EUR, Denmark RIVM, The Netherlands RIVM, The Netherlands

#### **Vice-President**

Marja van Bon-Martens	Trimbos Institute, The Netherlands
President	
Nicole Rosenkötter	NRW Centre for Health (LZG.NRW), Germany