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SANCO.C.2

**EXPERT GROUP ON HEALTH INFORMATION, MEETING ON THE POTENTIAL ERIC ON
HEALTH INFORMATION**

LUXEMBOURG 22 JANUARY 2014

SUMMARY REPORT

WELCOME AND INTRODUCTION

In his introduction the Chair of the meeting Stefan Schreck, Head of the Unit on Health Information of the Directorate-General for Health and Consumers (DG SANCO) of the European Commission, explained that the meeting was dedicated to the discussion on the potential health information ERIC (European Research Infrastructure Consortium) and that representatives of EU Member States and EEA/EFTA countries had been invited to participate. The key facilitators from the Ad hoc Core Working Group on the potential ERIC on health information had also been invited to participate and present the content of the scoping paper that was prepared as a background document to facilitate the debate. OECD representative had expressed interest in participating in the meeting and was also present.

HORIZON 2020: PERSPECTIVES FOR SETTING-UP OF RESEARCH INFRASTRUCTURE

Paul Tuinder from the Directorate-General for Research and Innovation (DG RTD) explained that calls for projects under Horizon 2020 include the design studies for ERICs. This is a competitive process, the deadline for submission of applications is in September this year and the budget available for all design studies is 15 million EUR. The evaluation of applications should be finished by the end of the year, thus the budget could be available from 2015.

The content of activities that could be performed in a design study proposal is:

- Scientific and technical work; concepts and engineering plans for the construction, as well as creation of final prototypes for key enabling technologies;
- Scientific and technical work enabling scientific communities to exploit the new facility from the start;
- Strategic work: integrate the new research infrastructure into the fabric of related facilities, identification of the best possible site, estimated budget for construction and operation, design of a workable legal and governance structure, planning of research services to be provided at international level.

Major subjects to be addressed when preparing for a possible establishment of a new research infrastructure are: sustainability of the research infrastructure; European value added (contribution to ERA); "real research infrastructure" and not a network; potential users defined and included in the definition of services that are to be developed by the research infrastructure; relation with existing research infrastructures and avoidance of overlap and duplication; key performance indicators developed to benchmark success of research infrastructure; identification of risks and possible mitigation.

EUROPEAN STRATEGY FORUM OF RESEARCH INFRASTRUCTURE (ESFRI): PRIORITIES FOR HEALTH RELATED RESEARCH INFRASTRUCTURES

Mr Murat Özgören, the Chair of the strategic working group on health and food of the European Strategy Forum on Research Infrastructure (ESFRI) presented the structure of ESFRI, its working methods and thematic areas dealt with by priority by the strategic working group on health and food. He also informed on the roadmap which ESFRI has established for the setting-up of new research infrastructure at EU level. He explained that ESFRI is in the course of reviewing the roadmap. This also includes prioritizing infrastructure on specific themes. The health and food strategic working group, following a workshop it held in October, has identified the following way for contributing to this review: developing concepts and ideas and their support routes, definition of next concrete steps, formation of ad-hoc working groups on thematic target areas for cooperation. Mr. Özgören proposed close interlinking between the strategic working group on health and food and public health experts be continued in the process of identifying priorities for setting up and further developing research infrastructure in the EU.

PRESENTATION OF A DRAFT SCOPING PAPER ON POTENTIAL ERIC ON HEALTH INFORMATION

The Chair briefly summarised the process since the last EGHI meeting in May 2013 when the option of the health information ERIC was first presented. The Ad Hoc Core Working group on the potential ERIC on health information was activated and proceeded on the initial discussions. The Council Working Party on Public Health at Senior Level on 8 October 2013 was informed of the initiated deliberations and also discussed the option. Following a debate in the SLWG Council conclusions on the "Reflection process on modern, responsive and sustainable health systems" were adopted on 10 December:

Council invites the European Commission and Member States to cooperate with a view to establishing a sustainable and integrated EU health information system, built on what has been already achieved through different groups and projects, such as ECHI-ECHIm projects, exploring in particular the potential of a comprehensive European health information research infrastructure consortium as a tool.

The key facilitators (*Peter Achterberg, Anke Joas, Antonio Sarria Santamera and Maria Hofmarcher*) from the Ad Hoc Core Working group on the potential ERIC on health information presented the scoping paper by focusing on the role, tasks and activities of the potential health information ERIC. This was complemented by the DG SANCO presentation of a possible governance structure serving as an attempt to demonstrate that certain concerns that had been raised in previous discussions on the possible health information ERIC can be appropriately addressed through the structure. The governance

structure had not been discussed within the Ad Hoc Core Working group as it needs to be carefully elaborated in a design phase.

One of the aims of the discussion was to see if there is any practical support to proceed into a design phase for the possible health information ERIC. The Chair additionally clarified that the scoping paper was just a background document to facilitate a debate of Member States. The scope and structure can be completely reshaped according to Member States' needs. Even though the Commission would welcome the involvement of all Member States in such an ERIC, it is up to any potential applicants to shape the content and the structure of any ERIC.

Prior to the meeting EU Member States and EEA/EFTA countries had been asked to give their opinion on proposed tasks in the scoping paper by grading them. 18 countries had provided their response. The answers revealed that there is interest in all suggested topics, with the strongest preference for the "Population health and health systems monitoring by common validated indicators". At the same time the overall results should not be over-interpreted as they do not necessarily reflect the level of involvement that countries are potentially considering, e.g. some countries interpreted the grading as the interest in the subject, while some interpreted it from the perspective of the potential involvement. The results should also not be interpreted as any kind of commitment for an ERIC, because at this stage there are still many open questions on the scope, budget and structure.

The extensive debate during the meeting showed that 11 countries (i.e. NL, SE, FI, MT, PL, PT, IT, DE, BE, ES and NO) are willing to be involved in a preparatory work /consortium for a design study application under Horizon 2020 call for projects and they can initiate the work at any time. Some other countries have not yet fully decided on their involvement at this stage. In addition those Member States that will not be involved in the design study or preparatory work for the design study welcomed to be updated and also consulted throughout the process. The discussion also revealed a number of elements important to Member States that would need to be further considered to produce a coherent proposal by a consortium.

The interest of Member States to continue the work in a design phase is however not a commitment to the future submission of the application for an ERIC. Nevertheless, the design study including the content, structure and budgetary implications would help Member States to take their decisions. Several Member States still believe that the extension of the European Centre for Disease Prevention and Control (ECDC) or a new EU Agency would be more appropriate alternatives to an ERIC. Although this is not a practical option at present the possible designing or establishment of an ERIC does not exclude this option in the future.

DG SANCO is willing to consider how the Expert Group on Health Information could be reshaped in view of potential ERIC.

The Ad Hoc Core Working group on the potential ERIC on health information will be informed on the conclusions of the debate during its meeting of 27 February 2014. The Commission cannot be involved in any preparatory work for an application for Horizon 2020 funds for a design study.