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20 December 2016

SUMMARY REPORT

- Subject:** Expert Group on Health Information (EGHI)
- Time:** 6th December 2016 (10h00 – 17h00)
- Venue:** HITEC Building 02/280, 11 Rue Eugène Ruppert L-2453, Luxembourg
- Attendees:** Petronille BOGAERT (BE); Anna DEMETRIOU (CY); Ondřej MAJEK (CZ); Eleri LAPP (EE); Mika GISSLER (FI); Alain FONTAINE (FR); Michel VERNAY (FR); Anne-Catherine VISO (FR); Lothar JANSSEN (DE); Apostolos KATERINOPOULOS (GR); Alan CAHILL (IE); Flavia CARLE (IT); Simona GIAMPAOLI (IT); Janis MISINS (LV); Aušra Želviene (LT); Nathalie DE REKENEIRE (LU); Neville CALLEJA (MT); Peter ACHTERBERG (NL); Maria Alexandra CUCU (RO); Pavol RIEGER (SK); Polonca TRUDEN-DOBRIN (SI); Maria BRATT (SE); Heidi LYSHOL (NO); Romeo ZEGALI (AL); Gaetan LAFORTUNE (OECD); Ivo RAKOVAC (WHO); Philippe ROUX (DG SANTE); Giulio GALLO (DG SANTE); Matthias SCHUPPE (DG SANTE); Fabienne LEFEBVRE (DG SANTE); Joaquin ARROYO SAN JOSE (DG SANTE); Marianne TAKKI (DG SANTE); Thilo SPANINKS (DG SANTE); Federico PAOLI (DG SANTE); Federico PRATELLESI (DG EMPL); Margarida DOMINGUES DE CARVALHO (DG ESTAT); Roisin ROONEY (DG JRC); Guy D'ARGENT (CHAFAE)

1. Welcome and Adoption of the Agenda

Philippe ROUX, Head of DG SANTE C2 (Country Knowledge and Scientific Committees), welcomed the participants, including newly nominated members from Sweden and Luxembourg, and observers from France. He emphasised the increasing relevance of high quality, timely and comparable health information in helping Member State governments to improve population health and the sustainability of health systems. He argued that the EGHI is in a unique position to improve the health information landscape across the EU by advising Commission services on health information needs and technical solutions; being the interface between EU-level health information activities and Member State authorities; facilitating the implementation of EU-wide health information initiatives in Member States, and creating synergies between health information initiatives across the EU and beyond.

The Proposed Agenda was adopted with no changes. The Draft Summary Report (Minutes) of the last meeting was approved as final with no changes. The Participants were informed that the report, together with the list of participants, would be published on SANTE's website. No one objected their name to be published.

2. EGHI Work Programme 2017-2020

Philippe ROUX set out an ambitious set of proposals in which the EGHI would transition from a forum for exchanging information to an output-oriented expert group that supports the Commission's work on health information and can make a real difference in improving Member States' capability in evidence-based policy making. He added that with aging populations and increased prevalence of chronic diseases, it is perhaps more urgent than ever to create smart health systems for which health information is essential. He argued that exchanging information should continue to form an integral part of the EGHI's role, but, since information can be effectively shared using alternative methods (such as the online Health Policy Platform), the in-person meetings should be used to concentrate on areas where the EGHI's technical and scientific advice can add the greatest value in improving population health and the sustainability of health systems in the EU¹.

To facilitate achieving these aims, and to address previous requests by members to clarify the Group's purpose, Philippe ROUX proposed to formalise the role of the Group by adopting a Terms of Reference and Work Programme for the EGHI. The Terms of Reference specifies that the EGHI's priorities would include: advising Commission services on health information needs and technical solutions; being the interface between EU-level health information activities and Member State authorities; facilitating the implementation of EU-wide health information initiatives in Member States; and creating synergies between health information initiatives across the EU. In more general terms, Philippe ROUX set out that the EGHI would have an integral role in providing governance to health information activities in the EU and, this way, improving EU mechanisms for collecting and generating health information.

According to the proposed Work Programme for the 2017-2020 period, the EGHI's work strands would include providing guidance on how to close gaps in health data as identified by the State of Health in the EU cycle, and mapping common areas of interest among International Organisations in view of reducing the reporting burden on Member States. More concretely, the EGHI's tasks would include advising Commission services on health information needs and priorities in Member States, offering technical solutions on how to collect the necessary data and construct the required indicators (including prioritising existing indicators), and steering the proposed Joint Action and ERIC on Health Information. Philippe ROUX added that the EGHI's advice would especially be sought in health information areas where the Commission's work can add real value without duplicating any national roles.

Discussing plans for a Joint Action on Health Information, Philippe ROUX set out that the initiative would bridge the gap between the end of the BRIDGE-Health Project and the launch of the proposed ERIC on Health Information with the objective of keeping up the built-up momentum, raising the visibility of the work and its benefits among Member States, and supporting the start-up phase of the ERIC. He argued that the Joint Action would not replace the ERIC, but the opposite, it would establish the conditions of a more successful ERIC launch with broad Member State support. He envisaged that the proposed Joint Action could offer Member States the opportunity to review the current landscape of health data and knowledge generation. It could start strategically steering these activities to ensure that EU health information activities are as relevant and useful for Member States as they can be.

Member State representatives welcomed formalising the role of the EGHI and approved its proposed Terms of Reference and Work Programme for 2017-2020. Member States who took the floor especially welcomed the aim to work towards reducing duplication between health information activities across the EU, and some Member States even suggested that the Mandate should go

¹ It was made explicit at the meeting, and in the proposed text, that EEA countries are also in scope.

further by committing countries to these roles. Clarifying the 'ultimate customers' of the EGHI's work, the Group agreed that the EGHI would continue to serve the needs of Member States' governments.

It has been suggested that, in order to increase the efficiency of its work, the EGHI would need to set up thematic sub-groups to work towards some of the objectives put forward by the text. Also, to free up time in the in-person meetings enabling the EGHI to concentrate on its objectives, the Group agreed that updates on ongoing and planned health information activities would no longer be presented at the meetings, instead these would be shared on the Health Policy Platform online.

Member States agreed that countries' Permanent Representations to the EU will be asked to review their nominations to the EGHI on the basis of the new mandate.

John RYAN, Director of DG SANTE C (Public Health, Country Knowledge, and Crisis Management), reiterated the increased role of health information at a time when most Member States are grappling with aging populations, increasing chronic disease prevalence, and fast-growing demand for healthcare. He argued that the EGHI will have a very important role in advising and steering EU-level efforts to collect, analyse, and communicate health information. He emphasised that through providing technical guidance to State of Health in the EU cycle, and steering the proposed Joint Action and ERIC on Health Information, the EGHI would be able to improve the policy-relevance of the generated health information and knowledge in the EU, while reducing the reporting burden on Member States at the same time. John RYAN welcomed the adoption of the Terms of Reference and Work Programme for 2017-2020 and wished the EGHI every success for its contribution to better health and more sustainable health systems in the EU.

3.a. Commission Services on Health Information Activities – The State of Health in the EU

The participants were shown a video (<http://ec.europa.eu/avservices/video/player.cfm?ref=I129434>) providing a short overview of the State of Health in the EU cycle and its deliverables: the Health at a Glance: Europe report; the 28 Country Health Profiles; a Commission Paper summarising common challenges, and Voluntary Policy Dialogues by Member States with the OECD, the European Observatory on Health Systems and Policies and the Commission. Philippe ROUX clarified that the aim of the State of Health Process is not to replace, or directly contribute to, the European Semester process, but to provide Member States with tools for making better policies.

Gaetan LAFORTUNE gave an overview of the first deliverable of The State of Health in the EU cycle: the Health at a Glance: Europe 2016 report, pointing out that the report includes new thematic chapters such as 'Labour market impacts of ill-health', 'Strengthening primary care systems', and 'Resilience, efficiency and sustainability of health systems'. He demonstrated the slow-down in the increase of health expenditure across the EU since the economic crisis and highlighted that spend on prevention and pharmaceuticals have decreased the most since 2009. By illustrating the human and economic costs of chronic diseases, as well as wasteful spending on hospital admissions with conditions that can be managed in the community, he made the case for greater and better investment to tackle non-communicable diseases, improve prevention, strengthen primary care, and broaden access to care across the EU.

Member State representatives welcomed the newly launched Health at a Glance: Europe 2016 report, especially its new thematic chapters, and agreed to share the report in their countries, not only within their health ministries, but with all national authorities with interest in population health and/or the sustainability of health systems (such as authorities responsible for the labour market, social security, and the economy as a whole).

3.b. Commission Services on Health Information Activities - Recent developments in the Commission

Continuing the discussion on the planned Joint Action on Health Information, Philippe ROUX explained that the preliminary Commission proposal is to make 4 million Euros available for joint work on improving health information. This, for example, could include identifying gaps in health data coverage and designing new health indicators. Philippe ROUX pointed out that broad Member State participation will be needed to achieve the objectives of the Joint Action. He proposed to facilitate a meeting on 16th February 2017, where interested Member States could learn more about Joint Actions in general, and exchange views to scope out the proposal on a Joint Action on Health Information including its Work Packages. Initial suggestions put forward by the Group for possible Work Packages under the Joint Action included: 'Designing an ideal health information mechanism and governance in the EU'; 'Improving the efficiency of health information activities and reducing reporting burden on Member States'; 'Prioritising on-going EU health information activities and reducing duplication between these'.

Several Member States (e.g. Italy, Finland, Belgium, Malta, Slovenia, Germany, the Netherlands, France, Luxembourg, the Czech Republic, and Norway) expressed interest in being part of the process scoping out the proposed Joint Action on Health Information, and agreed to meet on 16th February 2017 to start designing the Joint Action including its tasks and future interaction with the envisaged European Research Infrastructure Consortium on Health Information. An official invitation will be sent in due course to all EGHI Members. Since the Joint Action is co-financed by Member States, the EGHI agreed to discuss willingness of taking part in the Joint Action within their own governments before attending the scoping meeting in February.

Margarida DOMINGUES DE CARVALHO updated the EGHI on Eurostat's on-going and planned health information activities including its work on the European Health Interview Survey, Health Expenditure statistics, Causes of Death statistics, Diagnosis-specific Morbidity statistics and Occupational Disease statistics.

Federico PAOLI updated the EGHI on the work of the Expert Group on Health System Performance Assessment (HSPA). He highlighted the group's recently published report on Strategies across Europe to assess quality of care, mentioning some of its conclusions, and drawing attention to its online annex listing indicators used by selected Member States. He set out plans for publishing the group's next report on performance assessment in integrated care in the first quarter of 2017 after which the group will focus on performance assessment in primary care systems. The EGHI agreed that a joint, back-to-back meeting with the HSPA group would be desirable as it would help identifying scope for closer collaboration.

Federico PRATELLESI updated the EGHI on the work of the Indicator Subgroup of DG EMPL's Social Protection Committee designing the 'Joint Assessment Framework (JAF) in the area of Health'. He set out that the purpose of the JAF is to contribute to the European Semester process, potentially leading to Country-specific Recommendations, by assessing the access, quality, and sustainability dimensions of health systems in the EU. He gave examples of recent refinements and additions to the JAF Health indicator set.

Roisin ROONEY updated the EGHI on the work of the Joint Research Centre on EU-wide cancer, rare disease, congenital anomaly, and cerebral palsy registries as well as the work toward improving data quality and the interoperability of national registries.

Marianne TAKKI updated the EGHI on DG SANTE's work establishing a Steering Group on Promotion and Prevention with the objective to provide strategic steer for the implementation of actions against chronic diseases and help Member States achieving the WHO target on chronic diseases.

Adopting the proposal of the Chair, the EGHI agreed that presentations (including those from Member States, Commission services and international organisations) would be circulated electronically using the Health Policy Platform before future EGHI meetings and the in-person meetings would only be used to ask questions and/or discuss the circulated updates further.

4.a. Member States on Health Information Activities – ERIC on Health Information

Petronille BOGAERT and Neville CALLEJA provided an overview of the proposed core activities of the planned European Research Infrastructure Consortium (ERIC) on Health Information. They detailed the foreseen benefits for Member States of setting up an ERIC including the potential for increased efficiency in EU-wide health information initiatives through the ERIC's coordination activities. They envisaged that the EGHI could advise the future ERIC by delegating representatives to the ERIC steering group meetings, while the ERIC could also delegate members to attend the EGHI meetings.

They also introduced and invited comments on a brief 'policy paper', which would be presented at the upcoming Working Party on Public Health at Senior Level (3rd February 2016) to raise the visibility of the initiative and make the case for more Member States to participate in the ERIC. In particular, they asked the EGHI's views on how to improve the paper, and what specific services should the ERIC on Health Information plan to provide to increase its usefulness for Member States' governments and facilitate broader participation. They also asked which of these services should the ERIC prioritise in its initial stage, and which of them should only be taken on once the ERIC starts growing. As part of the discussion, it was emphasised that the ERIC will not replace existing elements of the EU system of health information, such as ESTAT, but could help define what data will become part of the EU Statistical System.

Neville CALLEJA emphasised that a positive reception by the WPPHSL would be essential in paving the way for a successful ERIC, and asked the EGHI to brief their country's representative to the WPPHSL group in advance of the meeting. To facilitate this, he would send the WPPHSL delegate list to the EGHI in due course. He also asked the EGHI to consult with their governments and decide by April 2017 whether they wish to be part of the ERIC preparations, emphasising that this will not have to be a final decision on membership, but a commitment to help the design, preparation and application processes of the ERIC. Philippe ROUX added that any country having doubts about the planned format should contribute to shaping the mechanism, thereby ensuring that the future system of health information generation in the EU is as useful for policy making as it can be while placing the least burden of data collection on Member States.

Those Member States where the ministries for research would be responsible for funding the ERIC, voiced their concerns regarding, what they perceived to be, the insufficient research element in the ERIC's stated goals and planned tasks to make a strong case for funding as a research infrastructure.

In particular, Alain FONTAINE called attention to the fact that, as confirmed through exchanges with colleagues in charge of research infrastructures in the French Ministry of Research, the primary goals and functions of a European Research Infrastructure Consortium should be to support research activities. While France shares the need for a sustainable EU Health Information System to provide reliable and relevant comparative information to European and national health policy makers, and recognizes the potential for productive interactions between such a system and the research community, this does not translate into assuming that setting up a European Research Infrastructure Consortium will be appropriate or sufficient to provide the services expected from a Health Information System. While setting up an ERIC could be justified to provide support to research, e.g. on the validation of indicators or by enabling access to different sources of data for research or

health information purposes, these will not be sufficient to constitute a Health Information System for policy making purposes.

The Group agreed that, since the ERIC will be aiming to facilitate evidence-based health policy making and translate research into policy implications, there will need to be a dialogue between the health ministry and the ministry providing the funding for the ERIC (if different); in any case, the ERIC will be aiming to facilitate evidence-based health policy making and translate research into policy implications.

Petronille BOGAERT invited the EGHI to register and attend their upcoming 'Health Information of the European Union - ERIC on Health Information as a Tool' event on 20th April 2017 in Brussels.

4.b. Member States on Health Information Activities – Recent developments in Member States

Neville CALLEJA updated the EGHI that the health thematic priorities of the Maltese Presidency will include 'Non-communicable diseases' with special attention to childhood obesity, 'Communicable diseases' with special attention to HIV prevention and control, 'Co-operation between health systems', and 'Health data as the key to personalised and sustainable care'.

Petronille BOGAERT updated the EGHI on Belgian health information initiatives including the National Burden of Disease Study, a study into Trends in Inequalities in Premature Mortality, and a study into the Impacts of Chronic Conditions and Multimorbidity on the Disability Burden in the Older Population.

Heidi LYSHOL updated the EGHI on a user survey conducted to study the usefulness of the Norwegian Institute of Public Health's Health Information Toolkit and improve access to the data. The user survey proved to be a useful tool both to improve access to the health information toolkit, and to inform users of its available features. She agreed to circulate a summary of an article on the findings.

Mika GISSLER updated the EGHI on a Finnish initiative to prioritise integrated care indicators, and on a change in the Finnish legislation to allow better access to registry data for health monitoring and research purposes. He agreed to keep providing updates on the indicator prioritisation exercise.

Romeo ZEGALI updated the EGHI on Albania's eHealth implementation and using data to improve health care delivery including electronic medical records, electronic database of insured patients, e-prescriptions, electronic signature of medical documents, electronic booking of 32 examination types, and a health situation monitoring system utilising the database of electronic medical records. He agreed to provide further updates on Albania's experience of implementing a comprehensive eHealth package.

Eleri LAPP updated the EGHI on Estonia's National Health Plan 2009-2020 which includes five strategic areas with indicator sets for monitoring and performance assessment purposes feeding into government policy.

5. International Organisations on Health Information Activities

Gaetan LAFORTUNE updated the EGHI on the OECD's wider work on health information, emphasizing that most of the OECD's work strands (e.g. Health at a Glance report; Quality of care and patient safety; Efficiency and value for money in health systems; Health workforce; and Ageing and long-term care) are run in close collaboration with the European Commission. He highlighted the OECD-EU-WHO joint data collections as good examples to promote comparability of the reported data while reducing the data collection burden on countries. He set out that the upcoming OECD Health

Ministerial meeting on 17th January 2017 is expected to endorse the OECD Council Recommendation on Health Data Governance (which he agreed to circulate among the EGHI in due course), and give the OECD mandate to develop patient-reported experience and outcome measures in cooperation with the European Commission. He also invited EGHI members to register and attend the upcoming OECD Policy Forum on 16th January 2017, discussing person-centred care, caring for people with complex care, and patient-reported outcome and experience measures with world-renowned experts.

Ivo RAKOVAC updated the EGHI on the activities of the European Health Information Initiative (EHII), emphasizing that the network now has 30 members, including Member States and associations and foundations. EHII is the coordinating mechanism for health information activities in the WHO European Region. Its aim is to achieve interoperable and harmonised health information. He brought to the EGHI's attention the achievements in EHII's all 6 strategic areas of work. The mapping exercise conducted by WHO revealed that 76% of indicators for Sustainable Development Goals (SDGs) and Health 2020 are aligned and WHO is working on a proposal for a joint monitoring framework for SDGs, NCDs and Health 2020. Upcoming work includes also further development of well-being indicators and work on understanding the cultural context of health and well-being. "Health for All explorer" on the European Health Information Gateway is the new WHO's online tool to visualize European health indicators. The series of "Profiles of health and well-being" and "Highlights on health and well-being" has produced several country-specific publications and more are on the way. Several HEN reports have been published recently, as well as two issues of WHO journal "Public Health Panorama". Capacity building activities such as the "Autumn School on health information and evidence informed-policy making" were conducted. WHO health information networks have met for the Small Counties Health Information Network and EVIPNET Europe. The new European Burden of Disease Network was established and is hosted jointly with the Institute of Health Metrics & Evaluation. WHO is also undertaking work to revise the "Support tool to assess health information systems and develop and strengthen health information strategies". Ivo RAKOVAC informed EGHI members that the Action plan to strengthen the use of evidence, information and research for policy-making in the WHO European Region and the accompanying resolution were unanimously adopted at the 66th Regional Committee. Ivo RAKOVAC added that the action plan sets the EHII as the implementation mechanism for the actions set for the WHO and the WHO European Member States in the area of evidence, information and research. Philippe ROUX urged EGHI members to follow more closely and participate in EHII activities in order to identify opportunities for closer collaboration and synergies.

6. Any Other Business

The Secretariat introduced the Health Policy Platform (<https://webgate.ec.europa.eu/hpf/>) to replace CIRCABC, highlighting that it provides a virtual space for online collaboration, and asked EGHI members to request access to its 'Expert Group on Health Information' network. The EGHI approved the proposal to share presentations on the Platform, as opposed to present them at the in-person meetings, so that the meetings have more time to concentrate on areas where the EGHI can add real value such as advising Commission services on health information priorities or identifying areas for greater collaboration. The Secretariat agreed to upload materials from previous EGHI meetings to the Health Policy Platform for reference purposes.

The Chair summarised the meeting's main conclusions as:

- i.) The EGHI endorsed its Terms of Reference and agreed it to be sent to the countries' permanent representations to the EU seeking (re)confirming EGHI members' nomination.

- ii.) The EGHI agreed to share the Health at a Glance: Europe 2016 report widely in their governments.
- iii.) From now on, updates by Member States, International Organisations and Commission services would be shared on the online Health Policy Platform. The in-person meetings would no longer feature these presentations except for Q&A and further discussions on the topics. The agenda of the next EGHI meeting would also be collaboratively produced using the Health Policy Platform.
- iv.) A meeting would take place on 16th February 2017 with interested Member States to provide them further information on joint actions in general and discuss how to design a Joint Action on Health Information. All EGHI members would receive an invitation to this meeting in due course.