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HEALTH AND FOOD SAFETY DIRECTORATE-GENERAL

Public Health
Health information and Scientific committees

Luxembourg, 20 January 2015
SANTE.C.2

EXPERT GROUP ON HEALTH INFORMATION (EGHI) MEETING

LUXEMBOURG 26-27 NOVEMBER 2014

SUMMARY REPORT

1-2. WELCOME AND ADOPTION OF THE DRAFT AGENDA

The Chair, Stefan Schreck, Head of the Health Information and Scientific Committees Unit of the Directorate-General for Health and Consumers (DG SANTE) of the European Commission, welcomed the participants, and in particular the recently nominated delegates from the Czech Republic and the United Kingdom.

The Chair informed that the presentations and documents are made available in CIRCABC. The summary report, list of participants and the presentations, with the agreement of authors, will also be made publicly available on the SANTE website. A document regarding data and privacy protection had been distributed before the meeting and the participants were requested to contact the Commission in case of any objection to publishing their names in the participants list on the website.

The amended agenda was adopted after that the participants were informed that there had been a cancellation of the presentation 'Update from DG EMPL'.

3. OPENING REMARKS

Acting Director for Public Health, John F. Ryan, gave opening remarks addressing health information in relation to the current and future challenges on public health and health systems. The new European Commission and the new Commissioner for Health and Food Safety, Andriukaitis, have a set of top priorities on health, the health systems performance assessment being one of them. The work on European health indicators and health information in general can provide technical support for this.

4. MINUTES OF THE PREVIOUS MEETING

The summary report of the meeting held the 20-21 May was adopted. The final version will be made publicly available on SANTE web site together with the list of participants and the presentations.

5. EU HEALTH INFORMATION SYSTEM

5.1. EGHI

5.1.1. PRESENTATION BY THE COMMISSION ON THE SURVEY RESULTS

Helmut Walerius from the Health Information and Scientific Committees Unit, DG SANTE, presented the outcome of the EGHI survey carried out during August-September. He said that the aim of the survey was to provide key elements for future discussion on the tasks and role of EGHI.

5.1.2. DISCUSSION ON THE FUTURE EGHI MANDATE

In the exchange of views (as well as in the survey) EGHI members stressed, that there is a need to formalise the definition of indicators by proposing necessary legal provisions, the importance to identify indicator gaps, need for stability and continuity in the indicator system and that it is time to update the ECHI shortlist. It was also suggested that EGHI could address cross-cutting issues such as the definition of the European standard population and also develop interactions with other parts of the Commission (not just health related).

The chair mentioned that the development in health information should be a user-driven process and that comments from the survey will support constructive discussions on the role of EGHI in the future.

Mr Ryan raised the question on cost estimation by the Member States on the collection (monitoring) of data as well as which cost would result for society if public health would not be monitored and thus no relevant data and evidence would be available.

5.2. PREPARATION OF A POTENTIAL EUROPEAN RESEARCH INFRASTRUCTURE CONSORTIUM (ERIC) ON HEALTH INFORMATION

5.2.1. STATE OF PLAY

Paul Tuinder, DG RTD gave an update on the setting up of ERICs in the EU. He informed that the ESFRI (European Strategy Forum on Research Infrastructure) Roadmap review process was ongoing. A new Roadmap is expected to be presented in spring 2016. ESFRI envisages proposals for new (or major upgrades of existing) research infrastructures of pan-European interest corresponding to the long term needs of the European research communities, covering all scientific areas. Research Infrastructure projects included in the Roadmap are expected to move to implementation in less than 10 years. Altogether, the number of projects will be reduced to around 25, i.e. there is space for 8-10 new projects, in addition to 16 projects which are likely to stay in the Roadmap from the 2008 and 2010 editions. ESFRI will assess candidate projects on scientific excellence, of pan-European relevance, socio-economic impact; based on e-needs and maturity level. In parallel with this assessment, ESFRI will carry out an in-depth analysis of the research infrastructure landscape in all scientific fields in Europe to provide a comprehensive picture of the existing research infrastructures of pan-European scope.

The 2014 implementation report on the ERIC regulation (available in CIRCABC) gives details on the current situation and next steps. Before the end of 2014 it is envisaged that 10 ERICs will be in place. At the moment 20 EU Member States participate in ERICs and 6 Member States are host countries. There is as well an interest outside Europe as it is seen that ERICs can facilitate international cooperation.

Following questions from the participants concerning which ministry should lead on the preparation of an ERIC Paul Tuinder explained that an inter-ministerial process, which in the case of health related ERICs would comprise the health and research ministry and relevant stakeholders, has proven to be most successful for this purpose.

5.2.2. NEXT STEPS

Herman Van Oyen, Scientific Institute of Public Health, Belgium, made a presentation on a project proposal on health information. The call under which the proposal was submitted is titled: Towards a sustainable health monitoring and reporting system. The proposal's generic and specific objectives, were set out, the expected outcome as well as the structure and distribution of work inside the project. The representative of the Consumers, Health and Food Executive Agency (Chafea) informed that the evaluation of the 2014 project proposals was ongoing and results were expected by the end of the year. The project proposal was presented to the EGHI members for information only, as the evaluation process is not concluded.

The Chair said that in order to support Member States efforts for setting up of an ERIC on health information, the Commission will organise a special EGHI meeting on the 28 January 2015 followed by a meeting of an ERIC Task Force on 29 January. The aim is to have a think tank discussion on a possible structure, content, format and legal aspects of a potential ERIC on health information.

6. INFORMATION ABOUT RELEVANT ACTIVITIES OF THE EUROPEAN CENTRE FOR DISEASE PREVENTION AND CONTROL

Dr Piotr Kramarz gave a presentation on ECDC activities related to health information and monitoring. The European Surveillance System (TESSy) is a flexible system (adapting to different systems in the Member States) for collection, validation, analysis and dissemination of data. The Surveillance Atlas of Infectious Diseases is a web interactive tool giving easy access to European infectious disease surveillance data. The infectious diseases surveillance and risk assessment is based on the Decision No 1082/2013/EU of the European Parliament and of the Council of 22 October 2013 on serious cross-border threats to health and repealing Decision No 2119/98/EC. A question was raised as regards the costs related to the surveillance system.

7. UP-DATES ON THE ON-GOING AND PLANNED HEALTH INFORMATION WORK BY EU MEMBER STATES, EEA, CANDIDATE COUNTRIES

EGHI members reported orally on relevant work in their countries. Some countries had sent contributions before the meeting and all were invited to send written input to the EGHI secretariat after the meeting. Web links of activities, that might be interesting for other countries, are welcomed in these reports. The Country reports document is regularly updated and made available in CIRCABC.

8. UPDATE FROM DG ESTAT

Matthias Fritz and Anke Weber from Eurostat gave information on current work in the area of health information. The revised dedicated section on health on Eurostat web site was shortly presented. The presentation covered information on disability statistics, mainly in reference to the EHIS, discussion on including GALI as a core indicator, recent developments in health care expenditure and non-expenditure statistics. Causes of Death

data based on the 2011 regulation has just been published, the second wave of the Diagnosis-specific Morbidity Statistics (MORB) will be launched beginning of 2015. Finally the future project HEDiC: Health Expenditures by Diseases & Conditions was presented; intended to give access to data on health expenditure by disease collected by social and commercial health insurance organisations.

(9. *UPDATE FROM DG EMPL cancelled*)

10. UPDATE FROM DG ECFIN

DG ECFIN, Christoph Schwierz, gave a presentation on the horizontal Thematic Assessment Frameworks (TAF) for structural-fiscal reforms in the fields of health care and long-term care. The TAF is an analytical tool with the view to identify the main structural challenges, and support consistent cross-country analysis through a "clear and transparent" methodology. It is intended to be used for structural fiscal country-specific recommendation (CSR) regarding pensions, health care or long-term care in cases when challenges are identified. The presentation gave in addition examples and comparative lists with values for some indicators in Member States related to LTC (long term care) systems.

11. STATE OF PLAY OF RARE DISEASES' CODIFICATION IN HEALTH INFORMATION SYSTEMS (ORPHANET)

Ana Rath from Orphanet, (European database for rare diseases, since 1997) gave a presentation about work on improving codification as a priority area in the field of rare diseases (priority area of the Council Recommendation of 2009). Rare diseases affect between 26 and 36 million people in the EU and it is a key health policy priority due to the limited number of patients and scarcity of knowledge and expertise. Currently only a small number of rare diseases have codes in international nomenclatures which makes it a challenge to trace patients with rare diseases in health information systems on a national and international level. There is no harmonisation in this area and different terminologies are being used, but there is a need to have a common language for sharing clinical data between health care centres as well as for databases and registries. The terminologies that are currently used were presented and information was given on the correlation of Orphacodes to the ICD and the inclusion of rare diseases of the ICD-11 revision. Ms Rath concluded her presentation by giving examples of Member countries' implementation of the Orphacodes. Member States plan to further cooperate on Orphacodes implementation within framework of the future Joint Action on rare diseases.

12. UPDATE FROM THE PUBLIC HEALTH UNIT, RTD

DG RTD, Ann Uustalu, gave a presentation on the implementation of the chapter 'Health, demographic change and wellbeing' of Horizon 2020 (H2020). She mentioned that H2020 is a core part of the Europe 2020 strategy on the Innovation Union & European Research Area. Demographic changes, chronic diseases and climate change are some of the main issues Europe needs to address in the health area. The new approach on research action of H2020 is challenge driven, with broad topics, broader topic descriptions, two year work programme and a stronger focus on end users. Ann Uustalu also presented the main public health topics in H2020 and the current work programme for 2014/15. Finally, she highlighted the new "European Human Biomonitoring Initiative" (EHBMI) which is under preparation by the European Commission, the EU Agencies and EU Member States as well as relevant stakeholders.

In this context, Paul Tuinder pointed out that a proposal for a separate ERIC on Human Biomonitoring should take into account the work ongoing on a potential ERIC on Health Information to avoid overlapping and to achieve synergies.

13. DOCTORS OF THE WORLD INTERNATIONAL NETWORK

Frank Vanbiervliet and Nathalie Simonnot gave information on the activities of Doctors of the World (Médecins du monde) Network. The presentation focused on activities of Mdm in Europe, their work with vulnerable groups which are not covered by healthcare systems (i.e. asylum seekers, migrants, homeless people, elderly, destitute EU migrants or destitute nationals, drug users, sex workers). Work on collection of data was also presented which are mainly carried out via questionnaires (social, medical and follow-up medical questionnaires) and cover population that are not visible in other official statistics. *Comments on this presentation received from Ministry of Health, Greece are available in the annex.*

14. EUROPEAN CANCER INFORMATION SYSTEM (DG JRC)

Jerica Zupan from the Joint Research Centre gave a presentation about the role of JRC in the European Cancer Information System and the main achievements hosting the European Network of Cancer Registries (ENCR). Key issues on data collection were described, as there are not unified registries in all EU countries this can create a burden for data collections. The results of the 2014 ENCR survey aims at improving the JRC database of European registries and to update information on registration practices. Details on on-going and future priorities of the JRC/ENCR were as well described.

The Chair thanked all presenters and gave information that the trilateral meeting between EC, OECD and WHO had not yet taken place but was scheduled for mid-December.

15. UPDATE FROM WHO-EUROPE

Ivo Rakovac, WHO Regional Office for Europe, provided an overview of its health information issues since the last EGHI meeting. Among the areas covered were: the new health information portal, the leaflet 'Core Health Indicators 2014 in the WHO European Region', two dedicated publications based on Health 2020 indicators and the forthcoming publication 'European Health Report 2015' which will highlight the progress of Health 2020 indicators. The Data Presentation System (DPS) is a free tool for data retrieval and comparison of data.

16. UPDATE FROM OECD

Gaetan Lafortune, OECD Health division, gave updates on latest developments. The presentation covered work on Health System Performance Assessment and Improvement, the Health Care Quality Reviews as benchmark efforts and other health quality improvement work. There will be a report published on Economics of prevention on Alcohol consumption 1st quarter of 2015. The publication 'Health at Glance Europe 2014', produced in collaboration with SANTE, is being published 3 Dec 2014 and contains health data on 35 countries based on the European Core Health Indicators.

17. UPDATE ON OECD/EUROSTAT/WHO JOINT QUESTIONNAIRES

Gaetan Lafortune gave updates on the joint OECD/Eurostat/WHO questionnaires; on Expenditure indicators ('Joint Health Accounts Questionnaire' - JHAQ - from 2005) and on Non-expenditure indicators ('Joint Questionnaire on Non-Monetary Health Care Statistics'; from 2010, extended in 2013). It is expected that there will be a full transition to the new JHAQ, based on SHA 2011, in 2016. In 2015 there are two new JHAQ parallel questionnaires planned on 'Households Out-of-pocket spending' and 'Spending on Long-term care services'.

18. ANY OTHER BUSINESS

The Chair thanked all participants and the speakers in particular. He concluded the meeting by saying that there will be a special EGHI meeting focusing on ERIC on 28 back to back with a meeting of the ERIC Task Force on 29 January 2015. The official invitations would be sent by the end of 2014. The next regular EGHI meeting will take place in May and the date will be communicated later.

ANNEX (Summary report EGHI meeting 26-27 November 2014):

As Greece has been depicted repeatedly in this presentation, we would like to state certain key points that should be emphasized: 1. the work of this non-governmental organization regarding the provision of health care services to a large number of people in need is important 2. In every entry point of our country and it is well-known that there are numerous of them with a large influx of undocumented immigrants crossing the borders, there is provision for medical examination screening to all persons free of charge. 3. Greece provides by law access to emergency and primary health care services of the national health system free of charge to all persons (destitute, uninsured, undocumented etc). 4. As a point for discussion: we have seen in various international scientific reports that one cause for the re-emergence of diseases that had previously been eliminated in the European region is the movement of populations from countries with a downgraded health system; in the case of Greece, we would mention for example tuberculosis and poliomyelitis that had been eradicated and re-emerged since the increase of the immigration influx to Greece. 5. The Hellenic Ministry of Health does not accept that there happens any discrimination in health care provision and coverage; if someone finds out that there is lack of vaccination coverage, for example, this has indeed occurred to a large number of persons but it has financial causes and is irrespective of whether they are immigrants, asylum seekers or nationals.