



EUROPEAN COMMISSION  
DIRECTORATE-GENERAL FOR HEALTH AND FOOD SAFETY

Public health, country knowledge, crisis management  
**Health programme and chronic diseases**

## NOTE OF THE MEETING

### STEERING GROUP ON HEALTH PROMOTION, DISEASE PREVENTION AND MANAGEMENT OF NON-COMMUNICABLE DISEASES 14 FEBRUARY 2019, BRUSSELS

#### Welcome and Introduction

Mr Seychell, the Deputy Director-General of DG Health and Food Safety (DG SANTE), chaired the meeting.

The participants were nominated representatives of the Member States, as well as of Norway and Iceland. In addition, colleagues from different Commission services, CHAFEA and the European Investment Bank attended the meeting.

The Chair welcomed the participants to the meeting. The draft agenda was adopted with a modification of starting with the discussion on the draft rules of procedure, which had been sent to the SGPP before the meeting. The Chair reminded that the draft rules of procedure had been discussed at the last meeting, they were also sent on 17 December for comments. Some Member States asked about the role of the SGPP in the context of the next Multiannual Financial Framework and the European Social Fund + in particular. In his response, the Chair reminded that the draft rules of procedure are based on the Commission Decision establishing the SGPP, which was adopted by the Commission last July. The rules of procedure only provide a framework for the functioning of the expert group, notably in relation to the meeting organisation. Generally speaking, all Commission expert groups have a horizontal approach for their operations.

As regards the next MFF and the proposal for the ESF+, the Chair stressed that as the negotiations in the Council and Parliament are ongoing it would be premature to consider the role of the SGPP in the next MFF.

Belgium asked to have more time to comment the draft rules of procedure and the Chair concluded that the SGPP would have still a possibility to provide comments. He also asked the Secretariat to review the draft rules of procedures and send them to the SGPP for comments.

#### Cooperation with the Expert group on health information

The Chair informed that, as agreed at the last meeting of the SGPP on 6 November 2018, the Expert Group on Health Information (EGHI) has prepared and agreed a Working Paper outlining three areas in which it can support the work of SGPP.

This includes support to the monitoring needs of SGPP in relation to their prioritisation work, advice on tools for best practice monitoring, and in the mid- to long-term support in identifying research gaps.

The Head of Unit of the Country Knowledge and Scientific Committees Unit from DG SANTE then presented the working paper and he also informed on the development of a monitoring mechanism on implementation of World Health Organization's Non-Communicable Diseases targets, which is needed to support SGPP in the future priority setting.

Following his presentation, a number of SGPP members welcomed the work of the EGHI and the synergies between the two groups. It was also stressed that overlaps with collection of health information and data of the World Health Organisation and the OECD should be avoided. In addition, it was suggested, that the EGHI could explore monitoring of transfer of good practices to allow for the assessment of the health impact.

Finally, the SGPP agreed that the SGPP members should receive the contact details of their national EGHI members and vice versa (this had already started with the request for consent to share contact details by the relevant SANTE units). This would ensure an effective flow of information between the two Commission expert groups and it would allow the EGHI to provide the necessary health information and intelligence for the SGPP.

The Chair concluded the discussion by asking the EGHI to keep the SGPP informed on the developments related to monitoring of implementation of NCD targets and the work of the EGHI.

#### Sustainable Development Goals: progress made in the EU

Ms Christine Wirtz, Acting Director for Directorate E 'Sectoral and Regional Statistics' and also Head of Unit for 'Agriculture and Fisheries' in DG ESTAT inform the SGPP on the process related to the EU monitoring of SDGs, and in particular, the health related SDG 3.

The Chair concluded that the SGPP has a key role in supporting Member States meeting the SDGs, and in particular, the UN 2030 Goal and Target 3.4. This target aims to reduce by one-third premature mortality from to promote mental health and well-being.

The SGPP welcomed in the initiative by DG ESTAT, and asked to be informed also in the future on the progress made by the EU towards these international goals.

#### Update on the selection of best practices and implementable research results

The next agenda point focused on the regular work of the SGPP, notably on best practices and implementable research results.

The Chair reminded the SGPP that the area of nutrition and physical activity had been selected by SGPP as a priority area for implementation for 2018. At the market place in Ispra in March 2018, Member States representatives had an opportunity to learn from 12

evaluated best practices, which were candidates for a possible transfer to other Member States or further scaling-up.

The Commission has secured significant funding from the Health Programme for this. The implementation of the highest ranked three best practices – i.e. monitoring of food reformulation, framing the marketing to children of alcohol and foods, public procurement to support healthy diets – is planned to be supported through a Joint Action. The Commission funding would come from the 2019 work plan of the Health Programme; the Programme Committee will vote on the draft work plan on 14 March 2019.

In addition, a call for proposals to implement the experience of the Danish Wholegrain Partnership Program has been launched on 20 December 2018 and is open until 10 April 2019. For the remaining best practices, e.g. on creating healthy school environments, funding opportunities such as the ERASMUS+ programme are being explored as well.

A representative from the Unit on Health determinants and international health, DG SANTE, then took the floor to provide some further details on the planned implementation of these best practices selected by the SGPP and urged the Member States to express interest and commitment.

The second area on best practices was then discussed. Last November the SGPP had decided that the focus on best practices in 2019 would be on mental health. Since then, DG SANTE has selected pertinent practices that have been collected by the “Mental Health Compass” action. In addition, DG RTD has collected implementable research results in the field of mental health.

The Chair pointed out that all pertinent practices and implementable results were presented in poster format during the meeting. A representative from DG RTD explained how the implementable research results were selected and highlighted the topics addressed in these posters.

After the meeting, the SGPP members will receive an online questionnaire along with a book featuring abstracts of the presented practices and implementable research results to be able to express priorities among the presented practices and research results. As usual, the practices with the highest number of votes are planned to be invited to a marketplace on mental health best practices.

In the following discussion, Member States suggested that they could be involved in an earlier stage of the best practice selection by e.g. providing key words for the search / call.

The Chair concluded that DG SANTE welcomes suggestions for improving the usefulness of best practices and research results for the Member States. He asked the Secretariat to reflect these comments and suggest a way to consult the Member States earlier on.

The third area of best practices was on digitally enabled person-centred integrated care services. Member States had the opportunity to learn more about selected best practices

in this field in the marketplace workshop in December 2018. In the following online survey, Member States expressed their priorities among the practices presented.

A representative from the Unit on Performance of national health systems, DG SANTE, presented the results of the Member State survey on their preferences and the resulting prioritisation of best practices. It is planned to support the transfer of the highest-ranking practices through a Joint Action. These include local ICT-supported strategies to manage chronic conditions in the Spanish Basque Country and in Catalonia, a population-based integrated care model from Germany and the digital road map for integrated care from Southern Denmark. The Commission funding would come from the 2019 work plan of the Health Programme; the Programme Committee will vote on the draft work plan on 14 March 2019.

The Chair then informed on the fourth and final area of best practices. DG SANTE and JRC had launched an open call for practices conducive to reaching the Sustainable Development Goal 3, target 3.4 on reducing mortality from non-communicable diseases on the best practice portal between November 2018 and February 2019. In total, we received 53 practices from 16 EU Member States.

More than 50% are actions to promote health and prevent non-communicable disease, chiefly promoting healthy lifestyles for children, healthy diet and physical activity. Other topics include mental health cancer and cardiovascular diseases, other diseases (e.g. autism and Parkinson's disease) as well as crosscutting issues like frailty prevention and medication management. The submitters represent a large variety of organizations, most of them being national or sub-national non-governmental organizations, but also regional governments, academic organizations and private companies.

The Chair concluded by saying that the SGPP's key area of work has been from the beginning prioritisation, selection and implementation of policy interventions and this has proven an effective approach.

#### Agreed policy actions – updates

1. Member States' contributions to the sustainability of Orphanet, the European portal and database for rare diseases (survey responses and potential next steps)

The Chair introduced this agenda item by reminding of the explorative exchange on the future of Orphanet at the SGPP meeting in November, based on a paper from France on options for Orphanet's sustainability. The Secretariat had followed this up with an eSurvey on this topic, combined with questions on the envisaged uptake of the new European Platform on Rare Diseases Registration hosted by the JRC.

Head of Unit C1, DG SANTE informed on the outcome of the eSurvey on Member States' potential contribution and support to the core activities of Orphanet. Several of the 14 Member States that replied to the survey expressed a readiness in principal to contribute to the core functions, either in kind and/or through a financial contribution. The vast majority of these 14 Member States expressed overall appreciation of Orphanet, and continued support for national activities already undertaken. Some countries indicated their administrative rules stand in the way of supporting work in another

country, be it financially or in kind, and some countries mentioned the lack the resources to contribute in it.

He noted that Orphanet has received EU funding for various activities since 2000. Continuous Commission funding is, however, not compatible with EU financial regulations. Therefore, it is important to understand Member States' interest and possibilities to contribute to the Orphanet.

He also reminded that the current direct grant to INSERM (as coordinator of Orphanet) includes a specific task to 'adopt a sustainability model' for Orphanet. Against this background, he suggested that Orphanet could further clarify the kind of contributions Member States could make. These descriptions could be included in a draft 'Framework Agreement' which would be a document providing details of such contributions for the future sustainable organisation of Orphanet. He concluded by suggesting that once Orphanet will have prepared such draft Framework Agreement, the SGPP could be consulted on it in June 2019. Once agreed, Member States could sign up to elements of this framework agreement befitting their specific needs and possibilities.

Overall, Member States' representatives expressed support for this approach, again acknowledging the added value of Orphanet. It was also stressed that to allow timely consultation of all relevant authorities and actors in Member States also about possible financial consequences, a more detailed proposal will need to be shared well in advance of the next SGPP meeting.

The French SGPP representative agreed the Orphanet direct grant would indeed allow for work on developing a new Framework Agreement on Orphanet. She offered to present a draft proposal for discussion at the next SGPP meeting.

The current grant beneficiaries, however, do not include representatives from health ministries. It was suggested that, as a following step, more detailed reflections on health ministries' contributions to Orphanet could be channelled via a temporary subgroup.

Some Member States representatives suggested that such a subgroup could also address broader issues with regard to rare diseases. The Chair invited Member States to indicate their interest, but reminded of the purpose of SGPP subgroup is to focus on very specific questions within a time-limited mandate.

## 2. EU Rare Diseases Registry Platform: Member States' envisaged uptake of and support for infrastructure and services (survey responses)

Acknowledging the good collaboration with DG SANTE, Head of Unit F1 from the Joint Research Centre (JRC) introduced the future European Platform on Rare Disease Registration as a new step forward to end fragmentation of the over 600 different registries currently existing across Europe. It aims to create the critical mass of information and data needed to tackle the burden of rare diseases, which affect over 30 million patients in Europe. The new Platform will incorporate two existing European registries: the congenital anomalies EUROCAT database, and the database of the Surveillance of Cerebral Palsy in Europe (SCPE) network.

The JRC's Head of the team working on the Rare Disease Platform gave a short overview of platform's objectives and components. It will bring together the wealth of data currently scattered across Europe and set EU-wide standards. The JRC will make the platform's infrastructure openly accessible and provide training for people either working on existing registries or aspiring to create new registries.

The JRC has developed a special infrastructure that makes existing registry data findable, accessible, interoperable and reusable across the EU. It is one of the main functions of the platform, facilitating dialogue and data exchange between the registries. The other two key components of the platform are its central metadata repository and a pseudonymisation tool.

The vast majority of the 14 Member States that had replied to the survey were supportive of joining the platform, using the infrastructure and services offered, and contributing to the envisaged research and studies. A similar positive picture emerged as regards the willingness to disseminate information about the platform. Those Member States responding more hesitantly referred to the fact that the platform is not yet operational – thus making any advance judgement difficult- or to their current use of European Reference Network (ERN) registries. The new platform will collaborate with these registries.

Approximately half of the responding Member States envisage to allocate resources to those registries in their country that will join the platform and use its European standards, or to support those registries for instance by enabling them to attend the training provided by the JRC. Again, some countries indicated it was difficult to provide clear indications before the platform was operational. Others who responded negatively referred to decentralised responsibilities or cited financial reasons. The JRC stressed all components of the new platform will be available free of charge to all interested registries. The fact that two-thirds of responding Member States indicated an interest to sign a Memorandum of Understanding with the JRC is very encouraging. The actual launch of the platform is scheduled for the Rare Diseases Day on 28 February.

### 3. Proton Therapy Subgroup

The Chair then turned to an update of the SGPP's subgroup on proton therapy centres. A representative of the European Investment Bank to provide an update on the progress made in the first phase of the work (the fact-finding and evidence review).

Director from DG SANTE informed the SGPP on a recent conference SAMIRA that had discussed the availability of medical radioisotopes. A number of Member States took the floor expressing their interest to explore in the SGPP the issue of availability of medical isotopes. Some also mentioned ongoing national discussions on whether and how proton therapy should be included into the portfolio or reimbursable therapies.

Following the discussion, it was decided that the availability of medical isotopes would be on the agenda of a future meeting of the SGPP. This agenda point would be prepared with colleagues from DG Energy.

### Possible new policy actions: proposal for a consultation process between CHRODIS PLUS and the Steering Group

The Chair introduced the agenda point by informing that CHRODIS PLUS is the second joint action in the field of non-communicable diseases co-funded by the third Health Programme.

The Joint Action seeks to consult the Steering Group in preparing one key deliverable which is a policy-level position paper concerning the European added value of cross-country collaboration in the field of Non- Communicable Diseases.

Mr Giovanni Nicoletti from the Italian Ministry of Health made a presentation on the CHRODIS PLUS, specifically the work package on “sustainability and policy implementation” and ideas for such consultation.

A number of SGPP members supported his suggestion for the particular case of CHRODIS PLUS, but also more generally, that results from joint actions could be useful for the SGPP’s reflections and prioritisation of activities. However, some SGPP members felt that endorsing results would go beyond the SGPP’s mandate.

The Chair concluded that the SGPP agreed to enter in a structured dialogue with CHRODIS PLUS, as it is imperative that the members of the SGPP who represent the Ministries of health are well informed about the planned outputs of the joint action at an early stage with a view to ensuring effective policy implementation. However, it was agreed that the SGPP would not be in a position to “endorse” the outputs but rather “take note” of the outputs as adequate. Finally, it was discussed that the exact timeline of the planned online survey and a possible workshop would be agreed later.

### European Semester: state of play

The Head of Performance of National Health Systems Unit informed the SGPP that European Semester also covers health because health systems are closely linked with the debate of cost-effectiveness of public expenditure and health sector should not be left out from discussions on macro-economic coordination. He mentioned that the Principle 16 of the European Pillar of Social Rights reiterate the importance of timely access to affordable, good quality health care which is also something that the European Semester takes into account.

He described the conceptual framework used in the European Semester to analyse health systems, and explained the future steps of the Semester. He then informed about the investment focus of the European Semester in 2019 and future changes when EU funds will be more closely aligned with the Semester analysis. The recommendations of the Semester will be used to define the outcomes of Cohesion Policy Funding. He also briefly introduced the study on the use of Cohesion Policy Funds in health in the period 2014-2020, where more than 7000 health projects had been mapped.

During the discussion, a comment was made that the use of the funds for specific Member States is dependent on the country report of the individual Member State (whether the Commission will prioritize certain areas). Different Member States would have different problems and challenges.

The Head of Performance of National Health Systems Unit stressed that the funds are aligned to support a certain number of structural changes that are necessary to address some of the challenges that the Semester has identified. He pointed out that as regards macroeconomic developments in health there are specific analyses of health systems in the Country Reports and specific recommendations where Structural Funds could be used.

In the context of cost-effectiveness of investments in health, he mentioned that the Semester has always had a holistic approach when it comes to socio-economic analysis. He argued that effectiveness is an important indicator that needs to be a part of the analysis and that an effective health system protects and improves the health of the population. Effectiveness is not only at the level of fiscal sustainability, it also includes quality and accessibility and this narrative is shared across the Member States. He concluded by saying that the Structural Funds have always supported health policies so there is no competence issue there, it is shared management.

#### Any other business

The Romanian SGPP member informed that one of the key themes of their Presidency is access to medicines. In this context, she raised the issue of access to orphan drugs. She mentioned that there are already some groups of like-minded countries and it would be interesting to share such information in the SGPP. A number of SGPP members took the floor stating that exploring the situation across the EU, as there is no legal basis for joint procurement as such.

The Chair concluded that there is a need to understand first underlying issues, which the different Member States are facing. It was agreed that the SGPP could look into this topic but there should be an endorsement at the political level first.

The Finnish health attaché informed on their Presidency plans. The main theme will be the economy of well-being. It is planned that there will be Council Conclusions on this issue. As regards specific health themes, he mentioned digitalisation, mental health at the workplace, nutrition, health security including antimicrobial resistance pharma

The Chair informed that all Presidencies are welcome to use the SGPP as a sounding board as the SGPP can be a useful resource, which Presidencies can benefit from

Finally, the Chair asked for any new topics for the SGPP, and antimicrobial resistance, dementia and patient safety were suggested. In particular, the follow-up of Council Conclusions in these areas could be looked at.

#### Conclusions and next steps

The Chair concluded the meeting by thanking the members of the SGPP for the lively discussions. He reiterated the role of the SGPP as an important strategic forum for the EU Member States, the Commission services, the EU agencies and the European Investment Bank. He reminded that on the following day there will be a joint meeting with the Horizon2020 programme committee for the first time and that the dates for the next meetings of the SGPP will be sent by mail.