Final Minutes

Meeting

Sub-group on Cancer under the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases

4 June 2021

On 4 June 2021, the Sub-group on Cancer under the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases held a virtual meeting, jointly chaired by DG RTD and DG SANTE. The representatives of 25 Member States plus Norway attended the meeting together with a number of Commission services¹.

General Update on Horizon Europe's Mission on Cancer

DG RTD updated participants on the Mission on Cancer, whose implementation plans have been submitted for political validation by Commissioners s in the course of June. A decision on the full implementation of Missions will be taken by the end of the month, with a Commission Communication on Missions foreseen for the autumn. the Mission Work Programmes is planned to be adopted during June, with the resultant opening of calls for 2021.

A session on Missions will also be held within the European Research and Innovation Days² on 23-24 June.

Europe's Beating Cancer Plan and Implementation Roadmap

DG SANTE informed participants on the state of play of the Europe's Beating Cancer Action Plan. In the middle of the month, a meeting of the Special Committee on Beating Cancer will take place in the European Parliament to exchange views on National Cancer Control Plans. The Commission Implementation Group has regular meetings scheduled to follow the implementation of the Europe's Beating Cancer Action Plan and the Mission on Cancer. The Stakeholder Contact Group, who discuss, advise and collaborate on implementation, had their first meeting at the end of May. There is evident high interest in the Europe's Beating Cancer Action Plan from Member States with attendance of 320 online participants, each of whom will choose which of the four pillars on which to focus. Cancer Screening Recommendations, which were adopted by the Council of Ministers in 2003, will be updated next year.

DG ENER then informed participants about the SAMIRA Action Plan³, which is a part of the Europe's Beating Cancer Action Plan. This included an overview of the main actions as well as the potential collaboration with the sub-group.

DISCUSSION

The Chair gave the floor to Member States.

¹ Directorates-General represented included Energy (ENER), Employment, Social Affairs and Inclusion (EMPL), Environment (ENV), Research and Innovation (RTD), Reform (REFORM), as well as the Joint Research Centre (JRC).

² https://ec.europa.eu/research-and-innovation/en/events/upcoming-events/research-innovation-days

³ SAMIRA: Strategic Agenda for Medical Ionising Radiation Applications (europa.eu)

Spain asked if more entities could be part of the stakeholders group, and how participants would be assigned among the thematic groups, whilst stressing the need for transparency in terms of interests. DG SANTE responded that for thematic groups, membership was not open, as stable membership is needed. In terms of thematic groups, the survey will identify interests.

Finland asked about the future landscape according to SAMIRA and specifically from the perspective of radiation and other treatment alternatives as to whether an increase or decrease was foreseen. DG ENER responded that they have undertaken a scoping study, which has identified many new aspects. In terms of numbers, the future will see an increase.

Spain asked about the invitation to the representative members for the Q&S group for SAMIRA; nominations will be requested in the next weeks.

Denmark asked if this network were working for European treatment and/or research networks with equal access to proton/ion treatment; this aspect is within scope, and it is expected to be part of the research roadmap.

Network of Comprehensive Cancer Infrastructures

An initial orientation on one of the flagships of the Cancer Plan was presentation, namely EU support to establish Comprehensive Cancer Infrastructures in each Member State and to their networking at EU level. It was explained that this flagship builds on recommendations of the Joint Actions on Cancer Control – CanCon and iPAAC – as well as on recommendations of the Mission Board on Cancer.

The Chair of the Mission Board on Cancer made a presentation summarising the current status and highlighting the position of Comprehensive Cancer Infrastructures (CCIs) within the Mission. Specifically, Recommendation 10 of the Mission on Cancer is to set up a network of such centres within and across all EU Member States to increase quality of research and care. This update was complemented by a presentation from iPAAC, the Innovative Partnership for Action against Cancer. It is proposed for an EU Network of CCIs to build upon existing initiatives, with each CCI taking into account the structure, governance, and geographical context; to liaise with the (EU-wide, national or regional) cancer and screening registries and with the European Reference Networks dealing with rare types of cancer; and to integrate data collection to allow quality assurance and data consolidation.

EUHealthSupport presented the results of the quick scan of stakeholders in research and care which revealed that almost all Member States have at least one cancer infrastructure that integrates scientific research and clinical care. Several already meet the criteria of a CCI and are accredited as such according to international standards; other identified cancer infrastructures show potential to develop towards becoming a CCI. In addition to hospitals, about half of the infrastructures include primary care centres, centres for community services and hospices. Regarding their involvement in scientific research, most of the reported cancer infrastructures not only conduct clinical trials, but also engage in human sciences and epidemiological studies. All reported infrastructures in EU Member States provide education to health care professionals; many also offer information and education to patients and citizens.

DISCUSSION

The Chair gave the floor to Member States to reflect on possible approaches and priorities for implementation and consider the usefulness of creating a first thematic group on this initiative within the cancer subgroup. Following broad-ranging discussion there was unanimity as to the need for such a thematic group. DG SANTE will ask Member States to nominate experts who wishes to be.

Romania asked if there would be support for centres to reach the required standards to be an accredited CCI and to reduce differences between Member States. DG SANTE responded with identification of a palette of support measures, including the launch of a preparatory action start as soon as the Work Programme is adopted, complemented by Horizon Europe and the Mission on Cancer.

Ireland, supported by Sweden, asked how important equity of access within individual countries would be in defining CCIs; this is rated highly important in the Mission on Cancer, ensuring that 90% of eligible patients have access to such Centres by 2030. **Portugal** considers that centralised cancer registries are important to share data and that they will help to reduce inequalities, especially in rare cancers.

Italy asked about the word 'specific', specific for cancer in general or specific for any cancer diseases/types; it was confirmed that the definition is very broad.

Spain raised the vastly different regional and national structure of healthcare systems in Member States. It was explained that the CCIs are intended not to replace but to complement existing structures and situations in Member States and that a regional or federal approach can be accommodated. Sweden opined on the benefits of a network rather than a CCI; in Sweden, regional networks comprise all regional healthcare outlets, which then link to teaching universities, which is considered optimal to connect with cancer patients. Finland explained their national situation, with high integration of research and involvement of patient advisory boards, and a network of five university hospitals supporting the national cancer centre. Finland stressed that benchmarking and collecting data is key and explained about their universal and well-established electronic health records. **Denmark** noted that regional and national networks will be key for outreach, however, the ambition to be accommodating of the national situation should still include multidisciplinarity and the linking of care and research.

Portugal added that cancer centres need to be multidisciplinary and to be linked to research; they consider the mandatory integration of reference centres in order to improve the quality of cancer care and to increase patient access to innovation. Portugal asked how Member States would be helped to build and expand the existing networks. DG SANTE explained about how ERNs could help cross-border, for example in rare cancers, as well as support for knowledge exchange and exchange of good practice. The JRC explained how they could support and then shared links to the EU Platform for Rare Diseases Registration⁴ and to the European Cancer Information System⁵. **Austria** added that an ERN on childhood cancer⁶ already exists. Italy shared the historical perspective with the rapid evolution of cancer care fuelling the need for new knowledge, thus the need to invest in European cooperation and to be forward looking. Portugal commented that data protection legislation and quality registries are issues that should be addressed. **Ireland** concluded by proposing a combination approach, i.e. a few specialist CCIs in geographically-distinct regions, with a broader network integrating them.

Italy described their experience of networks and the challenges faced with the current situation. Italy also stressed the importance of quality of care to all patients, which requires new solutions and networks. There are many models, but work should be undertaken at the European level for the highest quality to reach the highest number of patients, including the sharing of best practice.

Denmark asked about the timeline and how development would be stimulated. DG RTD responded that countries had innate interest in such development and that the EC

⁴ https://eu-rd-platform.jrc.ec.europa.eu/ en

⁵ https://ecis.jrc.ec.europa.eu/

⁶ ERN PaedCan | European Reference Network for Paediatric Oncology (ern-net.eu)

accepted that there are many different models. They identified examples of the available support to further developing the networks, such as twinning. DG SANTE complemented this by citing financial instruments for such support, e.g. the sharing of best practice, technical support. **Ireland**, supported by **Spain** and **Romania**, asked if there was any particular emphasis on types of accreditation process, as the pre-existing OECI model may not be fit for purpose for all countries or contexts; they requested information on the various models which work and which do not work. DG SANTE stressed that no system was being imposed in Member States but that the EC was open and flexible to suit national contexts. **Denmark** also stressed the need for clarity and transparency in communication, to show how everything fits together, which will ultimately be key for better survivorship.

Belgium shared their priorities, being work on sarcoma and secondly, on networks and structures for large multi-country clinical trials (e.g. comprehensive gene panel testing).

Spain asked if there would be specific actions addressed just to those accredited CCIs, and if the CCI concept could be addressed within a large non-thematic oriented hospital/research centre.

Following the agreement to establish such a thematic group, both **Austria** and **Portugal** asked if specific national experts could be nominated.

Cancer Inequalities Registry

DG SANTE then presented a flagship initiative of the Europe's Beating Cancer Action Plan, the establishment of a Cancer Inequalities Registry, whose aim is to identify trends, disparities and inequalities between Member States and regions. It was noted that addressing inequalities is also one of the objectives of the Mission on Cancer. The Registry will build on existing expertise and data, collaborating closely with a wide range of stakeholders. The DG SANTE presentation was complemented by that from the OECD⁷. The three potential elements were identified of a cancer inequalities registry, closely linked to ECIS and possibly including a dashboard, regularly updated country profiles based on the four pillars, and an overall report on the state of cancer prevention and care in the EU. The draft version of such a framework will be discussed at the next meeting of the subgroup.

DISCUSSION

The Chair gave the floor to Member States to present their opinions on the overall outline for and scope of the Registry, the elements proposed and on any additional data collection needs, as well as whether an ad-hoc technical network needed to be established. There was unanimity regarding the need to establish another technical group.

Italy considered it best to discuss the topic in a smaller group of epidemiologists and considered the exercise to be much more complex than the name registry implied. They stressed the need to integrate several sources of expertise. **Norway** supported Italy's wish to set up an ad-hoc group with experts to discuss the content of this registry and noted the lack of sufficient information currently on what kind of data is available.

Norway, supported by **Spain**, added that it was also important to consider cross-border data sharing. **Norway** also raised the issue of GDPR, with **Austria** and **Portugal** commenting that those working on the European Health Data Space are also dealing with the challenges of GDPR. DG RTD responded with the need for pragmatism using the currently available high-level data, which does not involve cross-border data exchange, but stated that GDPR will be very relevant later. It was explained that in order to avoid duplicate work, the sub-group had been formed involving both research and health and

 $^{^{7}\ \}text{htt} \underline{\text{p://www.oecd.org/els/health-systems/health-care-quality-and-outcomes.htm}$

working together with other stakeholders. The OECD thanked participants for the very good feedback and stressed the need for different types of expertise.

Slovenia commented on a book recently published, where the experience could contribute to the development of proposed reports on inequalities in cancer⁸.

Norway asked about the co-creation of these structures with the different cancer initiatives and fora to ensure a collaborative environment and to avoid parallel collaborative structures. DG SANTE responded that all involved stakeholders would be brought around the table following the meeting to see who could contribute where. The OECD added that they count on the EC to provide this enabling infrastructure.

Regarding the proposed country reports, **Belgium** asked if additional contributions were required from the countries, to which the OECD replied that it was still being discussed how data will be collated, but that it would be funded under the EU4Health Programme and addressed at the European level for optimal coherency.

Germany commented on the high ambition of the proposed registry and asked for an overview of existing data and which data and indicators are currently used for ECIS, for other databases and the envisaged registry framework including addressing their validity, comparability and EU-wide coverage. Regarding the dashboard, they requested information regarding the possible structure, membership and mandate, and suggested following a modular approach.

AOB

Participants were informed of the upcoming invitation-only UNCAN.eu webinar on 17 June. It was noted that the launch⁹ of the EC Knowledge Centre on Cancer will take place on 30 June from 14.00-15.30, to which participants were invited.

Spain, supported by **Sweden**, expressed their appreciation for the approach of 'one-page documents' to summarise the issues to be discussed in the sub-group.

DG SANTE will host copies of the presentations, and a link¹⁰ will be included in future agenda.

The meeting was concluded by identifying the dates of future meetings until the end of the year. The next meeting is foreseen for 8 July at 10.00 when discussion will take place on Workplans of Horizon Europe on Missions and of EU4Health programme. The following meetings are scheduled for the rest of the year: 23 September at 14.00, 12 November at 10.00 and 14 December at 14.00. Participants were thanked for their valuable and enriching input.

⁸ Social Environment and Cancer in Europe - Towards an Evidence-Based Public Health Policy | Guy Launoy | Springer

⁹ https://ec.europa.eu/jrc/en/event/conference/launch-ec-knowledge-centre-cancer

¹⁰ https://ec.europa.eu/health/non communicable diseases/events en#anchor3