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Call to Action

from the Expert Conference on Oncology

“Modern Cancer Control: Saving Lives through Smart Solutions”

within the Czech Presidency of the Council of the European Union

on 13–14 July in Brno, Czech Republic

(Draft)

Cancer is the second leading cause of mortality in EU countries after cardiovascular diseases. In 2020, 2.7 million people were expected to be diagnosed with cancer across the 27 EU Member States, and 1.3 million to die from it. By 2035, cancer cases are estimated to increase by almost 25 %, which means that without decisive action, cancer may potentially become the leading cause of death in the EU. Over 40 % of cancer cases are preventable, and mortality can be reduced through earlier diagnosis and improved care. Cancer has a negative impact not only on individual health, but also has considerable social and economic consequences, which makes it an immediate threat to our society. The COVID-19 pandemic has caused delays and disruptions across all facets of care, including a dramatic impact on the availability of cancer care. Especially during the peaks of the pandemic, access to cancer screening diagnosis, treatment and care have been delayed in several European countries which also further exacerbated socio-economic and health inequalities. Further deterioration of the situation could be expected in the context of the war in Ukraine.

The Czech Presidency organized the Expert Conference on Oncology: “Modern Cancer Control: Saving Lives through smart solutions”, which took place on 13 – 14 July 2022 in Brno, Czech Republic, to continue joint efforts on reducing the suffering caused by cancer. Moreover, it reinforced EU efforts on one of the key pillars of the strong European Health Union – the Europe’s Beating Cancer Plan - and on the objectives of the EU Mission on



Cancer, in accordance with the Statement from the Trio Presidency of the Council of the European Union of 3-4 February 2022 in Palais d'Iéna, Paris.

Participants, i.e. oncology experts of the EU Member States, including delegates from national oncology and health information organizations, representatives of leading European initiatives on cancer prevention, senior representatives of the European Commission and of the World Health Organization, and last but not least, representatives of European patient organizations, were invited to share their knowledge and national experiences on several interconnected flagship initiatives, which are linked to the leading European policies in the fight against cancer and need to be better understood in order to truly address the selected challenges of modern cancer control in Europe.

To ensure in-depth exchanges and to achieve ambitious outcomes in order to accelerate progress, the Czech Presidency of the Council of the European Union selected a few key EU flagship initiatives as Conference topics. These represent pressing issues especially with regard to persisting implementation challenges.

Particularly, the Conference focused on the following interlinked topics:

1. Comprehensive Cancer Infrastructures
2. Future of cancer registries and European Health Data Space
3. Improving early detection of cancer and screening schemes in EU

Participants of the Conference discussed the following points, of which several received broad support,

- reaffirming their strong support for the key pillars of the EU fight against cancer included in the Europe's Beating Cancer Plan and the objectives of the EU Mission on Cancer,
- and taking into account the output documents of the European Meeting of the French National Cancer Institute (INCA), which was organized under the French Presidency on 3 and 4 February 2022 in Paris, i.e. the Political Declaration and the



list of action against cancer recommended by a panel of European stakeholders in the framework of the working groups led by the French National Cancer Institute, have come to the conclusions formulated in the presented document, which aim to help finding ways to move forward identified interlinked EU flagship initiatives, accelerate their progress and bypass obstacles.

Please note, that the opinions expressed in this document are those which received broad support of the participants. They do not purport to reflect the opinions or views of the Member States. None of the conclusions provided is of a legally binding nature. The document will serve as a background document for further discussion by the ministers and eventually expressing their support at the Informal Meeting of the Ministers of Health on 6 - 7 September 2022 in Prague. Before this meeting, the content of the Call to Action will be reopened to Member States for further comments.



1. Comprehensive Cancer Infrastructures

Access to high quality cancer care, integrating prevention programmes, clinical care and research, still varies significantly not only across Europe but also within individual Member States. This situation is resulting in differences in treatment outcomes, survival rates and quality of life after treatment. These disparities need to be addressed so that every patient in every Member State can benefit from the equal access to high quality cancer care including the latest innovative diagnostics and treatments.

In response to these challenges, the Commission proposes to establish an EU-wide network of Comprehensive Cancer Infrastructures (CCIs) linking recognized National Comprehensive Cancer Centres and other existing cancer care networks in each EU Member State.

These CCIs have been identified in almost all EU Member States. However, follow-up efforts are needed to discuss the concept, methodology, and activities of CCIs, as well as to explore whether and how these CCIs could become part of an EU-wide network.

The methodology of recognizing CCIs should consider defining an outreach area for each CCI and the range and scope of services in the areas of prevention, diagnostic, treatment, supportive and palliative care, survivorship, research, education and patient involvement. In addition, this should include monitoring and evaluation of the quality of care, including patient reported outcome measures (PROMs) and patient reported experience measures (PREMs).

Given that the most advanced technologies cannot be available in all CCIs in all Member States, a functional cross-border collaboration could be important to ensure equal access to such healthcare services.

EU initiatives reflected in the Europe's Beating Cancer Plan and the EU Cancer Mission, including establishing an EU network of CCIs by 2025, will thus significantly contribute to the improvement of patients' access to quality-assured diagnosis and treatment including best practice, state-of-the-art therapies and clinical trials. The integration of the



recommendations and goals of the Europe's Beating Cancer Plan and the EU Cancer Mission in the concept of the CCI Network is key to ensure that the resulting innovative outcomes can reach all patients across Europe.

Taking the above-mentioned considerations into account, we call on the European Commission, EU Member States and all stakeholders to consider and support the following:

- Support Member States to drive forward the actions required to meet the ambitions set by Europe's Beating Cancer Plan, encouraging the uptake at national level to make progress towards the achievement of the agreed goals.
- Support and facilitate the creation of an EU Network of CCIs and the development of CCIs in each Member State (for larger countries one CCI per 5 million inhabitants is recommended), in an effort to ensure equal access to high-quality cancer care and multidisciplinary oncology services provided by CCIs to all EU citizens, while different national formats of CCIs are possible, they should always include intensive linking and collaboration effort within and between existing Comprehensive Cancer Centres (CCCs) and Comprehensive Cancer Care Networks (CCCNs), across levels of care.
- Develop a framework with standards for the assessment of comprehensiveness, quality and accessibility of cancer care and patient centeredness, and consider using existing European Guidelines and Quality Assurance Schemes as support for Member States.
- Further develop the concept and methodology of how these CCIs could become part of an EU network of CCIs, including by closely following the progress of and implementing findings from the ongoing JA CraNE.
- Facilitate awareness of the CCIs networks existence, purpose and of the principles of patient's centeredness care among the patients, carers and health care professionals.



- Support an efficient and meaningful interconnection between an EU Network of CCIs and cancer related European Reference Networks (ERNs), including the new networks of expertise on more common types of cancer and cancer conditions still to be established, as well as European Research Infrastructures and relevant federated infrastructures, in particular for cancer images and genomics, in order to extend cross-border cooperation in cancer prevention, care, research, training of health care professionals and education for cancer patients, survivors and families/carers.

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2. Future of cancer registries and European Health Data Space

Europe needs sustainable and value-based health systems that are driven by high-quality, comparable data. Such systems should consider the outcomes that matter to people and patients and be able to collect and analyse them in real time.

Comprehensive data and information are needed to provide support to cancer patients and improve cancer outcomes, to effectively design and evaluate cancer policies, and to conduct cancer research in order to keep improving all parts of the cancer control continuum. Strong support of all stakeholders is needed to improve cancer data infrastructures and their use, harnessing modern tools including artificial intelligence and high-performance computing. Traditional cancer registries, which for a long time have represented the backbone of cancer information, should be an important but not the sole part of a modern cancer information system. Providers of cancer care need to share data easily to provide a truly patient-centred care within comprehensive cancer infrastructures. These data need to be shared in line with clear technical and legal principles, in particular data protection rules, to support research and policy making at both national and EU levels. EU wide policies including the discussed proposal for a Regulation on European Health Data Space, and resources, such as the European Cancer Information System, European Cancer Inequalities Registry and the federated European infrastructures for cancer images and genomics data, should be important facilitators of this complex approach to share and use cancer data effectively. The proposal for a Regulation on European Health Data Space which is now under intensive discussion among Member States could become another important part of these EU wide policies in the future.

Taking the above-mentioned consideration into account, we call on the European Commission, EU Member States and all stakeholders to consider and support the following:

- Recognize the need to further discuss and consider the proposal for a Regulation on the European Health Data Space to ensure effective data sharing between



providers of cancer care and to support secondary use of data for research, innovation and policy making.

- Establish tools for effective sharing of data to support policy, research, and care for specific groups of cancer patients, such as paediatric patients, patients with rare cancers, patients with poor prognosis cancers.
- Strive to create and share an efficient and sustainable model for operation of population-based cancer registries in the context of modern digitized national healthcare system, strengthening the possibility to monitor and report clinically relevant health indicators, and at the same time harnessing the power of electronic health records and regulated secondary use of data.
- Support international governance and routine use of cancer control indicators to make sure that all countries can effectively identify gaps in their provision of cancer care. The European Cancer Information System and European Cancer Inequalities Registry should be further developed to facilitate monitoring and reporting essential cancer control indicators., as well as streamlining patient-centeredness by routinely reporting the uptake of PROMs and PREMs in all areas of cancer care.
- Inequalities in cancer prevention and care represent a key dimension of cancer control quality. Best efforts should be made to strive for equitable care for patients irrespective of their country, region, or cancer diagnosis. Cancer control indicators should aim for timely access to cancer care along the patient pathway, notably for patients with poor prognosis.
- Support the creation of a virtual European Cancer Patient Digital Centre (ECPDC) in order to enable the voluntary exchange of patients and survivors' clinical data for primary and secondary use in a standardised way. The ECPDC is perceived as a global centre of knowledge on cancer, which should provide patients, survivors, their families and caregivers with a possibility to use digital tools and data to promote patient-centred care, prevent cancer, detect cancer early, provide high-quality patient-centred care, and support sustainable health systems.



- Develop a set of conditions and quality standards as prerequisites for primary and secondary data use of cancer data, to facilitate larger-scale, high-quality, cross-border clinical, public health and other cancer-related research, maximizing the potential of outputs derived from this data to change (clinical) practice.
- Support Member States to invest more in health literacy and digital health literacy of patients and health care professionals.

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3. Improving early detection of cancer and screening schemes in the EU

One of the significant challenges in cancer control is the late detection of many cancer types. Whereas early detection of some cancers, namely pancreatic cancer, remains difficult and new innovative tools need to be developed by researchers, in several cancers the science of early detection is clear. We can significantly decrease mortality of breast, colorectal, and cervical cancer through population-based screening programmes. Combining screening data with other data sources such as genomic data can greatly enhance such programmes and should be considered whenever possible. It is necessary to implement and monitor these programmes as widely as possible, to ensure their high quality, and to remove all possible barriers so that as many people from eligible target groups as possible can participate. Effective tests for early detection of lung cancer and prostate cancer exist and need to be introduced – considering national context and resources and as part of organized and quality assured screening programmes – in an appropriate stepwise approach based on future European Guidelines with a view to maximize benefits and minimize harms. Data on cancer screening and early detection should be part of cancer information systems on the national and EU levels to ensure their continuous improvement.

The revision of the Council Recommendation on Cancer Screening is high on the agenda of the Czech Presidency of the Council of the European Union, which will make every effort to ensure smooth deliberations with a view to have the Recommendation adopted by the EPSCO Council in December 2022. It is important to ensure a comprehensive discussion of the recommendation to secure that citizens in the EU have access to high quality cancer screening programmes and can benefit from improved cancer survival. Moreover, early detection through improved health literacy and patient-centred networking of cancer care should be promoted beyond organised cancer screening programmes.

Taking the above-mentioned considerations into account, we call on the European Commission, EU Member States and all stakeholders to consider and support the following:



- Recognize the need to further discuss and consider the Council Recommendation amending Council Recommendation of 2 December 2003 on cancer screening, to promote EU-wide state of the art provision of evidence-based cancer screening.
- Timely availability of promising new technologies for cancer screening in a stepwise evidence-based manner, allowing for implementation and health services research for further optimization of existing and new screening programme pathways.
- The European Commission should promote the development and the implementation of European Guidelines and Quality Assurance Schemes, so that countries could adhere to the best evidence-based recommendations, and at the same time considering their local circumstances, resources' constraints, etc.
- The European Commission should consider the possibility of launching a joint action to streamline at appropriate time and support Member States' efforts to implement the Council Recommendation on cancer screening at national level.
- The European Commission together with Member States, with respect to national contexts, should make every effort to decrease striking differences between EU countries regarding provision of cancer screening, including identifying barriers and facilitators for utilization of screening services within different health systems. Further development of the European Cancer Information System and European Cancer Inequalities Registry regarding cancer screening indicators should be supported. Reforms and investments should be aimed at decreasing the inequalities.
- Structured sharing of good practices in screening and early detection between EU countries should be further strengthened. Multiprofessional teams should develop quality standards for piloting and rolling out modifications of existing and introduction of new screening programmes, to avoid quality discrepancies between Member States.
- Support research at all stages (preclinical/clinical/implementation/outcomes), so that screening and early detection, including the use of digital technologies,



contribute to decreasing considerable differences in survival between patients with comparable cancer diagnoses.

- Support awareness campaigns to ensure that EU citizens are fully informed about the availability of cancer screening programmes, while paying particular attention to communicate about their benefits as well as harms to ensure informed decision making about the uptake of screening-programmes.

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