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Public Health
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SANTE.C.2

EXPERT GROUP ON HEALTH INFORMATION (EGHI) MEETING

LUXEMBOURG 28-29 JANUARY 2015

SUMMARY REPORT

DAY 1: 28 JANUARY

1-2. REGISTRATION, WELCOME AND ADOPTION OF THE AGENDA

The Chair, Stefan Schreck, Head of the Health Information and Scientific Committees Unit of the Directorate-General for Health and Food Safety (DG SANTE) of the European Commission, welcomed the participants to the extraordinary meeting of the EGHI. The recently nominated delegates from the Czech Republic, Greece, Ireland, Sweden and the United Kingdom were particularly welcomed as well as the candidate countries Albania and the former Yugoslav Republic of Macedonia participating in the EGHI for the first time.

Information on the re-organisation followed. SANCO has become SANTE, as the Consumer part has been transferred to other DGs of the Commission and DG SANTE now encompasses Health and Food Safety. The name of the unit in charge of Health Information has been changed to 'Health Information and Scientific Committees'.

The Chair informed that the presentations and documents would be 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 SANTE website.

The amended agenda was adopted after that the participants agreed to discuss the 'Proposal for a Regulation on the processing of personal data...' of the Council Working party on Information Exchange and Data Protection, under Any other business.

4. MINUTES OF THE PREVIOUS MEETING

The summary report of the meeting held the 26-27 November 2014 was adopted. The final version will be made publicly available on SANTE web site together with the list of participants and the presentations after consent by the presenters.

4. EU HEALTH INFORMATION SYSTEM

4.1. INTRODUCTION

The Chair summarised the current state of play and emphasised the need for high quality comparable data. The Commission wants to ensure sustainability of data collections, higher transparency of indicator development as well as a full participation of Member States in selecting these indicators as a user-driven process. The objective is to establish an EU health information system to serve both policy-making and research. The presentations that followed demonstrated current and emerging needs of data for policy-making, explained recent projects for a coherent framework and subsequently outlined a possible EU health information system and described the preparatory processes.

4.2 POLICY NEEDS FOR HEALTH INFORMATION SYSTEM

Attila Balogh, SANTE C4/ Health determinants unit, presented current and emerging data needs for regular standardised data collection on NOPA (Nutrition, Obesity and Physical Activity) and for alcohol data, underlining the importance of reliable data and solid governance. It should be kept in mind that the burden of disease comes from NCD's and in this area increasing comparability and sustainability in data collections could be more valuable than getting new data. Agnes Molnar, as well from SANTE C4, presented challenges for data on social determinants and health inequalities. EGHI members acknowledged alcohol policy as a complex and important public health matter and highlighted that recent project developments have shown that streamlining and structural solutions are necessary. Furthermore, closer cooperation with ESTAT and RTD is needed. All of these areas require closer links between indicators and decision making.

In her presentation, Jerica Zupan, Joint Research Center (JRC) – Institute for Health and Consumer Protection – presented data and information needs in cancer information system to support policy-making in the Commission and by the EU Member States. She highlighted the importance of data quality (reliability), that cancer registers should be based on population and evidence rather than estimates. Good quality data are necessary for policy-making as well as for research and development. A call for data to Member States will be made during 2015. Jerica Zupan also gave information on JRC setting up a rare diseases registries platform and the current mapping exercise for this purpose. The registries will be valuable for clinical research tests for orphan drugs. In the discussion that followed EGHI members mentioned the importance of creating a sustainable structure for cancer data as well as the confidentiality issue on (cancer) registries. Jerica Zupan answered that only anonymised basic data are collected therefore prevalence, mortality, incidence, detection of cancer and personal data are protected.

Sofie Nørager from DG RTD gave an overview on health related research of Horizon2020. There is now a closer link between science and benefit as well as well-being of citizens. She mentioned that CNECT also is an important partner to be involved with regards to health data and research. There is a need for comparable data and standardised methodologies, finding new ways of making information accessible. A step forward would be to preserve information from projects and advance towards open access to data and publications. EGHI members raised that an ERIC could take over repositories and research project information that otherwise could be lost.

4.3 BACKGROUND OF THE EU HEALTH INFORMATION SYSTEM

Mika Gissler, Finland, presented the background of the ECHIm projects (ECHI-1: 1998-2001, ECHI-2: 2002-2004 and ECHIM: 2005-2008; and the Joint Action for ECHIM: 2009-2012) with their main objectives and key outcomes. Data collections for policy-making should be continued and as many member states as possible should be involved

in this process, but the ECHI short list needs to be updated. Data dissemination and reporting are important parts of the future EU health information system. The main problems of the ECHIs are that they have been project-based and their governance has not been determined. The participation has varied substantially between the member states. EGHI members recognised this impressive work, which shows the limits for what can be done through projects and that it is important to define the indicator selection criteria. Mika Gissler underlined the importance to set up a repository of data of indicators and that Finland is still hosting the echim.org web site for this purpose. He concluded by mentioning that when the process of updating the ECHI 'Quality of care' starts the member states and health indicator experts should be involved.

Sigurlaug Hauksdottir, SANTE C2, presented the main findings of the ECHI evaluation which was carried out by an external evaluator during 2012-2013. The full report and an executive summary can be found on SANTE web site. She also gave the main points of the EGHI survey conducted by SANTE C2 in Sept-Oct 2014; its summary having been presented in the last EGHI meeting (Nov 2014).

4.4 COMMISSION INITIATIVE TO SET UP THE EU HEALTH INFORMATION SYSTEM

In this presentation Marianne Takki and Stefan Schreck, SANTE C2, presented the first ideas for a possible Commission initiative to set up a sustainable EU health information system, as a follow up to the Council Conclusions of December 2013 and to provide basis for developing health systems performance assessment.

Stefan Schreck outlined a number of challenges in health and health services which the initiative would address. He also presented a set of possible approaches towards a formalisation of indicator establishment. The EGHI will be consulted during a possible impact assessment (see 4.5). Pascal Wolff, Eurostat, took the floor and expressed initial support for the initiative which would be useful for strengthening data collections. However, he mentioned the need to review the list of indicators in particular in taking into account the developments in the statistics' legislation and the work on the Joint Assessment Framework (JAF) for Health which is used in the Europe 2020 context.

4.5 PREPARATORY STEPS FOR THE INITIATIVE

Giulio Gallo, SANTE C2, summarised the steps to prepare a possible health information initiative, explaining the role of a roadmap and planning process of an impact assessment. Member States would be consulted along these stages; concerning the final roadmap, the impact assessment; and the Commission will as well ensure continuous exchange with Member States during a possible legislative process. Giulio Gallo finished his presentation by explaining that an inter-service steering group will be set up composed of the relevant Commission services to guide the work on the impact assessment.

5. DISCUSSION

During the following discussion 13 Member States took the floor to encourage the Commission to continue its work along the lines explained in the presentation and noted that several issues would still need to be addressed. Several countries expressed that a legal framework would be a step forward, that there are needs of pragmatic solutions and a thorough review of the European Core Health Indicators short list. Denmark raised that the possibility to comment on and discuss the initiative was impaired as the content of the

initiative had not been distributed to the EGHI members in advance; it had thus not been possible to consult colleagues or other relevant persons in respective countries for input. The Commission welcomed the initial support expressed by the EGHI members. In his conclusions, the Chair said that SANTE was encouraged to continue working on the initiative and that a consultation of Member States will be carried out as visualised in the presentation. The Chair invited EGHI members to inform the Commission at any time of the process about their suggestions, ideas and concerns on a possible initiative.

6. ANY OTHER BUSINESS

Under this point the Maltese representative drew the attention to amendments of the "Proposal for a Regulation on the processing of personal data". He mentioned that there are serious concerns in the health and research communities as regards the current text and suggested the EGHI members to raise these reflections with the representatives of their respective country at the Council Working Group on Information Exchange and Data Protection.

DAY 2: 29 JANUARY

7. WELCOME AND INTRODUCTION

Stefan Schreck introduced the agenda. He said that the focus of the meeting would be on the BRIDGE-Health project and the setting up of a potential ERIC on health information. In this regard the EGHI would have the opportunity to hear presentations by DG RTD and the different work package leaders of the BRIDGE-Health project.

8. EUROPEAN RESEARCH INFRASTRUCTURE CONSORTIUM ON HEALTH INFORMATION

8.1 BRIDGE PROJECT

Herman Van Oyen, Scientific Institute of Public Health, Belgium, leader of the project, gave an overview of the BRIDGE-Health project which was selected for funding following the call '2.1.3.3 Towards a sustainable monitoring and reporting system' of the Work Programme 2014 of the Third Health Programme 2014-2020. The project is intended to integrate and connect key EU projects on health information for a possible future European Research Infrastructure Consortium on health information. The project will focus on enhancing transferability of health information and knowledge for policy; reducing health information inequality and; development of a blueprint for a sustainable and integrated EU health information system; comprised in twelve work packages. Following Dr Oyen's presentation, the work package leaders presented objectives and methods of their work plans. The kick-off meeting of the project is planned for May. The length of the project will be 30 months.

EGHI members raised the question how the interaction could be strengthened between BRIDGE-Health, SANTE and EGHI. The Chair suggested that this could be discussed under agenda point 9 (Setting up of a Task Force on HI ERIC) and said that this project is a big step forward after years of separate projects and in ensuring that the work done on health information will not be lost, but made for a full use for the future policy-making.

8.2 BIOMONITORING INITIATIVE

DG RTD, Sofie Nørager, presented the European Human Biomonitoring initiative (EHBMI). It is a science-policy initiative to address the exposure of European citizens to chemicals and the potential impact of such exposure on human health. It will bring together national and EU HBM activities and related policies with the aim of strengthening the use of and capacities for HBM in the EU. RTD pursues the initiative in cooperation with other Commission services competent on the subject and experts from Member States. As a next step Member States have, via the Permanent Representations of Member States to the EU, been invited to nominate up to three representatives from relevant sectors, e.g. health, environment, research, to a Steering Group for the initiative. A workshop to consult on the initiative with Member States' representatives will take place on 17 March 2015. A call for a European Joint Programme Co-fund instrument is planned to be included into the 2016/17 work programme of Horizon 2020 in order to support the initiative. This work would need to be closely linked to the WP 10 and 12 of the BRIDGE-Health project.

8.3 ESTABLISHMENT PROCESS OF AN ERIC

Paul Tuinder, DG RTD, gave an update on setting up ERICs in the EU. The roadmap of the European Strategy Forum on Research Infrastructure (ESFRI) is being reviewed and an updated version will be put forward in spring 2016. Included in the roadmap are proposals of new (or upgraded existing ones) pan-European research infrastructures. The projects included in the roadmap are expected to move into implementation phase within 10 years. Key criteria for the evaluation of the eligibility of ERIC applications are scientific quality and management capacity built into the infrastructure. Paul Tuinder explained the different steps of the process of establishing an ERIC. Major stages are the preparation of a draft agreement for signature by Member States interested in which the scope, content and governance structure of a potential ERIC are laid down; after that the submission of a formal application in which Member States commit to the setting-up and operation of an ERIC; followed by a formal opinion of the ERIC Committee and subsequently a Commission Implementing Decision establishing the ERIC. Currently there are 10 ERICs in place and 4 applications ongoing. All of the existing ERICs have a decentralised structure in which national hubs play an important role. The Chair mentioned that an ERIC would have a scientific and technical support function in a future sustainable structure of EU health information.

9. SETTING UP OF A TASK FORCE ON HI ERIC

In order to steer the process of inter-linking existing projects on health information, the preparation of a potential ERIC on Health Information and the coordination with other initiatives relevant for Health Information, it was agreed to set up a Task Force.

Key objectives of the Task Force are:

- to guide the consultations and discussions on the scope, tasks and activities as well as governance structure of a possible future ERIC on Health Information, or alternative solutions;
- to improve the inter-linking of existing projects on health information at the EU level with the aim of integrating them into a future research infrastructure as a sustainable framework in the field.

The meeting approved – with some modifications – a mandate of the Task Force presented by the Commission (See annex).

The Czech Republic, Finland, France, Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Lithuania, Malta, Slovenia and Poland expressed their interest to participate in the Task Force. The first meeting will be organised in Luxemburg, date to be confirmed.

10. NEXT STEPS

The Commission will convene the first meeting of the Task Force. The date depends on the kick-off of the BRIDGE-Health project. The Commission will inform all EGHI members on the scheduling of the meeting.

11. ANY OTHER BUSINESS

The Chair thanked all participants and the speakers in particular. The next regular EGHI meeting will take place 19-20 May 2015.

Annex:

Mandate – Task Force on the future of the BRIDGE-Health project and on preparing a proposal for setting-up a European Research Infrastructure Consortium on Health Information