



DRAFT MINUTES OF THE 08/06/2017 MEETING OF THE EXPERT GROUP ON HEALTH INFORMATION

Participants: Philippe Roux (SANTE - Chair), Claudia Habl (AT), Herman Van Oyen (BE), Petronille Bogaert (BE), Ivan Pristas (HR), Vasilios Scoutellas (CY), Ondřej Májek (CZ), Eleri Lapp (EE), Mika Gissler (FI), Hanna Tolonen (FI), Alain Fontaine (FR), Anne-Catherine Viso (FR), Emmanuelle Bauchet (FR), Lothar Janssen (DE), Thomas Ziese (DE), Angela Fehr (DE), Alan Cahill (IE), Flavia Carle (IT), Luigi Palmieri (IT), Giovanni Nicoletti (IT), Janis Misins (LT), Aušra Želvienė (LV), Nathalie de Rekeneire (LU), Neville Calleja (MT), Peter Achterberg (NL), Mariken Tijhuis (NL), Arleta Zaremba (PL), Piotr Szymanski (PL), Paulo Jorge Nogueira (PT), Luis Lapao (PT), Maria Alexandra Cucu (RO), Ján Čáp (SK), Tatjana Kofol Bric (SI), Metka Zaletel (SI), Isabel Noguier Zambrano (ES), Maria Bratt (SE), Katarina Paulsson (SE), Robyn Wilson (GB), Ronan Lyons (GB), John Newton (GB), Gudrun Gudfinnsdottir (IS), Heidi Lyshol (NO), Romeo Zegali (AL), Ahmet Sönmez (TR), Gaetan Lafortune (OECD), Tina Dannemann Purnat (WHO Europe – over videoconference), Ilze Burkevica (ESTAT), Lucian Agafitei (ESTAT), Giulio Gallo (SANTE), Matthias Schuppe (SANTE), Franz Karcher (SANTE), Fabienne Lefebvre (SANTE) David Vizer (SANTE), Wojciech Kalamarz (SANTE), Stan Van Alphen (SANTE), Annette Scherpenzeel (SHARE).

1. Welcome and Adoption of the Agenda

The Chair, Philippe Roux, Head of the Country Knowledge and Scientific Committees Unit of DG SANTE, welcomed the participants and proposed to use most of the meeting to shape the Joint Action on Health Information (JAHI). He continued by providing a brief recap of the Joint Action preparations so far. He recalled that the extraordinary EGHI meeting in February proposed Prof Herman Van Oyen, the Belgian EGHI member, to be the future coordinator of the JAHI, which has been confirmed by competent authority representatives on 7th June 2017 at the CHAFEA info-day in Luxembourg. He also recalled that the February EGHI meeting proposed the inclusion of the following work areas in the JAHI:

- Mapping currently produced health indicators to policy priorities and agreeing on criteria to identify duplications and gaps in the data coverage;
- Prioritising health information generation activities;
- Improving the coverage and robustness of health indicators in high priority areas;
- Mapping capacity and building capacity where needed; and
- Producing health indicators more efficiently and in a more cost-effective manner.

Philippe Roux outlined that 26 EU Member States and 4 EEA or Candidate countries have nominated competent authorities for the JAHI by the 11th May deadline, and a meeting of competent authorities on 18th May in Brussels refined the preliminary work areas further to include:

- Status of health information systems in MS and regions;
- Strengthen EU countries' health information capacity;
- Proof of concept of ERIC on Health Information;
- Platform for health information and health indicators;
- Research in health information;
- Interoperability of health information.

Philippe Roux emphasised that the final set of work packages, their precise content, and the participating partners can still be shaped until the 28th September deadline by which time the detailed proposals have to be submitted to CHAFEA, and proposed to use most of the EGHI meeting to further refine these work areas. The agenda was approved with no changes.

Philippe Roux set out that the presentations will be made available in the EU Health Policy Platform (<https://webgate.ec.europa.eu/hpf/>) – both in the EGHI and in the Joint Action on Health Information networks. He added that travel reimbursement forms and supporting evidence must reach the secretariat within 30 days of the meeting, otherwise reimbursements cannot be paid.

2. Adoption of the minutes of the previous EGHI meetings

The draft minutes of the 6th December 2016 EGHI meeting and 16th February extraordinary EGHI meeting have been adopted as final with no changes. The participants were told that the minutes of the current meeting and the list of participants will be, as usual, published on SANTE's website, and participants were asked to tell the secretariat during the meeting if they do not wish their name being published on SANTE's website.

3. State of Health in the EU Update

Gaetan Lafortune from the OECD presented the state-of-play on the Country Health Profiles as part of the State of Health in the EU cycle, the analytical reports written by experts from the OECD and the European Observatory on Health Systems and Policies. He gave an overview of the structure of these reports which would include an analysis of the country's health status (including health determinants), and a description and assessment of its health system along the 'effectiveness', 'accessibility' and 'resilience' dimensions in line with the 2014 Commission Communication. Each profile is up to 16 pages long, written with a consistent structure, to be read as part of the wider State of Health in the EU series, and is designed for multiple audiences (including policy makers in Member States, and the general public).

In terms of its objectives, the profiles aim to give policy makers and other readers a snapshot of the key strengths and challenges in their country, how they are doing relative to others in the EU, where are potentials for mutual learning, and how the EU might add value in supporting collaboration between Member States. He added that the country profiles aim for a 'series' feel with sufficient similarity across the reports but without insisting on uniformity too much so that relevant country-specific information can be included where and when appropriate.

He outlined that the OECD and Observatory will launch a written consultation on the profiles starting in mid-July, with a deadline of 7th August, involving EGHI members and EU countries' health ministries. The purpose of the consultation is to identify instances where the expert authors may have missed important evidence and/or policy developments. EGHI members will subsequently receive embargoed country health profiles a few days in advance of the tentative launch date of 23rd November 2017.

Some countries asked if they could provide supplementary data from national sources, to which Gaetan Lafortune suggested that they would review each of these requests, but, due to consistency and comparability reasons, the inclusion of national data may not always be possible, and the reports would predominantly feature consistently collected OECD-Eurostat data. Gaetan Lafortune also reassured the Norwegian and Icelandic members that country profiles will be produced for their countries as part of the second cycle (in 2019).

4. Examples of European Research Infrastructures Related to Health Information

The Chair introduced "The Survey of Health, Ageing and Retirement in Europe (SHARE)" as a cross-national longitudinal database on health, socio-economic status and social and family networks, covering more than 120,000 individuals aged 50 or older in 27 European countries. The SHARE has been running since 2004, and has become the first ever European Research Infrastructure consortium in 2011. He gave the floor to Annette Scherpenzeel from SHARE to introduce the survey and explain how the ERIC as a tool supports Member States' work in the area of health and social data collection.

Annette Scherpenzeel underlined that the SHARE is a longitudinal study with representative samples of individuals aged 50+ (with spouses) covering 21 countries. The survey conducts face-to-face interviews every two years covering a broad range of questions, measurements and tests including socio-economic status (labour force participation, retirement, income, wealth, housing, consumption, pension...), health status (subjective and objective, conditions, physical performance tests, biomarkers such as HbA1c, CRP, cytokines, blood lipids...), health behaviours, health utilization, insurance coverage, and social participation.

She explained that the European Research Infrastructure Consortium (ERIC) organisational form is used to coordinate the participating 5 main nodes, 28 country scientific partner institutions, 31 independent survey agencies with 2500 mostly free-lance interviewers, and 57 funding sources. She argued that the ERIC structure ensured stable governance structure, close cooperation with other ERICs, and stable funding for most countries.

However, she also pointed out that, although the ERIC could benefit from various funding sources, the ERIC structure is too reliant on decentralised funding (in particular, over 80% of SHARE funding is decentralised). This results in unstable funding for the central coordination activities as well as unstable funding for some countries' activities (including some of the richer countries). The strong reliance on decentralised funding also inhibits the ERIC's ability to reallocate funds helping countries with temporary financing issues, and hence cannot automatically offer long-term sustainability.

Answering member states' questions on whether SHARE duplicates what others, including Eurostat, are doing, Annette Scherpenzeel argued that the longitudinal (i.e. panel) nature of the study makes it unique and adds an extra layer of very useful information that is not possible to obtain from cross-sectional studies. The Chair thanked Annette Scherpenzeel for the frank and honest account of the challenges the SHARE ERIC has been facing, but noted that the SHARE ERIC has been in operation for its 7th wave.

5. Joint Action on Health Information

The Chair invited Prof Herman Van Oyen and Petronille Bogaert, the elected coordinators of the Joint Action on Health Information (JAHl) to lead a discussion on the proposed work packages including their titles, contents and leaders.

Petronille Bogaert set out that the overall objective of the Joint Action is to work towards a sustainable EU health information system, reduce health information inequalities, develop and use transparent health information prioritisation methods and to produce concrete outputs that are useful for Member States. She added that nothing is set in stone regarding the proposed work packages, and called for all interested countries to contact the nominated work package leaders of all work packages in which they wish to take part. Then, she invited each work package leader to introduce the proposed content of their work packages, who set out the following set of proposed activities:

WP1: Management of the Joint Action (Lead: Belgium)

- Coordination of the Joint Action
- Administrative Project Management
- Risk Management

WP2: Dissemination (Lead: Belgium)

- Coordination of internal and external communication
- Visual identity
- JA on tour
- Audiovisual communication
- Publications

WP3: Evaluation (Lead: tbc)

Discussing WP3, Member States suggested that the leader of the work package should be different from the leader of WP1 and WP2. The Coordinator of the Joint Action agreed to identify a non-Belgian leader for WP3.

WP4: Sustainability of an EU health information system supporting country knowledge and capacities, health research and policy-making (Lead: Spain, co-Lead: France)

- Set up of a governing board
- Review implementation of a health information system across Europe
- Policy dialogues to raise awareness and acceptance in decision makers on innovative actions to improve health information system
- Establishment of the 'Health Information for Research and Evidence-based policy' ERIC

Discussing WP4, Member States pointed out that the sustainability of a health information system strongly depends on close collaboration with international organisations such as OECD and WHO. The WP leader confirmed that part of the work package would look into how this collaboration could work in practice.

WP5: Status of health information systems in MS and regions (Lead: Germany, co-lead: Malta)

- To map and assess health information systems in Europe
- To prepare for the establishment of a stakeholder consultation platform for aligning the health information landscape in Europe

- To catalogue health information projects and initiatives at EU level by (Lead: Netherlands, Partners: Finland, Italy)
- To engage in the prioritization of health information developments, also with a view to tackling health information inequalities in Europe

Discussing WP5 and the proposed prioritisation of health information activities, the coordinator pointed out that sustainability of the health information system can only be ensured by producing what is useful and relevant, and in the most efficient way, in other words by using the health information networks optimally. Tina Dannemann Purnat supported the use of the WHO Support tool to assess health information systems and develop health information strategies.

WP6: Strengthen EU countries health information capacity (Lead: Portugal, co-lead: Finland)

- Mapping capacities and education/training programmes in health information across MSs
- Designing and piloting a training program to improve MS capacities in population health and health system performance analysis and monitoring
- Evaluating training program
- Roadmap for sustainability of these training/educational programmes on a financial and curricular level

Discussing WP6, it has been suggested that the Work Package should map training needs across the EU first and design the necessary training accordingly. Several Member States also pointed out that collaboration with WHO in its training programmes would be essential, to which the WP leaders confirmed that this is indeed their plan. Tina Dannemann Purnat welcomed plans for collaboration and envisaged that WP6 could contribute to WHO Europe's Autumn School and other capacity building platforms, perhaps by adding extra modules. She added that WHO tools for capacity building could also be used for other work packages.

WP7: Proof of concept of sustainable structure on health information (Lead: Belgium, co-lead: Netherlands)

- Define the desired structure and content areas of a functional networks of networks
- Business case and roadmap for implementation
- Landscape financing resources
- Align all governance related outcomes proposed

Discussing WP7, some Member States called for the work package to demonstrate the usefulness of a future ERIC or similar structure for Member States. Answering Member States' questions, Herman Van Oyen explained that the Joint Action should not be confused with the planned and piloted sustainable structure under WP7. In fact, WP7 will trial the structure envisaged by the BRIDGE Health project for a sustainable health information system, but given the funding mechanism of the Joint Action, it cannot, in itself, deliver sustainability.

WP8: Health Information Support Platform (Lead: Italy, co-leaders: Netherlands, Slovenia)

- Generating knowledge on data collection methods and procedures
- European Common Health Indicators: renewal and design for a sustainable update procedure
- Guidelines for accessibility, availability and reporting of health information including quality of data/indicators and quality of reporting
- Establishment and maintaining of the network of community of health information experts for involving them in the work of entire JA

Discussing WP8, Member States urged the work package also to look into the policy translation of health information. Gaetan Lafortune added that the international organisations (such as OECD, and WHO) and the European Commission (EUROSTAT) already do a lot to improve accessibility of health information, and urged the work package to analyse the problems with the current system first before designing a support platform, such as gaps and problems affecting interoperability such as the use of different standard populations. Member States suggested that the work package could look into developing a repository for metadata and the underlying surveys if applicable, and/or to improve data availability at lower geographical levels.

WP9: Innovation in Health Information for Public Health Policy Development (Lead: France, co-lead: Lithuania)

- Review emerging (e.g. recently developed or planned to be shortly developed) indicators on morbidity, health risk factors and health care quality, different from those already compiled in existing health information databases (OECD, WHO, Estat...), NPHIs and collaborating academic research teams use.
- Review and identify emerging and promising sources of data to develop relevant indicators on morbidity, health risk factors, and health care quality, at different geographical scale (e-data...), with special attention to the utilization of data from different sources (primary care, drug prescription, health care reimbursement and hospital discharge).
- Develop and propose generic and shared methods, best practices and standards to define, construct, validate, relevant and reliable emerging indicators from new data sources.
- Apply these best practices to health indicators to several priority public health targets that are of interest to demonstrate the value of the infrastructure for MS and potentials users of the infrastructure (such as different DGs from the EC, OCDE, WHO...) of indicators for public health/prevention/health systems governance purposes at multi-country level.
- Propose further development of composite health indicators, including Burden of Diseases outcomes (Disability Adjusted Life Years), population attributable fractions due to potentially preventable risk factors (behavioural, metabolic and environmental...), mortality amenable to health care, preventable death (articulation with ESTAT project), based on morbidity indicators, indicator sets that track the Sustainable Development Goals
- Test the feasibility of merging mortality and morbidity information (from hospital discharge records, primary care electronic records, and vital statistics reports) among different geographical regions in different MS. Regional or local differences may be then used to explore both the quality of health information systems and inequalities in access to health care
- Exploring mechanisms for the uptake/integration of indicators into the regular EU data collection system (Eurostat regulations), WHO and OECD data collections.

Discussing WP9, Member States called for collaboration with the Joint Action on Health Inequalities, and asked the WP to avoid any duplication with related activities by Eurostat (e.g. morbidity indicator development), and the Expert Group on Health System Performance Assessment. It has also been suggested to link this work package with WP6 on capacity building, and that the proposed activities under the WP should be prioritised on the basis of policy priorities.

**WP10: Interoperability of health information systems and supporting digital assets
(Lead: Croatia, co-lead: Spain, Italy, UK)**

- Legal and organisational levels of interoperability as well as interoperability governance – mapping, tools and guidelines
- Semantic and technical interoperability – overview and coordination
- Interoperability consultation platform - communication
- Health information interoperability enablers – action plan (or recommendation as actionable items to be implemented by national HISs)
- Piloting several key interoperability assets

Discussing WP10, Tina Dannemann Purnat proposed collaboration with the WHO in this area, as there is already good collaboration established in interoperability with DG CONNECT. It has also been suggested that, beyond pure legal aspects, the practical implementation of legal rules should also be looked into by the WP.

As part of a general discussion, EGHI members welcomed the proposals but several Member States called for better prioritisation among the proposed activities, better collaboration within work packages and with international organisations. Supporting the notion, Petronille Bogaert emphasised the need for building on what has already been achieved by other projects and initiatives including the European Health Information Initiative by WHO, OECD projects, and projects outside the health domain. Herman Van Oyen added that they would meet with WHO representatives the following week, and a similar meeting is planned with OECD, too, to discuss cooperation.

The Chair also encouraged work package leaders to identify synergies with other Joint Actions, especially the Joint Actions on eHealth and Health Inequalities, and collaborate where possible. Wojciech Kalamarz, Head of the Health Determinants and Inequality Unit of DG SANTE, gave a brief overview of the Joint Action on

Health Inequalities. He listed work packages where synergies may be identified with the JAHl such as WP5: Monitoring of health inequalities (led by the Swedish Public Health Authority); WP6: Healthy Living Settings (led by the German Federal Centre for Health Education); WP7: Migration and health (led by the Norwegian Centre for Migration and Minority Health); and WP8: Universal health access for vulnerable groups (Lead by Spain).

It has been reiterated that the contents of work packages are still being shaped and partners can still join any work package and/or can suggest changes or additions to the proposed activities. In particular, country representatives have been encouraged to review the proposed activities of each work package (which are listed in the Joint Action on Health Information area of the Health Policy Platform (<https://webgate.ec.europa.eu/hpf/>), and make contact with the Work package leaders if they wish to suggest changes or propose to take part.

Herman Van Oyen outlined that throughout June bilateral meetings would be held with work package leaders, followed by a plenary meeting on 30th June, after which the provisional plans for the budget will be drawn up and communicated to competent authorities. For this to be possible, he asked each member states to contact the leaders of each work package in which they wish to take part before the 30th June. He also encouraged work package leaders to list the required activities so that Member States can sign up to concrete activities if they wish to participate.

Discussing the co-funding rate, which depends on the composition of countries and the allocated budget, it was revealed that some Member States would find it easier if the co-funding by the Commission would be 80%, whereas other countries felt that they could achieve more with a Commission co-funding rate of 60% and with self-funding worth 40%.

6. Preparations for the EGHI-HSPA Joint Session

The Chair set out that the EGHI and Expert Group on Health System Performance Assessment (HSPA) joint meeting the next day would discuss how the two expert groups could more closely collaborate in the future.

Showing a stylised graphical representation of how a sustainable health information system might operate, he outlined the possible complementary roles of the EGHI and HSPA in this structure such as:

- The HSPA could work towards identifying gaps in health indicator coverage in highly policy-relevant areas, and the EGHI (with the Joint Action on Health Information) could advise on technical requirements and solutions for developing the required indicators.
- HSPA members could assist their countries' EGHI members in contributing to the Joint Action's mapping exercise by assessing the policy-relevance of on-going health information activities.
- HSPA and EGHI members could collaborate at the national level to advise high priority indicator-development projects, such as the joint PaRIS project (on patient-reported outcome measures) by the OECD and the Commission. These projects create a natural opportunity for the HSPA group to advise the direction of the work from the viewpoint of their government's policy priorities, whereas the EGHI members would provide technical advice (such as what data could be made nationally available for the indicator).
- HSPA and EGHI members could effectively contribute to their countries' participation in the voluntary policy dialogues with the OECD and European Observatory as part of the State of Health in the EU process.

The participants agreed to suggest these proposed complementary roles at the EGHI-HSPA meeting.

7. AOB

The next EGHI meeting is foreseen in November 2017. Exact date is to be confirmed in due course.