



SUMMARY REPORT

Subject: *Joint Action on Health Information towards a sustainable EU health information system that supports country knowledge, health research and policy-making – Meeting to exchange views with interested EGHI Representatives*

Time: 16th February 2017 (10h00 – 16h30)

Venue: HITEC Building 02/280, 11 Rue Eugène Ruppert L-2453, Luxembourg

Attendees: Petronille Bogaert (BE), Herman Van Oyen (BE), Vasilios Scoutellas (CY), Ondřej Májek (CZ), Mika Gissler (FI), Alain Fontaine (FR), Anne-Catherine Viso (FR), Lothar Janssen (DE), Georgina Tzanakaki (GR), Alan Cahill (IR), Flavia Carle (IT), Sabrina Montante (IT), Simona Giampaoli (IT), Giovanni Nicoletti (IT), Nathalie de Rekeneire (LU), Neville Calleja (MT), Peter Achterberg (NL), Polonca Truden-Dobrin (SI), Maria Bratt (SE), Katarina Paulsson (SE), Tongtong Qian (UK), Heidi Lyshol (NO), Romeo Zegali (AL), Tina Dannemann Purnat (WHO), Claudia Stein (WHO), Marleen De Smedt (Eurostat), Jacques Lanneluc (Eurostat), Philippe Roux (SANTE), Giulio Gallo (SANTE), Franz Karcher (SANTE), Fabienne Lefebvre (SANTE), Matthias Schuppe (SANTE), Guy D'Argent (CHAFFEA).

1. WELCOME AND ADOPTION OF THE AGENDA

Philippe ROUX opened the meeting by emphasising the need to make health information generation more sustainable and to further develop a blueprint for a system of health information in the EU that supports country knowledge and helps evidence-based policy making. He set out that the Joint Action is a tool to facilitate Member State cooperation and Member State-led initiatives in this area, adding that the purpose of the meeting is to identify the general direction of the Joint Action, to scope out the main work areas, and agree on next steps in the application process.

The Agenda was adopted with no change.

2. GENERAL INTRODUCTION TO JOINT ACTIONS

2.1 Joint Action application process and other formalities: Guy D'ARGENT (CHAFFEA)

Guy D'ARGENT outlined the most important rules relating to joint actions, also adding that much greater detail can be found in his slides which are being circulated. He emphasised that only one competent authority partner can sign the grant agreement from each country. Competent authority partner can be any government body that is responsible for health policy (either nationally or

regionally), or any agency to which this responsibility has been delegated by the government (e.g. a national or regional institute of public health). In turn, each competent authority partner can nominate multiple 'affiliated members' and could co-fund their activities using the funds received from the Commission. Competent authority partners may also use 'subcontractors', which can be paid from the Joint Action funds, and can also nominate 'collaborating stakeholders', but these cannot be paid from the Joint Action funds.

He outlined that Member States' Permanent Representations to the EU will shortly receive information on all joint actions, and they should nominate a competent authority partner from their country by 11th May 2017. Following this, by 7th September, these partners should submit their proposals also outlining their chosen 'affiliated members' and the principles for collaboration between partners and affiliated members. It is important to note that the competent authority partner must remain responsible for the contractual, financial, and knowledge management roles of the Joint Action and have reporting responsibilities towards CHAFEA and DG SANTE.

Each Work Package needs to be led by a named partner who oversees contribution by collaborating partners. The overall management for the Joint Action is undertaken by a Steering Committee / Executive Board involving the Work Package leaders and the overall coordinator of the Joint Action. In addition, there shall be an Advisory Board consisting of external specialists who would advise on the coordination, evaluation and dissemination of the Joint Action, and give recommendations on specific objectives and outputs of the project.

The proposals must include budget proposal by each partner. The co-funding by the Commission is either 60% or 80% in case of "exceptional utility". Each partner must be responsible for 40% (or 20% in case of exceptional utility) of their own budget, but there is no requirement for each partner to contribute equal amounts to the Joint Action. He added that Member States' contribution can be provided in human resources, too.

Guy D'Argent added that CHAFEA will help preparing the applications if needed, and it would not reject applications per se, but would give constructive feedback and help partners rectifying the issues. The agreements between CHAFEA, partners, and members, should be signed by the end of 2017.

2.2 Experiences with other Joint Actions: Ingrid KELLER (DG SANTE.C1)

Ingrid KELLER shared some practical advice on the basis of two other joint actions run by DG SANTE: the *Addressing Chronic Diseases and Healthy Aging Across the Life Cycle Joint Action* (CHRODIS) and *Joint Action on Frailty*. She emphasised that a joint action has to have a strong policy focus, and the requirement for affiliated members to report back to the competent authority members aims to ensure that this requirement is fulfilled. She added that the one of the four mandatory work packages ('sustainability and link to national policies') further strengthens this angle.

She set out that the CHRODIS Joint Action made use of a governing board with all Member States invited (as well as WHO and OECD as observers) to make sure that it is steered in such a way that it can maximise EU value added. In addition, they also had a stakeholder forum where NGOs (including those who have not been nominated by official Member State partners) could share thoughts on the Joint Action's general direction.

In terms of practical suggestions, she argued that it is best to explicitly agree by the partners and members in advance on who would do which tasks and how responsibility is shared. This should then be followed by a calculation of partners' budgets based on human resource costs for the agreed functions and tasks. She also emphasised the importance of synergies between work packages and the need to agree on this at the beginning. Finally, she emphasised the need for good dissemination strategies including the use of digital communication channels and a final conference.

The Group thought that setting up a governance board for the Joint Action on Health Information, that is open to non-participating Member States and stakeholders, would be a good idea since this could help ensure that the Joint Action adds value at the EU level and that the Joint Action is aware of what other actors are doing in the field and can help facilitating wider synergies.

3. BRAINSTORMING – DESIGNING A JOINT ACTION ON HEALTH INFORMATION

3.1 Presentation by the Commission Philippe ROUX (DG SANTE.C2)

To kick-start the brainstorming session, Philippe Roux summarised the recommendations of the BRIDGE Health project, the views of the recent Working Party on Public Health at Senior Level meeting regarding the ERIC preparations, as well as preliminary suggestions by EGHI members on the scope of the Joint Action. Among these, some common themes emerged including the need for an effective coordination mechanism that can prioritise on-going health information generation activities, reduce the data collection burden on Member States, and identify gaps in the data coverage in high priority areas. Also emerged the need to better align health information with policy priorities; to make health information generation more sustainable; to improve the quality and Member State-coverage of the collected data; and to improve the interoperability of data and knowledge platforms.

Envisaging where the work might lead to, he outlined SANTE's vision of an ideal self-reinforcing cycle of health information generation where policy priorities influence the development of health information, which, in turn, can improve policies, also leading to new health information requirements. He pinned down the role of a future Member State collaboration (e.g. in the form of an ERIC) as developing technical solutions, helping develop policy relevant health indicators, and entering these into permanent data collections.

He reiterated that a budget of 4 million Euros would be made available for a 3-year period to put in place some of the core components to achieve these aims. He suggested that a mapping of health information generation to Member States' policy priorities should precede the work, followed by an agreement on the criteria to prioritise health information generation activities, and envisaged that the EGHI, with all Member States on board, could contribute to this work.

3.2 Proposal for the leader of the Joint Action

Belgium had expressed interest to become the leader of the Joint Action. Member State representatives did not oppose Belgium's expression of interest.

3.3 Discussion on the possible work packages led by the proposed leader of the Joint Action

Herman VAN OYEN (the Belgian EGHI member) continued chairing the meeting. He summarised ideas received so far for potential work areas as: reducing duplications, aligning health information generation with policy priorities, establishing criteria for prioritisation of health information generation and networks, capacity building, and developing protocols for interoperability of data networks. He emphasised that there is a need for the criteria to include policy utility and added that these activities could be the basis to develop a business model for the planned ERIC on Health Information. He invited further ideas on the scope.

The Group agreed on the broad aims and there was general support among participants for the initial set of work areas. It has been clarified by DG SANTE that all countries can (and should) take part in the Joint Action, and not only those who have been participating in the BRIDGE Health

project, since the Joint Action would not be a "BRIDGE2". Instead, the Joint Action would work towards designing an efficient health information coordination system in the EU, and towards rationalising data generation in all Member States, for which all Member States' input and strategic steer would be useful.

Several Member States reiterated the need to work with WHO and OECD to achieve the intended aims. Philippe ROUX confirmed that this is indeed the Commission's aim, as has been clearly expressed by Commissioner Andriukaitis, adding that the Commission would like to build on the mapping work already started by WHO's European Health Information Initiative (EHII). Claudia STEIN (WHO) confirmed that these aims are indeed compatible with the EHII's aims and welcomed the Joint Action's proposal to build on the EHII's mapping exercise.

The Group also expressed their wish to more closely collaborate with Eurostat, to contribute to Eurostat's legislative cycle, and for Eurostat to take over some of the high priority data collections and indicators which the Joint Action (and future ERIC) would develop and pilot. Marleen DE SMEDT (Eurostat) welcomed these aims and highlighted the example of the Eurostat-OECD-WHO joint data collections as best practice towards reducing the data collection burden on Member States. Recognising the need for indicators to be policy-relevant, she added that Eurostat would be very interested to see the outputs of the mapping of health indicators to policy priorities, hoping that the mapping exercise would also include qualitative and contextual data, which is needed to augment quantitative data to generate 'knowledge'.

Several Member State representatives expressed the need for the Joint Action to work towards creating a sustainable health information system in the EU and develop a Member State-led structure such as an ERIC, since the broad aims of the Joint Action cannot be fulfilled in the long run without creating a sustainable mechanism for health information coordination. In particular, some Member States have envisaged the Joint Action as a proof of concept for a future Member State collaboration (e.g. an ERIC) in the area of health information, and to test the feasibility of some of the ERIC's envisaged aims also demonstrating to all Member States the benefits of such cooperation. It has also been suggested that the business model for this future structure can build on the experiences of the Joint Action in collaborating with different institutions and organisations (such as WHO, OECD, and Eurostat).

Member States supported the idea of agreeing on a set of criteria, and validating this with the all-Member State Expert Group on Health Information, to facilitate prioritisation. The French delegate suggested that, for successful coordination, the Joint Action should separately analyse data demands by different international organisations (e.g. Eurostat, OECD...) as well as the supplied data by different national entities within countries (e.g. government, statistical institute...).

There was a strong push towards starting the actual work towards the sustainability, greater policy relevance and greater coverage of indicators as opposed to only plan future work or only issue recommendations. Several Member States suggested that they would only be willing to take part in the Joint Action if it would have concrete deliverables around reducing duplications in data collection, rather than just planning how it should be done. Philippe ROUX reiterated the importance of building on relevant projects in the field, so that the Joint Action could start enacting their applicable recommendations rather than having to do the work from scratch. Some Member States expressed concerns for losing the expertise of health information networks if these are not funded during the prioritisation phase, but others welcomed the idea of taking stock and reviewing which of the current health information generation activities are useful for continuation.

Some Member States suggested that the aims should also include mapping out health information inequalities since this could help attracting additional funds for reducing these inequalities – also contributing to the overall aims of the Joint Action (and future ERIC). Herman VAN OYEN suggested building on the expertise of health information networks and other EU initiatives (such as the health

system performance assessment initiative) in bringing together countries, establishing expert nodes, and reducing health information inequalities.

After lunch, the meeting continued by randomly splitting the Group into two sub-groups for more detailed workshop-type discussions to take place and to identify an initial set of work areas.

The subgroup (on the 2nd floor) identified the following work areas for the Joint Action:

- Mapping health indicators to policy priorities
- Establishing priorities in terms of policy relevance
- Prioritising health information networks to be sustained
- Improving the robustness of indicators in areas with high policy relevance
- Piloting tasks planned for a sustainable health information system under a future ERIC
- Working to establish conditions for better digital interoperability of health databases

The subgroup (on the 3rd floor) identified the following work areas for the Joint Action:

- Diagnosing the problem: the quality and robustness of health information
- Aligning health information with priorities
- Linking research and health indicator development
- Training and capacity building in health information generation
- Coordinating health information generation within countries

Grouping the ideas resulted in the following preliminary list of work areas:

1. Mapping currently produced health indicators to policy priorities and agreeing on criteria to identify duplications and gaps in the data coverage (in collaboration with WHO and OECD)
2. Prioritising health information generation activities (and networks).
3. Mapping capacity and building capacity where needed
4. Improving the coverage and robustness of health indicators in high priority areas
5. Producing health indicators more cost-effectively using electronic / administrative data
6. Finalising the blueprint for a sustainable EU Health Information System building on 1-5

It has been clarified that multiple Member States could be part of each work area, and each Member State could be part of multiple work areas. Some country representatives tentatively expressed their interest to take part in and/or lead certain work packages: DE (4), NL (1,2,4), SI (3,5), IT (1,5), FR (2,6), CZ (5) NO (1), MT (1,2,6), FI (4), GR. Others agreed to discuss further with their national governments and confirm participation in writing.

4. NEXT STEPS

The participants agreed that Herman VAN OYEN would circulate the set of proposed work areas within a few days, and Member States would have two weeks to refine the list and confirm their participation (including expressions of interest to lead work packages), so that Permanent Representations can make their official nominations by the 11th May deadline. Philippe ROUX reiterated his call for all Member States to review the objectives of the Joint Action and consider taking part in the initiative to be able to influence the Joint Action's strategic direction and maximise its utility to all Member States.

The participants tentatively agreed to meet twice in person before the September application deadline to develop the proposals further and to prepare the application.