Europe's Beating Cancer Plan:

factual report from the targeted stakeholder consultation

European Observatory on Health Systems and Policies
a partnership hosted by WHO

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List of abbreviations

AI	Artificial Intelligence
CCC	Cancer Care Centre
CEE	Central and Eastern Europe
DG	Directorate-General
EBCP	Europe's Beating Cancer Plan
EC	European Commission
ECAC	European Code Against Cancer
ECIBC	EC initiative on breast cancer
EMA	European Medicines Agency
ENCR	European Network of Cancer Registries
ERN	European Reference Network
EU	European Union
GDPR	General Data Protection Regulation
GP	General practitioner
HiAP	Health in All Policies
HPV	Human papillomavirus
HRQoL	Health-related quality of life
HTA	Health technology assessment
IARC	International Agency for Research on Cancer
iPAAC	Innovative Partnership for Action Against Cancer
JRC	Joint Research Centre
KPI	Key performance indicators
MS	Member States
NCCP	National Cancer Care Plan
NCDs	Non-Communicable Diseases
PAG	Patient Advocacy Group
PREMs	Patient-reported experience measures
PROMs	Patient-reported outcome measures
TSC	targeted stakeholder consultation
TTPA	Time-to-patient-access
WHO	World Health Organization

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Introduction

This targeted stakeholder consultation (TSC) is one of the key stages in the European Commission's EBCP consultation process that was rolled out in February 2020. This report incorporates detailed accounts from the targeted stakeholder meetings (Appendix 2), as well as a synthesis of points raised by the stakeholders (see consolidated findings).

The TSC was an opportunity for DG SANTE to garner more in-depth and focused views. It sought detailed thematic inputs from the key international organizations (including patients, professionals, academics, the public health community, international agencies and industry representatives) around Europe.

At the beginning of each focus group meeting it was made clear that the European Commission acts according to the principle of subsidiarity and that it was within this principle that the contributions from stakeholders were sought. However, the discussions inevitably reflected a wide range of issues and challenges of particular relevance for each type of stakeholder, and therefore do contain points where the EC does not have competency to act. These are recorded nonetheless as they are important in establishing the context in which the EBCP will be implemented, representing as they do insights and knowledge gained from a range of key stakeholders across Europe.

Methods

Key stakeholders (organizations and interviewees) for the TSC were identified based on relevance to, and expertise in, cancer, as well as for their ability to represent an EU-wide perspective and/or organizational position on behalf of a wide group of cancer stakeholders. The consultation meetings (focus groups, n=6) and supplementary interviews (n=4) were carried out between 20 July and 8 September 2020. Focus group meetings were organized around stakeholder type (patient representatives, professional associations, the cancer community, public health, bio-med-tech industry and international agencies). Participants of the focus groups were asked to reflect on selected questions (see Appendix 1) developed in line with the EBCP Roadmap, and then participated in a facilitated discussion. Notes from the focus group meetings in the form of key messages representing the focus-group perspective were sent to all invitees for further comments and then consolidated and analysed. The results formed the basis of the section on consolidated findings (below), and were also used to inform the overview report and the synopsis report that can be found here: https://ec.europa.eu/health/non_communicable_diseases/cancer_en.

Consolidated findings

The findings that represent the views of targeted stakeholders were grouped in line with the EBCP Roadmap structure of four pillars (prevention, early detection and diagnosis, treatment and care, quality of life for cancer patients, survivors and carers) as well as additional cross-sectional topics that were systematically raised across multiple groups. Some of the areas have overlapping points, but may be reflected from different angles that are pertinent to a particular stakeholder's perspective.

Pillar 1: Prevention

- Assessing and **recognizing the value of prevention** is one of the cornerstones of the battle against cancer. Focus on the overarching policy approach can strengthen the roots of public health, in which the EBCP is framed, leading to the development of principles outlined in article 168 of the EU Treaty with a 'Health-in-All-Policies' approach. This should be done both by means of structural approaches to providing the right environment for protecting and promoting health, along with behavioural approaches for improving lifestyles. Prevention of NCDs in general will have an impact on preventing cancer.
- Beyond the existing EU activities contributing to the fight against cancer, the EBCP needs to **address all known cancer risk factors** and prevention interventions. Areas deserving increased attention in the Plan could include providing further support to the European Code Against Cancer, encouraging countries to implement WHO NCD 'best buys' (i.e. evidence-based policies to improve NCD prevention) and fostering the enforcement of existing regulations.

- Further **strengthening of regulation on alcohol and tobacco** (including pricing, marketing and labelling; the alcohol industry is still being promoted via agricultural incentives), as well as unhealthy foods and artificial tanning devices is also needed.
- **Environmental regulation** (reducing air pollution, carbon emissions and plastic – Green Deal) at the European level is also relevant to cancers. Healthy and sustainable diets – in connection with the Green Deal and the Farm to Fork EU Policy – are a blueprint to cancer prevention. Transition to the Green Deal needs to be done in a socially just way – without disadvantaging vulnerable populations.
- Addressing **commercial determinants of health**. Our existing public health models may risk framing public health problems and solutions in ways that disguise the role that certain large transnational companies play in shaping the broader environment and individual behaviours, and thus population health outcomes. This issue should be reflected in some operational way in the EBCP.
- EU-level policy development on **cross-border marketing and advertising**, including digital, provides an important opportunity for synergies across alcohol, tobacco and food, especially also with a view on protecting children and young people (in line with the EU's agenda on children's rights). The EU has taken measures in the past, but more can be done on obesity and inactivity. Next steps could involve the development of policy toolkits to support MS in implementation of effective measures in these areas, e.g. with a view to designing and implementing sugar taxation policies; assisting municipalities with guidance on the implementation of urban planning policies for fast-food outlet density in a way that is compatible with EU law; assisting municipalities with the development of active and clean transport policies, etc.
- The concept of **the value of vaccinations that are effective** needs to be reinforced in the Plan, with HPV vaccination having the potential for the elimination of HPV-associated cancers as a public health problem. Counteracting fake news around vaccination and anti-vaccine movements are also critical to raise citizens' adhesion to vaccination programmes.
- **Budget for public health/prevention** across the EU is still very small in terms of share of health expenditure (around 3%), and so is the budget for public health research.
- It is essential to move towards the **systematic assessment of the value and impact of cancer prevention interventions** (fostering outcome research for cancer prevention, including economic assessment, to convince policy-makers to invest in prevention). This should also include better risk communication to public and long-term realism of cancer prevention among policy-makers through provision of long-term data and evidence, including projections.
- Health is a **political will** – the EU can lead and encourage decision-makers in MS. A lot of existing knowledge, particularly on prevention, has not been implemented. An EU-led process could encourage health system reforms towards prevention (e.g. through European Semester). A European Programme of Work could be used to maintain momentum and work in synergy. European public health groups can contribute with advocacy actions.

Pillar 2: Early detection and diagnosis

- Secondary prevention (early diagnosis and screening) need to be strengthened and **standards set across the EU**. The large proportion of patients diagnosed at a late stage shows that early diagnosis of symptomatic cancers needs to be improved. The EU could encourage countries to develop early diagnosis programmes as part of their NCCP.
- Screening can improve outcomes for a few types of cancer, but in many EU countries it is not well organized, nor is **screening programmes' quality adequately assured**. Cancer screening requires a push for a more widespread introduction of existing screening programmes, uptake of best practices (e.g. HPV self-sampling), better monitoring and evaluation, as well as quality improvement systems. A more targeted approach to screening is warranted and appropriate stratification should be considered when relevant, as well as more research to better understand risk stratification and targeted interventions.
- The EU may have a particular role in **fostering evidence-based best practices** focusing on quality and equity, notably for early diagnosis, where it can set a model of good standardization for quality. Regulation is also important for efficient interaction

between academia and biotech partners to limit the market-driven biases.

- **Non-evidence-based screening practices** are increasing in the EU (e.g. out-of-screening-age mammography, screening for prostate cancer, stomach cancer, etc). These are driven by market forces and call for adequate regulation.
- There was a view that the EC could support **further research to identify biomarkers** for early detection of cancer through coordination of large population cohorts; investing in infrastructure for population cohort research; promoting efficient interaction between academia, biotech and population cohorts; and working to ensure promising biomarkers for early cancer detection are brought forward into practice. However, this was contested by the position that there is no early detection biomarker that is eligible for large population cohorts yet. This would mean that such research may divert resources from other important areas (for example implementation research of early diagnosis programmes). There was a strong view against supporting investment in biomarkers for early detection and new screening technologies, and in favour of putting resources into early diagnosis of symptomatic cancer (i.e. better services).
- The EU could play a larger role in **supporting high quality diagnostics** with more dedicated funding, supporting laboratory capacity, as well as clear guidelines, stricter regulation and quality control.
- The EC could support the MS to have **efficient systems of data collection** across screening programmes and use data to estimate quality indicators and ultimately improve quality of screening programmes. This will minimize the harms of screening and maximize the impact. An EU-wide monitoring programme (now and during the following years) will be useful to motivate and assess the efficiency of interventions directed at early diagnoses and screening programmes.
- Timely access to early diagnosis is crucial for all cancers, but there are **different mechanisms** for common cancers (with emphasis on the importance of screening programmes as well as early detection programmes and action at local/national level) and rare and paediatric cancers – where early access to specialists/specialist centres, as well as international expertise, are particularly important.
- **Consequences of earlier cancer diagnoses** should be taken into account for healthcare system directions and cancer research (e.g. changes to clinical trial populations, possibly types of outcome endpoints, patients having exhausted all effective treatments will remain important even if possibly less frequent).

Pillar 3: Treatment and care

- **Treatment standards and access** need to be ensured across the EU. The EC could support and endorse guidelines across MS in areas where it does not make sense for clinical practice to be divergent.
- Given the heterogeneity of the types of cancer, it may also be useful to work on the **treatment pathways** (itinerary) and patient experience by stratifying by type of cancer. This should also be reinforced by the development of multidisciplinary teams, where – apart from the different professional disciplines involved in the patient pathway – patient voice needs to be clearly present. In addition, mental health support is not reflected enough in the EBCP and is important at all stages and needs to be integrated into pathways.
- For rare cancers in particular, **early access to specialists**/specialist centres, as well as international expertise, is particularly important. In this regard, fostering of the European Reference Networks Directive and cross-border care is crucial. ERNs were identified as an excellent organizational tool, which received a lot of support and interest, but all of the speakers who supported them spoke of the complete insufficiency of funding, which prevents ERNs from expanding and from becoming truly relevant. The role of the ERNs could not be stressed enough for the access of cancer patients to the best European cancer expertise. The ERNs should be financially and organizationally supported and linked to similar national reference structures. Flexibility, speed of patient access, and the possibility of cross-border healthcare are key elements for the growth of the ERNs.
- **Investment in cross-border cancer care** is needed, with appropriate reimbursement procedures for patients and for professionals providing virtual cross-border advice.
- **Paediatric cancer is a distinct area** for care, treatment and innovation, but there is little incentive

to develop treatments for childhood cancer, and it is not consistently recognized as a distinct area in NCCPs. Transition from paediatric to adult cancer care is a complex issue and needs to be better developed systematically across Europe.

- There are **other aspects of cancer**, which the EU could encourage MS to systematically include in NCCPs: e.g. linking of radiotherapy to other cancer treatments; mental health care and psychosocial care are necessary areas of integrated multi-professional cancer care pathways, but there is a lack recognition, funding, and standardization across MS; distress should be added as the sixth vital sign for measurement, in order to be monitored and treated in cancer patients; pain should be recognized as a cause of distress and development of standards of pain management is needed; palliative care should be integrated in NCCPs from the beginning of care/ treatment process, not at the end.
- **All cancer treatment modalities need to be given attention** within the EBCP. Increased emphasis and support are needed for cancer surgery, radiation therapy, interventional oncology and nuclear medicine. Most pressing issues to be addressed in these areas include workforce education and shortages, support to research, professional qualification recognition and investment in required infrastructures.
- Work on the **quality assurance mechanisms** is necessary, ranging from accreditation mechanisms through a network of accredited CCCs and their related networks through to the implementation of adopted guidelines. The EU could push for more accredited national CCCs.
- The number of cancer patients with multimorbidity is increasing, and so is the number of geriatric cancer patients. This requires **integrated models of care** that could be highlighted more in the EBCP. Despite continuous increase in burden of geriatric oncology it is not recognized as a distinct area in the EBCP, although should receive at least some attention.
- **Better communication between healthcare professionals and patients**, and referrals to specialists and other supportive care services are key for quality cancer care.

Pillar 4: Quality of life for cancer patients, survivors and carers

- It is critical that the EBCP provides **increased attention to the physical/medical needs of cancer survivors** in respect to their health and quality of life. The management of increasing cancer treatment long-term side-effects and cancer co-morbidities needs to be integrated in care pathways. Currently, there is no model at the EU level that could be taken as a starting point for addressing cancer survivorship. Cancer survivorship integration in the cancer pathway has to be designed and planned, taking into consideration the CanCon recommendations.
- Implementation of survivorship follow-up care plans, infrastructures and interoperable IT tools including a Survivorship Passport and integration of patient-reported outcomes to facilitate an appropriate **life-long informed care model** would allow cancer survivors to live their life at its best potential. The EU can facilitate the implementation of the Survivorship Passport model and long-term follow-up guidance across all MS.
- More focus on issues such as **addressing stigma, discrimination and financial implications** (through implementing the right-to-be-forgotten), returning to work, and other aspects is needed in the EBCP, together with consideration/support for families and carers' needs, as they are crucial to survivorship, especially in the long term.
- The **needs of younger patients**, paediatric, teenage and young adult (i.e. <40yrs old) should be mentioned and planned for at a national level.

Cross-cutting themes

Further to the main four pillars, a number of aspects discussed were more cross-cutting or were reflected on from a broader perspective than in the context of the main pillars. These are listed below.

Inequalities, access to quality care and support

- Inequalities in quality of cancer care and access across the EU continue to be stark, and need to be tackled. **Quality of oncological care shows excessive variation** across the EU and even within MS. The EC could play a crucial role in encouraging the use of accredited methodology and

promoting quality, standards and certification of cancer care centres, as well as encouraging research and excellence.

- In some MS there are **issues of access, sometimes due not to the cost of, but to a shortage of, effective and not expensive medicines**, as well as shortage of effective care structures.
- Health inequalities are one of the biggest challenges in the EU. **Different dimensions related to health inequalities need to be addressed**. The drivers of these inequalities include socioeconomic and commercial determinants of health, and factors such as risk behaviours (e.g. tobacco, alcohol, food-related) and can be addressed by policies at the EU level that focus on creation of health-enabling societal conditions and living environments to empower and facilitate healthy living. All countries have vulnerable groups that are also more at risk of cancer and with less capacity to deal with its consequences. Financial toxicity of cancer and impact on households should be assessed to help identify best practices re social security for citizens.
- Finding practical ways to minimize unjustified diagnostic and therapeutic variability, and its consequent inequalities, involves a commitment to **ensure that clinical practice guidelines and the evaluation of biomarkers and medical devices are established at a European level**, promoting digital technologies and innovations that are truly useful. Inequality in access to cancer treatments (affordability and capacity of the systems to deploy integrated care models) is also an important challenge that needs to be addressed.
- An important parameter to **monitor is the time-to-patient-access (TTPA)**. There are a number of issues to be improved in terms of process, reimbursement (e.g. take into consideration the value of diagnostic information for diagnostics as well as the barriers to access in interventional oncology), health system readiness; evidence requirements; novel endpoints; sufficiency of evidence; fast access to patients.

Data and information exchange

- Data interoperability between MS is lacking, and challenges for data collection and exchange at the national and international level need to be addressed. **Standards and guidance should be developed to facilitate the direct capture of data from electronic health records**, to improve the efficiency, quality and quantity of data reporting. The EU could play a larger role in supporting data sharing infrastructure (e.g. platforms for data sharing) and promoting availability of information for decision-making at the national and the EU level.
- The improvement of information systems/creation of structures in research centres to collect and share data is needed to **systematically use interoperable metrics, and ensure inequalities can be assessed**. Need to go beyond traditional outcomes (mortality and survival) and include differentiation by stage, co-morbidities, socioeconomic levels, performance status, response indicators, etc; as well as person-centred outcomes (PROMS, PREMS).
- General Data Protection Regulation (EU GDPR) is interpreted differently across countries. More work in **harmonization and clarification on implementation of GDPR** could be done at the EU level. Challenges on sensitivities over health data exist and are recognized by stakeholders, but some successful examples of implementation can serve as proof of the room that exists in spite of the GDPR limitations.
- The opportunities offered by artificial intelligence (AI) need to be explored. **A synergy is needed among the various efforts being made at EU level to develop AI-based algorithms** in cancer prevention, early detection and cancer management. AI requires large repositories of data, images and biospecimens. The EC should take a lead in developing such a repository addressing all ethical, legal, equity and technological issues. Exploration of ethical principles of AI and big data collection, and special attention is needed to ensure transparency on usage of patients' data concerning in particular paediatric cancers.
- There is a need to appreciate the **cancer register landscape across Europe** – 20 registries, 120 sub-registries, and a great divide between countries. Cancer registries should be promoted, supported, funded and guided. EC-Santé, ENCR (European Network of Cancer Registries via EC JRC secretariat), EMA (including HMAs) and WHO-IARC should be working jointly in this endeavour. The work of JRC could be more proactive to support MS in their development of quality cancer registries.

- Interoperable population-based **high quality cancer registries should be better connected with the clinical and screening registries** and also linked to data related to survivorship. In addition, harmonization of data on screening is also essential to improve quality of national screening programmes. Data linkage with population registries would assist in assessing the benefits of cancer screening on outcomes.
- Generating knowledge and collecting data require support, facilitation and funding for cancer clinical trials, for observational studies and for translational research since registry data cannot be enough for evaluating new interventions and treatment strategies/sequences. This is a large topic area where some **alignment of stakeholders (academia, pharma, HTA, EMA) is needed with respect to goal-setting, data sharing and practical collaboration**.
- There is an opportunity from **linking genomics and outcome data** (e.g. through standardized registries) on a European level. These databases could be made accessible to European public and private research institutions and would as such strengthen Europe as an innovation centre.

Research and innovation

- **Research strengthening and funding** at the EU level should, beyond clinical, epidemiological and economic research, cover outcomes-based research, epidemiology and prevention, implementation, translational and organizational research, as well as funding on knowledge translation for policy-making. Research for policy development and implementation is also needed to facilitate MS' policy efforts.
- Particular shortcomings and insufficiencies are present in **translational, outcomes and organizational research**. These areas of research in cancer need to be strengthened and incentivized in order to improve cancer care through evidence of best practices.
- The EU could support and promote **research of European population cohorts**, including investing in joint infrastructure – for broader NCD (including cancer) prevention and population risk stratification.
- Generation of knowledge aiming to optimize treatment in the post-marketing phase is a neglected area of research that could generate significant **information for optimizing treatment allocation** to patients who are likely to benefit the most, optimize treatment schedules to maximize benefits and minimize harms, etc. A framework to conduct academically-lead independent trials, involving multiple stakeholders (e.g., patients, health-economic organizations, medicines regulators), and independent evaluation of the data, would be essential to achieve treatment optimization.
- Optimizing anti-cancer multidisciplinary treatments needs better **balance between commercial and independent research**. EBCP could provide structure for independent research.
- The EC could play a role in **supporting multi-centre clinical trials and improving access** to them; cross-border clinical trials should be enabled by simplifying procedures.
- Innovation can play an important role in cancer care, but requires resources that in some MS are more limited than in others. Development and validation of new diagnostic methods (imaging, genomics, liquid biopsy, minimum invasive strategies) with **focus on efficiency and cost-effectiveness** are needed. Genomics with focus on cancers could be facilitated by the EU, as it requires linking platforms at international level.
- A more dynamic uptake of **innovation should be promoted, especially in rare and ultra-rare cancers** (e.g. paediatric field). There is ample room for improvement, following examples of good practice in this field. Moreover, innovation is not restricted to pharmaceutical or technological aspects alone. Organizational innovation, respecting and supporting patients in their journey, proper shared decision-making models are of outstanding importance. At the same time, what is regarded as 'innovation' should always be superior in terms of clinical outcomes and quality of life improvements compared to the well-established standards of care.
- **Making use of big data and innovative technologies** that could provide broader and more extensive analyses, new knowledge and base for future research and insight into different challenges of treatment and after-care. Looking also at the environment, considering exposure to contextual and/or occupational toxicants, consumption and

eating habits (e.g. consider working together with the veterinary and agricultural services), drug intake and spotting 'clusters' should all be part of the intelligent management of this information.

Person-centredness

- The need for **patient empowerment and patient-centredness** is a point consistently shared by all stakeholder groups. Cancer patients' role needs to transform into being an active partner, governing their health data, choosing options for medical care and research engagement, fostering and maximizing patient autonomy and informed benefit-risk decisions through optimal information and decision analysis tools. Dedicated projects should be initiated to support patients and to advance their role.
- **Patient-relevant and patient-meaningful outcome and experience measures are the ultimate measures of the quality** of cancer care. They should be introduced as key indicators internationally, as well as across the national, regional and institutional levels. Health-related Quality of Life (HRQoL) as an indicator is currently now used systematically together with clinical outcomes, and its significance is often not part of the oncology specialization training.
- Adequate **provisions should be made in the population-based and clinical registries to include measures of quality of life and patient experience**. These currently lag in their importance behind clinical outcomes, while they are just as important and need to be collected and harmonized across the EU.
- Tangible reference points are needed for patients and families, including **providing information about the patient journey along the whole pathway**. Currently there are gaps in clinical pathways, as they do not necessarily reflect needs of patients.
- The **importance of ensuring the patient voice is heard in regulatory actions**, both pan-Europe and nationally, and including in health economics. This should also take note of, and promote, PROMs as primary outcomes in clinical studies.
- The EU could foster a proper framework where all **communication between healthcare professionals and the patient and their family takes place in the patient's native language**. Patients need to be informed, to be able to understand their disease and goals of treatment. Patient empowerment in practice means information at doses patients can receive and use.
- Apart from including information available in native languages, communication; **patients should be referred to patient associations once they receive diagnosis**. Patient organizations have covered the gap in officially available information in many EU MS.
- **Patient advocates' education** together with adequate health and digital literacy are important tools towards meaningful patient involvement in the debate about cancer policy in National Cancer Care Plans (NCCPs). Health literacy and awareness are very important for prevention and early detection.
- NCCPs should involve patients from the start (including prevention and rehabilitation, and not only regarding treatment or palliative care). While patient involvement has improved at the international level, in MS this is often not the case. **Patient involvement in key areas of the cancer pathway is of vital importance**, alongside their contribution to designing and planning cancer policy, framing cancer research questions important to cancer patients, having a seat at the table at HTA negotiations.
- Often development of a patient pathway for specific cancers is left to patient associations, as they have the necessary experience. Therefore **patient associations are an essential asset in beating cancer in Europe**. Involvement of European patient advocacy group (ePAG advocates) and their education/training is central, given their complete view of the patient journey, and the collective intelligence of these organizations, including the consequences and the conditions of living with/surviving cancer.
- In order for patient associations to be able to carry out their role, it is important to address their funding model, and, ideally, to **provide adequate public support and funding in order to increase transparency and effectiveness**, while reducing the dependency on funding from industry and other sources that can potentially have undue influence/undermine the legitimacy of its work. This approach would also help to reduce the existing differences in the level of patient associations' presence.

Value-based care

- More research is needed for **understanding and precisely articulating the value** to patients, payers and various stakeholders, as well as cost-effectiveness, of therapeutic interventions, notably for high-cost treatments. The EU could encourage **adherence to evidence-based practices** (prevention and intervention), and discourage practices with no evidence on effectiveness. Patient involvement in decision-making, including for HTA, is very important. Emphasis should be on the availability of quality/effective and cost-effective interventions.
- The EU could play a role in finding ways to **mitigate rising costs of promising but extremely expensive treatments and ensure equal access** to those. Stimulating close cooperation between health economists, epidemiologists and clinical researchers will improve the ability to critically assess value of treatments and set priorities, as well as establish best practice on issues like duration of treatment, combination, sequence, etc. There is a need to develop EU-level economic evaluation strategies.
- Despite the knowledge that we have of the seriousness of the disease and the cost that it entails, it is alarming to note the **lack of knowledge about the impact of interventions**, which in itself is related to alarming scarcity of studies that assess the outcomes of the disease and of the interventions carried out. The information should be readily accessible to address this challenge.
- Further cooperation on combined purchasing, exchange of coverage schedules and price arrangements, such as by working with the European Fair Pricing Network, may assist in supporting cancer services' sustainability. The EU could play a larger role in **transparency on pricing of medical products and information sharing**, although it is recognized that pricing decisions are ultimately in the remit of the MS.
- HTA should be promoted to give rationality and European coherence to decision-making. **Centralizing HTA at the EU level would provide more power for competent decision-making**. New types of datasets should be generated for this purpose. These should reflect the needs of cancer patients and of the medical community. These should be generated free of commercial interest. As a minimum, the EU could also support collaboration and cooperation between HTA bodies.
- There is a need for **availability of scientific data on both positive and negative results**, particularly for HTA agencies – a move which could be supported by the EC. National HTA bodies need better evidence and transparency on medicines and clinical interventions.
- **Independent evaluation of treatments, including multidisciplinary interventions**, is needed. This must be based on prospective clinical research assessing medical interventions based on clinically meaningful end-points which make a difference for cancer patients.
- At the EU level, the **therapeutic value of digital tools** (e.g. in diagnostics, patient monitoring) could be better recognized and receive more prominence.

Health professionals' training and a multi-professional approach

- Human resources continue to play the key role and investment in the development of human resources is key to the future strength of oncological care in Europe. **Training and retraining of professionals who can help navigate patients with complex needs through care pathways is essential**. There is a large divide across Europe in the education of health professionals working with cancer. The EC could play a role in establishing common frameworks for education.
- **Oncology workforce planning for future needs could also be done at European level**, as shortages of some cancer specialties are becoming visible already, resulting in longer waiting times for patients. Some MS have a particular deficit in expertise – cross-country tumour boards are a welcome initiative but need to be supported at the EU level.
- **Investment in public health skills**, advocacy; training the next generation of public health professionals is particularly important for cancer prevention.
- Tackling cancer needs a **multi-professional approach, in addition to multi- and inter-disciplinarity**. Broadening the scope of professionals involved in cancer was widely supported by representatives of various professions and disciplines.
- More recognition of the contribution of nursing to cancer care is needed, as well as ensuring **appropriate safety measures for nurses who**

work in oncological care and encounter hazardous materials and conditions. There is very large variation in education/qualification of cancer care nurses and safety standards across the EU.

- In addition to cancer care specialists, **general practitioners (GPs) must be involved and informed in the patient pathway**, starting with prevention; better referral systems are needed in case of suspected cancer.
- Mandate for **setting standards in communication skills in oncology setting is required** (e.g. announcement of diagnosis is often poorly done) and would have additional benefits in promoting adherence to treatment and psychosocial functioning of cancer patients.

International synergies in policies and actions

- **Synergies between a number of existing international initiatives**, such as updating of the European Code Against Cancer (ECAC) (IARC), work on the EBCP (EC), iPAAC Joint Action, JRC (EC), Cancer Mission Board, etc., should be strengthened.
- **Policy coherence across the EU** is important (e.g. alcohol-related policies) – applying Health-in-All-Policies (HiAP) across the board (agriculture, food, environment, etc.). The EC can play a steering role in fostering political will of MS to tackle determinants and adopt HiAP in line with EU policies and WHO recommendations. Health policy platforms could be used more for communication with the Commission and across the MS.
- **Collaboration is needed across different parts/ DGs of the EC** on EBCP – e.g. Cytotoxic safety includes DG Employment and Social Affairs and Recognition with DG Grow; the S2 mechanism requires reference to the Regulation on the coordination of social security systems.
- EU added value could be in **highlighting best practices**. The EU plays a crucial role in promoting consistent and coherent quality standards in the European context, e.g. implementation of uniform screening programmes, setting standards for quality of treatment. The EC initiative on breast cancer (ECIBC) model, which includes an evidence-based approach and good communication with MS, as well as providing updated guidelines and harmonizinglab measures/indicators (ISO standards), could be developed for other cancers. Work on a similar initiative is currently ongoing for colorectal cancer.
- There are **multiple cancer initiatives** happening across the EU, but none of them maps all the initiatives at the European level. Such mapping would be very useful to show where there are gaps and where to focus effort, funding, etc.

Collaboration and European Reference Networks

- Networking and **collaboration of cancer institutions within and between countries is essential** for research and for further quality improvement in cancer care. They also play a role in bridging the gap in access to high quality cancer care as well as in overcoming the existing differences. EBCP could serve as a policy instrument to encourage creation of cancer networks within countries and internationally. Networking would also help in providing better access to clinical trials, provide adequate research capacity and power to smaller MS.
- **ERNs were widely recognized as a welcome initiative with huge benefits**, in particular for rare cancers, and positive experience among cancer organizations. It was also recognized that ERNs were well set up and with good vision, but they are **severely underfunded and should be invested into** much more. Also, better coordination at international level is needed.
- Better **access to expertise through cross-country molecular tumour boards** for difficult cases (e.g. rare diseases) is needed. At the moment it is not possible in certain countries to upload or share patient data for consultation on cloud platforms with physicians in other countries. A uniform agreement for online consultations through standardized exchange platforms across Europe would be a welcome step.

EBCP evaluation

- There is a need to **ensure that the EBCP is effectively implemented and systematically evaluated**. In order for the EBCP implementation to be successful, it needs to be realistic and measurable,

so it should come with a dashboard of indicators that can be monitored, and which would enable evaluation (the data dashboard should include key performance indicators (KPI), metrics and key data points to monitor the effectiveness of this plan).

- Reduction of inequalities across Europe can only be addressed through systematic evaluation of existing and future initiatives. Furthermore, evaluations should focus on identification of obstacles that hinder progress at the EU and national level.

Contribution of the stakeholders

All organizations involved in the targeted stakeholder consultation meetings expressed their support and willingness to contribute to the development and implementation of the EBCP within their area of competence. Many of them have already contributed to multiple stages of the process, as well as to other related initiatives (e.g. Cancer Mission, etc.).

Conclusions

There was wide support for EBCP as a much-needed step to enhance prevention, ensure early detection and improve care and quality of life of cancer patients, survivors and carers across Europe. The outline of the EBCP, from the stakeholders' perspective, showed the understanding of the European Commission of the need to take action on multiple aspects that impact cancer and of the need to find pan-European and innovative solutions. There was a large amount of overlap across groups of stakeholders on the main pillars, as well as on cross-cutting topics such as inequalities, research and data sharing, value-based care, patient-centredness, etc. At the same time, the contribution of each group is unique because it provides detailed insights and particular knowledge and experience in dealing with cancer. The findings of the targeted stakeholder consultation meetings synthesize these various perspectives to build a comprehensive reflection by the cancer community on the issues that Europe is currently facing. Interpretation of these findings as well as broader conclusions and key messages are summarized in the accompanying overview report: https://ec.europa.eu/health/non_communicable_diseases/cancer_en.

Appendix 1:

EBCP targeted stakeholder consultation sample questions

A selection of the following questions was presented in advance to the stakeholders to prompt the discussion around EBCP aspects most relevant to them.

- What could be particular actions driven at EU level that would improve prevention, early detection, effectiveness of treatment, life after cancer and research agenda? Which actions should be given particular priority and why?
- What are other large scale problems (beyond access to prevention, effective treatment and medicines; lack in post treatment care; regional and socioeconomic inequalities) that may be better addressed by the EU and in which EU has competences?
- Are there any existing EU activities contributing to the fight against cancer which should be improved and how? (E.g. tobacco legislation, European Reference Networks, carcinogenic substances at work and in consumer products, etc.) Are there any approaches, methodologies, technologies or evidence that could be used at EU level in the fight against cancer?
- European Code Against Cancer – how to proceed for its stronger implementation and potential updating? Do we need a European institution for cancer or NCDs? Which of the actions that can be tackled at the EU level have the biggest impact on lifestyle habits (e.g. diet, physical activity, tobacco or alcohol consumption)?
- How often should screening programmes be reviewed at the EU level? Should the EU extend recommendations for screening of other types of cancer, beyond breast, cervical and colorectal cancer? How do you see the introduction of new screening programmes? Who should carry out the supervision over and accreditation of the screening programmes? What is the role of the EU in the development of professional capacity for screening, its implementation and evaluation? What is the role of early detection and how do we steer the split between organized screening programmes and enhanced early detection?
- Should EU MS converge in quality of cancer services, set standards of care and follow-up, and harmonize patient pathways? Is it possible to set standards or a minimum for expenditures on cancer care and control? How can this process be initiated, and who should lead on it?
- What can the EU hope to do to better inform patients about diagnosis and possible treatments? What can be done in the context of a European Action Plan to better support patients (also carers and families) through treatment inside and outside the healthcare setting? What are the key challenges that cancer survivors experience?
- How can the EU add value in helping to achieve better patient involvement in: the development of the National Cancer Control Programmes (NCCPs), shared decision-making in the whole trajectory from diagnosis to end-of-life care, extended treatment or remission?
- How do you see the gaps in the present status of research in the field of cancer? Which topics

and which areas would need to be incentivized through Horizon Europe? How can clinical trials be promoted and extended? How can they be made multinational with better inclusion of patients from CEE countries?

- The role of registries – what actions could be taken? E.g. strengthening of population-based registries; introduction of additional datasets; building separate clinical and screening registries?
- Are there particular cancers other than the ones already considered by EU legislation (rare and paediatric cancers) which deserve specific EU attention and why?

Appendix 2

Notes from the meetings

The following notes are the summary record of the targeted stakeholder consultation meetings, held between 20 July and 8 September 2020. All invitees were given the opportunity to review and comment on the notes.

2.1 Patient representatives

Stakeholder organizations:
CCI-Europe, Digestive Cancers Europe,
Europadonna, Europauomo,
European Cancer Leagues (ECL),
European Cancer Patient Coalition (ECPC),
Lung Cancer Europe,
Lymphoma Coalition,
Melanoma Patient Network Europe,
Sarcoma Patients EuroNet

Key points:

1 **The importance of patients' associations, their advocacy role and their funding mechanisms**

- Patient associations (PAs) are an essential asset, and their voice should be taken into account throughout the process of elaborating the EBCP and beyond. Involvement of European patient advocacy group (ePAG) advocates and their education/training is central. This is so given their complete view of the patient journey, and the collective intelligence of these organizations, including the consequences and the conditions of living with/surviving cancer. Often the development of a patient pathway for specific cancers is left to PAs, as they have the necessary experience. NCCPs should involve patients from the start (including prevention and rehabilitation, and not only regarding treatment or palliative care). While patient involvement has improved at the international level, in MS this is often not the case. Patient involvement in key areas of the cancer pathway is of vital importance to cancer patients, like designing and planning cancer policy, framing cancer research questions important to cancer patients, having a seat at the table at HTA negotiations.
- In order for patient associations to be able to carry out their role, it is important to address their funding model, and, ideally, to provide adequate public support and funding in order to increase transparency and effectiveness, while reducing the dependency on funding from industry and other sources that can potentially have undue influence/undermine the legitimacy of its work. At the same time, this initiative, which we propose should be generalized in the MS, would entail accountability and transparency in terms of the use of public funds received. This approach would also help reduce the existing differences in the level of patient associations' presence. Starting from the Health Programme it should be reviewed so that registered EU umbrella organizations are eligible to apply for funding.

2 **Patient pathways, standards of care and patient experience – improving quality, setting standards and addressing cross-country variations**

- Given the heterogeneity of the types of cancer, it may be particularly useful to work on the treatment pathways (itinerary) and patient experience by

stratifying by type of cancer. This should also be reinforced by the development of multidisciplinary teams, where – apart from the different professional disciplines involved in the patient pathway – patient voice needs to be clearly present.

- Timely access to early diagnosis is crucial for all cancers, but there are different mechanisms for common cancers (with emphasis on the importance of screening programmes as well as early detection programmes and action at local/national level) and rare cancers – where early access to specialists/specialist centres, as well as international expertise, is particularly important. In this regard, it is considered very important to foster the European Reference Networks Directive and cross-border care. The role of the ERNs and of cross-border healthcare cannot be stressed enough for the access of cancer patients to the best European cancer expertise. The ERNs should be financially and organizationally supported and linked to similar national reference structures. Flexibility, speed of patient access and possibility of cross-border healthcare are key elements for the growth of the ERNs.
- Measures of quality of life and patient experience currently lag in their importance behind clinical outcomes, while they are just as important and need to be collected and harmonized across the EU. In addition, the EU plays a crucial role in promoting consistent and coherent quality standards in the European context, e.g. implementation of uniform screening programmes, setting standards for quality of treatment, activities by JRC in standardizing all aspects of care for breast cancer (ECIBC), and is currently working on a similar initiative for colorectal cancer. HRQoL should be paired with clinical outcomes, but there is a gap in this area in medical education and clinical oncology specialization training.
- The importance of ensuring that patient voice is heard in regulatory actions, both pan-Europe and nationally, and including in health economics. This should also take note of, and promote, PROs as primary outcomes in clinical studies.

3 More focus on cancer survivorship and rehabilitation is needed in the EBCP

- Focus on cancer survivorship and rehabilitation, including issues such as the right-to-be-forgotten, financial implications, care for cancer carers, addressing discrimination, returning to work, and other aspects.
- Consideration/support for families and carers needs to be addressed as they are crucial to survivorship, especially in the long term.
- Structured follow-up and late effect management also need to be integrated in care pathways. Currently, there is no model at the EU level that could be taken as a starting point for addressing cancer survivorship. Cancer survivorship integration in the cancer pathway has to be designed and planned, taking into consideration the CanCon recommendations.
- Implementation of survivorship follow-up care plans, infrastructures and interoperable IT tools including a Survivorship Passport and integration of patient-reported outcomes to facilitate an appropriate life-long informed care model allowing cancer survivors to live their life at its best potential. The EU can facilitate the implementation of the Survivorship Passport model and long-term follow-up guidance across all MS.
- The needs of younger patients, paediatric, teenage and young adult (i.e. <40yrs old), should be mentioned and planned for at a national level.

4 Data and information collection, management and use across the EU

- There are multiple cancer initiatives happening across the EU, but none of them maps all the initiatives at the European level. Such mapping would be very useful to show where there are gaps and where to focus effort, funding, etc.
- Data interoperability between MS is lacking, with General Data Protection Regulation (EU GDPR) being interpreted differently across countries. More work in harmonization and clarification could be done at the EU level.
- Despite the knowledge that we have of the seriousness of the disease and the cost that it entails, it is alarming to note the lack of knowledge about the impact of interventions, which in itself is related to an alarming scarcity of studies that assess the outcomes of the disease and of the interventions carried out. The information should be readily accessible to address this challenge.
- Challenges for data collection and exchange at the national and international level need to be addressed.

- The opportunities offered by artificial intelligence (AI) need to be explored. In the light of AI and big data collection special attention is needed to explore ethical principles and implications of using AI technology and further ensuring transparency on usage of patients' data concerning in particular paediatric cancers.

5 Fostering innovation

- A more dynamic uptake of innovation should be promoted, especially in rare and ultra-rare cancers (e.g. paediatric field). There is ample room for improvement, following examples of good practice in this field. Moreover, innovation is not restricted to pharmaceutical or technological aspects alone. Organizational innovation, respecting and supporting patients in their journey, and proper shared decision-making models are of outstanding importance.
- What is regarded as 'innovation' should always be superior in term of clinical outcomes and quality of life improvements compared to the well-established standards of care.
- Issues related to accessibility and affordability of prevention, treatments and care services should be at the heart of the EBCP.

6 Improving patient awareness and health literacy

- The EU could foster a proper framework where all communication between healthcare professionals and the patient and their family takes place in the patient's native language. Patients need to be informed, to be able to understand their disease and goals of treatment. Patient empowerment in practice means information at doses patients can receive and use.
- Apart from including information available in native languages, communication; patients should be referred to PAs once they receive diagnosis. Patient organizations have covered the gap in officially available information in many EU MS.
- Patient advocates' education with adequate health and digital literacy are important tools towards meaningful patient involvement in the debate about cancer policy in NCCPs.
- The role of health authorities in the Commission and in MS is to provide trustworthy information and ensure citizens can find it.
- Better communication between HCPs and patients and referrals to specialists and other supportive care services are key for quality cancer care.

7 Addressing commercial determinants of health

- Our existing public health models may risk framing public health problems and solutions in ways that disguise the role that certain large transnational companies play in shaping the broader environment and individual behaviours, and thus population health outcomes. This issue should be reflected in some operational way in the EBCP.
- Financial toxicity of cancer and its impact on households should be assessed to help identify best practices re social security for citizens.

Table 1 *Further comments added by patient representatives*

CCI Europe
There should be a clear dedicated section on paediatric cancers in the Europe's Beating Cancer Plan, which enables not to forget the specificity of the issues in this population. CCI Europe has built a broad network of patients, parents and survivors in the company of trusted and well-founded partnership with healthcare professionals and other patient- and survivor- organizations at the European level (e.g. SIOPE, PanCare). Our cross-border European 'patient voice' proactively contributed to numerous European projects on childhood cancer (e.g. ENCCA, ExPO-r-Net, JARC and PanCareFollowUp), ensuring that urgent needs of children and adolescents with cancer are not overlooked. Healthcare professionals should acknowledge parent, patient and survivor representatives as patient advocates at national and local levels, by approaching and involving them systematically in healthcare systems and further policy cycles. Better integration of patients, parents and survivors as expert stakeholders should be fostered in all MS. Close and respectful collaborations between patients and HCPs in national health policies is pivotal in achieving better outcomes in the area of paediatric oncology. CCI Europe was instrumental in developing the SIOP Europe Strategic Plan – A European Cancer Plan for Children and Adolescents. Based on this framework, CCI Europe is making collaborative steps to pursue the mission of achieving 'zero deaths' and 'zero late effects' from childhood cancer in Europe, with clear milestones to mark progress over time. CCI Europe's involvement in ERN PaedCan is three-fold. First, it had a prior longstanding relationship with the coordinating institute and other centres of the network through the SIOP Europe community and EU projects. Second, the head of the CCI Europe Committee is directly

represented in the Oversight Committee of ERN PaedCan and thus is integrated in the decision-making structure of the network. Third, CCI Europe has four committee members elected to the ERN PaedCan ePAG, a participative patient structure affiliated with the ERNs created by EURORDIS.

The EU can empower patients, survivors and their families all across Europe by involving parent, patient and survivor representatives in development of cancer and health policy instruments, from development to implementation, monitoring and evaluation.

Attachment: CCI Europe (2020). European children and young patients with cancer need action now! Position paper (pdf).

European Cancer Leagues (ECL)

Prevention

The process to update the European Code against Cancer should be initiated by the Beating Cancer Plan. The next edition of the Code should have tailored messages, policy recommendations, and pragmatic guidance for decision-makers and promoters of health (i.e. civil society groups who are intermediaries between scientific knowledge and the general public). This would help develop the Code from being a reference point for reliable evidence on cancer prevention towards being a tool that can help support the adoption of cancer prevention recommendations. The next edition should also be accompanied by a comprehensive evaluation (ECL is drafting an article with IARC on this topic, which should be submitted for review shortly).

Occupational exposure to carcinogens is a significant issue that can be addressed by EU-level action to update and better understand the existing burden and support better compliance to health and safety legislation at the national level. Bold action should be initiated to eliminate occupational cancers – see https://osha.europa.eu/en/publications/reports/report-soar-work-related-cancer.

Artificial tanning devices for cosmetic purposes (sunbeds) are currently regulated by DG GROW under the Low Voltage Directive. We advocate for the cancer plan to take responsibility for initiating a public health-driven approach to regulation of these devices which, according to the scientific risk assessment committees of the EU, are shown to have no safe value and are categorized a class 1 carcinogen by IARC. Ultimately, a policy should be in place to phase out these harmful devices which requires a mixture of action at national level (concerning point of use) and EU level (concerning technological standards and safety) – our recent open letter is at https://www.europeancancerleagues.org/wp-content/uploads/Open-letter-to-LVD-working-party-January-2019.pdf.

We believe that the current crisis provoked by the coronavirus pandemic leads us to emphasize even more strongly that proven, evidence-based measures that are cost-effective and acceptable should be prioritized in order to make best use of scarce resources. Inefficient or non-supported practice should be discouraged or de-implemented with more vocal support by the EU in cooperation with WHO. Action within Europe should also take into account implications at a global scale, for example with regards to the availability of vaccines against HPV, the vaccines should be prioritized towards immunizing girls at an acceptable rate in the currently recommended age group, especially in global regions of greatest need, before age extension or gender-neutral strategies are considered.

More detail on the fiscal policies and other population-wide measures regarding the main determinants of health and key modifiable risk factors for cancer are outlined in our position paper.

Early detection

It is timely to update the council recommendation of 2003 in view of recent developments in cancer screening. The implementation reports on cancer screening should be supported by the EU via a platform that enables the continuous monitoring and evaluation of screening programmes in Europe and facilitates the networking of those institutions managing and working on cancer screening in Europe. The data should be used to assist countries in improving the performance in cancer screening considering the variation that exists on key performance indicators – I attach a report of a recent meeting we have had on this issue and an article on the 2003 recommendation.

Professional groups and patient representatives continue to advocate for the introduction of more screening, e.g. lung, prostate, etc.; which have not yet been recommended for systematic implementation. In the context of the current pandemic, we strongly resist the calls to push ahead at the EU level with implementing costly new programmes without much greater understanding of cost-effectiveness, resource implications and overall balance of benefits and harms. The EU should support WHO efforts and guidance to assist MS in prioritizing effective early diagnosis strategies (specifically for the cancers not covered by existing cancer screening programmes – breast, colorectal and cervical) and discouraging or de-implementing ineffective practice.

Other issues

The EU should make a more overt and visible contribution to the Global Strategy for Elimination of Cervical Cancer. The burden remains unacceptably high in Baltic states and Eastern Europe. The EU can enhance its direct support to countries most in need to implement better proven effective methods in vaccination and HPV testing – see attached articles. The next edition of the cervical cancer screening guidelines is needed soon and should be prioritized.

Considering the important role that the EU Joint Research Centre (JRC) has in EU cancer control actions it would be beneficial to invest further in this resource with additional expertise and support to boost the operational capacity.

2.2 Professional associations

Stakeholder organizations:
European Association for Palliative Care; European Association of Urology (EAU);
European Oncology Nursing Society (EONS);
European Pain Federation (EFIC);
European Society of Gastroenterology, Endoscopy and Nutrition;
European Society of Gynaecological Oncology;
European Society of Medical Oncology (ESMO);
European Society of Paediatric Oncology (SIOPE);
European Society of Radiology (ESR);
European Society of Radiotherapy (ESTRO);
European Society of Surgical Oncology (ESSO);
European Society of Thoracic Surgeons;
European Union of General Practitioners (UEMO);
International Psycho-Oncology Society (IPOS);
World Organization of National Colleges, Academies and Academic Associations of General Practitioners/ Family Physicians (WONCA Europe)

Key points:

1 **Prevention and early detection**

- At least four aspects of prevention were widely agreed as being key:
  - health promotion (including health education and information, strong vaccination programmes), Electronic Cancer Checklist Resources (ECC) could be used/disseminated more;
  - screening, including targeting and risk stratification, health literacy;
  - early detection & early diagnosis; and
  - use of genomics and innovative data analysis.
- The existing screening programmes should be enhanced and provided across all of the MS.

2 **Multi- and inter-professionality**

- Focus group composition and contributions of various health professionals reflected the need for multi-professionality, in addition to multi- and interdisciplinarity ('inter-' emphasizing the interaction and the real synthesis of approaches). Broadening the scope (i.e. ensuring multi- and interdisciplinary care and approach are integrated into treatment planning and decision-making) was widely supported.
- Recognition of contribution of nursing to cancer care (in addition to medical specialties), as well as appropriate safety safeguards;
- Mental health care and psychosocial care are necessary areas of integrated multi-professional cancer care pathways, but lack recognition, funding and standardization across MS and are not included in NCCPs. Distress should be added as the sixth vital sign for measurement, in order to be monitored and treated in cancer patients.
- GPs must be involved and informed in the patient pathway, starting with prevention; better referral systems are needed in case of suspected cancer.

3 **Treatment**

- Linking of radiotherapy to other cancer treatments is currently not featuring adequately in the NCCPs.
- Paediatric cancer is a distinct area for care, treatment, innovation, but there is little incentive to develop treatments for childhood cancer, and it is not consistently recognized as a distinct area in NCCPs.
- Transition from paediatric to adult cancer care is a complex issue and needs to be better developed systematically across Europe.
- Pain needs to be recognized as a cause of distress; standards of pain management need to be developed.
- Palliative care should be integrated in NCCPs from the beginning of care/treatment process, not just at the end.
- Development of multidisciplinary guidelines.

4 **Digitalization and comprehensive data and information management**

- Need for interoperable population-based high quality cancer registries (properly maintained and funded), which should be better connected with the clinical and screening registries and also linked to data related to survivorship.
- Need to invest in research and use of data to continuously improve outcomes for patients and maximize the potential of innovation.
- Making use of big data and innovative technologies that could provide broader and more extensive analyses, new knowledge and base for future research and insight into different challenges of treatment and after-care. Looking also at the

environment, considering exposure to contextual and/or occupational toxicants, consumption and eating habits (e.g. consider working together with the veterinary and agricultural services), drug intake and spotting 'clusters' should all be part of the intelligent management of this information.

5 Access and equity

- These domains were identified as extremely important in view of the challenges of cancer as a complex chronic disease, which requires a strong multi-level and longitudinal approach.
- Inequities not only due to cost, but also shortage in some MS of specific cancer medicines, as well as effective care structures and equipment.
- Inequalities in access to all areas of pathway from prevention to follow-up.

6 Education

- Education was mentioned in different contexts, such as population health literacy and awareness of prevention and treatment options, fight against stigma, education of health professionals (e.g. twinning programmes through ERNs), educating patients, especially in view of the chronic nature of cancer.
- Very large variation in education/qualification of cancer care nurses across the EU.
- Need for harmonization of education and training standards across Europe, to ensure mobility, and agreement on EU curricula.
- Mandate for standard in communication skills in oncology setting is required (e.g. announcement of diagnosis is often poorly done) and would have additional benefits in promoting adherence to treatment and psychosocial functioning.

7 Research and innovation

- Research was identified as one of the key issues in securing the strengthening of the cancer sciences and professional development (by finding solutions to unresolved issues).
- Other angles of research aspect were also mentioned:
  - cross-border clinical trials should be enabled by simplifying procedures;
  - the need to better develop translational, implementation and organizational research; and
  - More focus on outcome-based research is needed.
- Development and validation of new diagnostic methods (imaging, genomics, liquid biopsy, minimum invasive strategies) with the focus on efficiency and cost-effectiveness.

8 EU-wide approaches (broadly)

- Need for strategic action at the EU level (e.g. for monitoring and evaluation).
- Common approach to medicine pricing, safeguarding access to treatment, both for medical devices and medicines.
- Ensuring availability and affordability of medical devices and medicines, and investment in health services research, especially on the cost-effectiveness of healthcare system and specific treatments and in future capacity planning.
- Supporting, endorsing and mandating guidelines across MS (it does not make sense for clinical practice guidelines to be unreasonably divergent).
- Patient at the centre of EU policy.
- European Reference Networks (ERNs) were identified as an excellent organizational tool, which received a lot of support and interest, but all of the speakers who supported them spoke of the complete insufficiency of funding, which prevents ERNs from expanding and from becoming truly relevant.
- Investment in cross-border cancer care when justified, with appropriate reimbursement procedures for patients and for professionals providing virtual cross-border advice.
- Collaboration across different parts/DGs of the EC on EBCP – e.g. Cytotoxic safety includes DG Employment and Social Affairs and Recognition with DG Grow; the S2 mechanism requires reference to the Regulation on the coordination of social security systems.

Table 2 *Further comments added by professional associations*

European Association of Urology (EAU)

Health literacy/health information is crucial to tackling cancer and an EU-wide awareness-raising campaign on prostate cancer early detection would be highly valuable in terms of increasing health literacy in men across Europe.

European Society of Medical Oncology (ESMO)

ESMO (2020) European Society for Medical Oncology's suggestions for the Beating Cancer Plan

https://www.esmo.org/content/download/325787/6548855/1/ESMO-Response-to-Beating-Cancer-Plan-Roadmap.pdf.

European Society of Paediatric Oncology (SIOPE)

A dedicated section on paediatric cancers in Europe's Beating Cancer Plan is ideally positioned to highlight the specificity of the issues faced in this disease area across the patient pathway and to focus implementation efforts accordingly. In this way, Europe's Beating Cancer Plan can drive life-enhancing change for children and adolescents with cancer and position the EU as the global leader in this field. A specific focus on paediatric cancers is supported by the outcomes of the EU Joint Action on Rare Cancers, the new WHO GICC effort dedicated fully to childhood cancer, and evidence of limited public funding of research in this disease area globally, with the need for further investment.

SIOPE is the single, united European organization of academia and healthcare professionals dedicated to childhood and teenage cancers, working across the whole spectrum of activities in this disease area in partnership with parents, patients and survivors. We represent the sector with a track record of fruitful cross-border collaboration in Europe for more than 50 years, including through coordinating roles in EU programmes on cancer. We are thus well positioned to further mobilize stakeholders around the dissemination and successful delivery of the paediatric cancer dimension of the EU Cancer Plan.

In 2015 SIOPE, in partnership with patient advocate groups and the survivors' community, including the umbrella organization Childhood Cancer International Europe (CCI Europe) and the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare), published a detailed long-term strategic plan focused on healthcare and research initiatives to increase survival and the quality of life for children and adolescents with cancer in Europe by 2025. This strategic plan is evolving to keep pace with emerging innovations and can provide a range of pertinent resources for the development of the European plan to beat cancer.

Additional information:

SIOPE (2020). Beating Cancer in Europe: let's not forget our children and adolescents. Attachment to SIOP Europe response to Europe's Beating Cancer Plan Roadmap Consultation.

https://siope.eu/media/documents/siope-response-to-roadmap-consultation-europes-beating-cancer-plan.pdf.

European Society of Radiotherapy (ESTRO)

Develop new frameworks for timely HTA for innovative technologies for locoregional treatments such as RT and surgery.

European Union of General Practitioners (UEMO)

UEMO is strongly of the opinion that general practitioners should be consulted and involved in all policy decisions. They are the first medical contact for 90% of the population and they remain the closest medical source of information. They are often the physician who is most involved with the patient's palliative care and they are charged with the care of the patients' family after the event. The patient and their family are involved in these events. It is essential that communication between the family physician and the cancer specialists is clear and timely in order to facilitate and improve patient care.

2.3 Cancer community

Stakeholder organizations:
European Academy of Cancer Sciences (EACS);
European Alliance for Personalised Medicine;
European Cancer Organisation (ECCO);
European Cancer Prevention (ECP);
European Organisation for Research and Treatment of Cancer (EORTC);
European School of Oncology (ESO);
Organisation of European Cancer Institutes (OECI)

Key points:

1 **There is a need to ensure that the EBCP is effectively implemented and systematically evaluated**

- In order for the EBCP implementation to be successful, it needs to be realistic and measurable, so it should come with a dashboard of indicators that can be monitored, and which would enable evaluation (the data dashboard should include key performance indicators (KPI), metrics and key data points to monitor the effectiveness of this plan).
- There was wide support for the EBCP and it was noted that along with the Cancer mission it shows an understanding of the need to innovate.

- Variation in access to and quality of care results in large variation of outcomes across Europe, and this is one of the key problems. It can only be addressed by systematic evaluation of what has been done, and what achieved, and by the identification of obstacles and barriers at both the EU and national level.

2 **Prevention is one of the cornerstones of the battle against cancer**

- The EBCP could lead in fostering the elimination of HPV-associated cancers as a public health problem by encouraging uptake of HPV vaccination, including proposing a gender-neutral approach, which currently is not implemented uniformly across the EU. Education and counteracting fake news around vaccination are also critical to raise citizens' adhesion to vaccination programmes.
- The EBCP needs to address all known cancer risk factors and prevention interventions. Areas deserving increased attention in the Roadmap include providing further support to the European Code Against Cancer and fostering the enforcement of regulations in areas such as tobacco packaging, food and alcohol labelling, restriction of advertising for unhealthy food products and alcohol, and the banning of artificial tanning devices (sunbeds). See the work of the Association of European Cancer Leagues (ECL), a member of the European Cancer Organisation, in this respect.
- Literacy and awareness are very important for early detection. This is true both among patients and, in a more specialized way, among health professionals.

3 **Early diagnosis and screening**

- Cancer screening requires a push for a more widespread introduction of existing screening programmes, uptake of best practices (e.g. HPV self-sampling), and considering the introduction of some of the proposed.
- A more targeted approach to screening is warranted and appropriate stratification should be considered whenever relevant.
- Early diagnosis remains important in parallel and should be enhanced using the knowledge from sciences, such as genomics and AI, biomarker testing.
- The EU could play a larger role in supporting high quality diagnostics with more dedicated funding, supporting laboratory capacity, as well as clear guidelines, stricter regulation, quality control and more emphasis on education.

4 **Inequalities in quality of cancer care and access across the EU continue to be stark, and need to be tackled**

- Quality of oncological care shows excessive variation across the EU and even within MS. The EC could play a crucial role in encouraging the use of accredited methodology and promoting quality, standards and certification of cancer care centres, as well as encouraging research and excellence.
- Work on quality assurance mechanisms is necessary, ranging from accreditation mechanisms through a network of accredited CCCs and their related networks through to the implementation of adopted guidelines. The EU could push for more accredited national CCCs.
- At the EU level the therapeutic value of digital tools (e.g. in diagnostics, patient monitoring) could be better recognized and receive more prominence.
- Emphasis should be on the availability of quality/effective and cost-effective interventions.
- In some MS there are issues of access, sometimes not due to the cost of, but to a shortage of effective and not expensive medicines.
- OECI have been building consensus in achieving core quality standards for cancer centres ('100 Core Standards for Europe' was published in Lancet Oncology in August 2020).

5 **Collaboration, ERNs**

- Networking and collaboration of cancer institutions within and between countries is essential for research and for further quality improvement in cancer care. They also play a role in bridging the gap in access to high quality cancer care as well as in overcoming the existing differences.
- The EBCP could serve as a policy instrument to encourage the creation of cancer networks within countries and internationally.
- Networking would also help in providing better access to clinical trials, and provide adequate research capacity and power to smaller MS.
- ERNs were widely recognized as a welcome initiative with huge benefits, in particular for rare cancers, and a positive experience among cancer organizations. It

was also recognized that ERNs were well set up and with good vision, but they are severely underfunded and should be invested into much more. Also, better coordination at international level is needed.

- Access to expertise through cross-country molecular tumour board settings for difficult cases (e.g. rare diseases). At the moment it is not possible in certain countries to upload or share patient data for consultation on cloud platforms with physicians in other countries. It would be good to find a uniform agreement for online consultations through standardized exchange platforms across Europe.

6 Data sharing for research and decision-making

- Creation of structures in research centres to collect and share data, including PROMs and PREMs, clinical outcomes, economic evaluations. Collection and use of real-world data.
- The EU could play a larger role in supporting data sharing infrastructure (e.g. platforms for data sharing) and promoting availability of information for decision-making at the national and the EU level.
- There is an opportunity from linking genomics and outcome data (e.g. through standardized registries) on a European level. These databases could be made accessible to European public and private research institutions and would as such strengthen Europe as an innovation centre.

7 Education, expertise, creation of human resources in cancer care

- Human resources continue playing the key role and investment in the development of human resources is key to the future strength of oncological care in Europe.
- There is a large divide across Europe in education of health professionals working with cancer. The EC could play a role in establishing common frameworks for education.
- Some MS have a deficit in expertise – cross-country tumour boards are a welcome initiative but need to be supported at the EU level.
- The EBCP could consider oncology workforce planning for future needs, as shortages of some cancer specialties are becoming visible already, resulting in longer waiting times for patients.

8 Person-centredness and user experience

- Patient-relevant and patient-meaningful outcome and experience measures are the ultimate measures of the quality of cancer care. They should be introduced as key indicators at national, regional as well as institutional levels. Adequate provisions should be made in population-based and clinical registries to provide for the respective datasets.
- Tangible reference points are needed for patients and families, including providing information about the patient journey along the whole pathway.
- There are gaps in clinical pathways, as they don't necessarily reflect needs of patients.

9 Research and innovation in cancer is essential for further successful advances

- It needs to be stressed that particular shortcomings and insufficiencies are present in translational, outcomes and organizational research. These areas of research in cancer need to be strengthened and incentivized in order to improve cancer care through evidence of best practices.
- The EC could play a role in supporting multi-centre clinical trials and improve access to CTs.
- Innovation can play an important role in cancer care, but requires resources that in some MS are more limited than in others.
- Genomics with focus on cancers could be facilitated by the EU, as it requires linking platforms at the international level.

10 Costs, HTA and independent evaluations

- The EU can play a role in finding ways to mitigate rising costs of promising but extremely expensive treatments and ensure equal access to those. Stimulating close cooperation between health economists, epidemiologists and clinical researchers will improve the ability to critically assess the value of treatments and to stimulate appropriate priority setting in research to take forward public health questions such as duration of treatment, combination, sequence, etc., which will provide better grounds to identify the true medical added value and support for coverage schedules.
- Further cooperation on combined purchasing, exchange of coverage schedules and price arrangements, such as by working with the

European Fair Pricing Network, may assist in supporting the cancer services' sustainability.

- HTA should be much more centralized at the EU level, which would provide more power for competent decision-making. New types of datasets should be generated for this purpose. These should reflect the needs of cancer patients and of the medical community. These should be generated free of commercial interest.
- Independent evaluation of treatments, including multidisciplinary interventions, is needed. This must be based on prospective clinical research in healthcare systems assessing medical interventions based on clinically meaningful end-points which make a difference for cancer patients. Optimizing anti-cancer multidisciplinary treatments needs better balance between commercial and independent research. EBCP could provide structure for independent research.
- All cancer treatment modalities need to be given attention within the EBCP. Increased emphasis and support are needed for cancer surgery, radiation therapy, interventional oncology and nuclear medicine. The most pressing issues to be addressed in these areas include workforce education and shortages, support for research, professional qualification recognition and investment in required infrastructures. See the work of the European Society of Surgical Oncology (ESSO), the European Society for Radiology and Oncology (ESTRO), the Cardiovascular and Interventional Radiological Society of Europe (CIRSE) and the European Association of Nuclear Medicine (EANM), all members of the European Cancer Organisation, in these areas.

11 **Other points: survivorship and geriatric oncology**

- Survivorship: addressing financial discrimination, through widespread implementation of the 'right to be forgotten'. It is also critical that the EBCP provides increased attention to physical/medical needs of cancer patients and survivors in respect to their quality of life, including the management of increasing cancer treatment long-term side-effects and cancer co-morbidities. See the work of the Multinational Association for Supportive Care in Cancer (MASCC), a member of the European Cancer Organisation, in these areas.
- Geriatric oncology is an increasing burden, yet is not mentioned in the EBCP, and should receive at least some attention. See the work of the International Society of Geriatric Oncology (SIOG), a member of the European Cancer Organisation, in this respect.

Table 3 *Further comments added by cancer organizations*

European Academy of Cancer Sciences (EACS)

1 Multidisciplinarity and innovation are essential for achieving high-quality cancer care and rehabilitation. The organizational model is the Comprehensive Cancer Centre (CCC) as these institutions have the mission to deliver multidisciplinary care and innovation. Currently, they are accreditation methodologies developed by the OECI and German Cancer Aid, and today we have 35 accredited CCCs in the EU, two of which are designated as CCCs of Excellence by the European Academy of Sciences (EACS) quality assurance of translational cancer research. There is a need to have at least one CCC per EU country and in countries with a larger population one per 5 million inhabitants. Each CCC should have the responsibility to quality assure a geographical outreach area. Development of CCCs will contribute to decreasing present inequalities both within and between countries.

A prerequisite for translational cancer research, which is needed to innovate, is to integrate research and healthcare; meaning that healthcare is a part of the infrastructure required to carry out this research. To reach the critical mass and to cover all the components of the cancer care continuum, networks of CCCs will be essential to build infrastructures for early translational research, clinical trials and outcomes research. Coordination of clinical trials activities for therapeutics and early detection, including prevention screening and evaluation of benefits for the healthcare by outcomes research, is an unmet need. Structuring outcomes research for both prevention and healthcare requires standard clinical guidelines with follow-up linked to quality-assured clinical cancer registries and collaboration with population-based cancer registries.

2 Make better use of current evidence from prevention research, implementation research and evaluation of effectiveness and health economics by outcomes research. Improve interaction/integration between research and organizations responsible for primary and secondary prevention.

3 It is critical to separate early detection of invasive cancer from prevention based on detection of premalignant tumours. The lead-time bias due to early detection of invasive cancer may have spurious effects on both incidence and survival. Evaluation of effectiveness, including health economics of screening programmes, is essential. Research is needed to develop diagnostics technologies for identification of relevant early tumours and improved selection of high-risk individuals. It is also

necessary to avoid unnecessary surgical treatment of indolent tumours. Biomarker research to identify early lesions, both premalignant and malignant, is recommended, as well as registries with clinical and biological data for computational science.

4 Stimulate the development of CCCs in all MS, promote collaboration in networks, and build infrastructures for early translational research, clinical trials and outcomes research with accessibility to researchers in all MS. Expand educational activities to support all MS. The EACS and the newly established Central-Eastern European Academy of Oncology have agreed to collaborate by bridging cancer research in Western and Central-Eastern Europe with the ambition to cover and improve cancer care, rehabilitation, prevention, research and education. Creation of 'twinning' between centres is one recommendation, which has been implemented between the German Cancer Research Center, Heidelberg, and Athens, and between Stockholm and Budapest.

5 The development of personalized/precision cancer medicine is necessary, given the large number of subgroups within each cancer diagnosis. Furthermore, in the future, all diagnostic tumour groups will be rare. As mentioned above, networks of CCCs will guarantee the necessary infrastructure support.

6 Promote quality assurance of clinical and biological data.

7 —

8 Bridge critical gaps: supportive care, psychosocial oncology, rehabilitation, long-term follow-up and survivorship.

9 Quality of cancer care and innovation partly overlap. Priorities between different areas like therapeutics, prevention and the various components of the cancer care pathway are essential. Recommendations as to how to build infrastructures and select areas of research priority are presented in 'Towards a cancer mission in Horizon Europe: recommendations' (attached). The EACS will continue outlining strategies for infrastructures and research together with other cancer organizations. Aligning priorities and policies between the European Commission and the MS is a major challenge, and here the EACS´ Science Policy Committee is willing to contribute.

10 Well developed outcomes research is a prerequisite for assessment of health economics. Structuring practice-changing clinical trials linked to implementation research should involve evaluation of clinical effectiveness and health economics as a gatekeeper before dissemination of innovations to healthcare.

Additional information:

Towards a cancer mission in Horizon Europe: recommendations.

Berns A, Ringborg U, Celis JE et al. (2020). Mol Oncol, 14:1589–1615. doi:10.1002/1878-0261.12763. https://febs.onlinelibrary.wiley.com/doi/full/10.1002/1878-0261.12763.

European Alliance for Personalized Medicine

1 Particularly in cancer, the important role of high quality diagnostics (Dx), as well as pathological expertise, is not yet broadly recognized. Dx are not regarded as an innovation in the same way as medicines, but more as a cost centre. Misdiagnosis causes poor outcome and unnecessary costs. We see opportunities for more dedicated funds, clearer guidelines, stricter regulation, quality control and more emphasis on education.

2 In many countries, there is a lack of expertise, particularly as science in oncology is evolving so quickly. We do see two opportunities here:

- Access to expertise through cross-country molecular tumour board settings for difficult cases (such as rare diseases). At the moment it is not possible in certain countries to upload or share patient data for consultation on cloud platforms with physicians in other countries. It would be good to find a uniform agreement for online consultations through standardized exchange platforms across Europe.
- Classification of algorithms and services that support physicians during diagnosis and the identification of best treatment pathway (decision-support), so these services can be paid for and as such expert knowledge can be scaled.

3 Many countries still have separate scientific/HTA bodies and reassess what has already been assessed by others re cost effectiveness and therapeutic value. This unnecessarily delays access to innovation and could be handled through a more coordinated, centralized approach.

4 Access to clinical trials is quite limited in most countries. If there was a more networked approach to it, that could also help early access to innovation.

- There is a huge opportunity from linking genomics and outcome data (e.g. through standardized registries) on a European level. These databases could be made accessible to European public and private research institutions and would as such strengthen Europe as an innovation centre. It could also allow us to apply analytics to learn from patient cases in real time for future decision-making
- There is also work at EU level to recognize the therapeutic value of digital tools e.g. in the area of diagnostics or patient monitoring during/after the disease episode. In the area of patient monitoring, it can save costs for unnecessary visits, respectively too late interventions while improving survival and quality of life.

European Cancer Organisation (ECCO)

In support of the comments provided by the European Cancer Organisation during the July and August 2020 targeted stakeholder consultation, please also see:

Strengthening Europe in the Fight Against Cancer, July 2020

The European Cancer Organisation was commissioned by the European Parliament to produce a landmark study on the current state of play in Europe's battle against cancer. Compiled with input from 61 experts over a six month period, the study's 45 recommendations are intended to provide Members of the European Parliament with a strong evidence-based foundation for their scrutiny and suggestions for the Europe's Beating Cancer Plan, the EU

Cancer Mission and associated initiatives such as the new EU Pharmaceutical Strategy and EU4Health Programme.

Eliminating HPV-Caused Cancers & Diseases in Europe, December 2019

The publication sets out the evidence base for policy actions on HPV-caused cancers. To be conducted as part of the WHO's Global Strategy for the Elimination of Cervical Cancer, the European Cancer Organisation is calling for urgent evidence-based action to eliminate cancers and diseases caused by HPV in Europe. Key points raised in the document include:

- HPV-caused diseases can be prevented by vaccination, ideally before exposure to the virus;
- Vaccination is most effective if provided to both sexes. However, most countries in Europe do not yet vaccinate boys; and
- Vaccination uptake remains low in some countries and needs to be improved.

Cervical cancer screening is provided in most EU countries, but not all. Most countries do not yet offer HPV testing, now recognized to be the most effective screening method.

Response to the Beating Cancer Plan Roadmap consultation, February 2020

Conveyed 12 key areas (alongside associated policy recommendations) that members of the European Cancer Organisation, supported by its Patient Advisory Committee, consider should be covered in Europe's Beating Cancer Plan:

1. Set Ambitious Goals to Inspire and Galvanise
2. Ensure ALL Stakeholders are Involved
3. Focus on the Quality of Cancer Care
4. Take Action to Improve Survivorship and Quality of Life
5. Achieve Better Integration of Primary Care into the Cancer Care Pathway
6. Address Inequalities
7. Support Healthcare Professional Education and Mobility
8. Improve Data Use and the Evidence Environment in European Cancer Care
9. Be Courageous on Primary Prevention
10. Increase Health Literacy
11. Assist Early Detection Including by Updating EU Screening Recommendations
12. Improve Access to Outcome-Improving Innovation

Shorter summary here: https://www.europeancancer.org/policy/13-policy/1-the-europe-s-beating-cancer-plan.

European Code of Cancer Practice

Building on concepts developed by the *European Cancer Patient's Bill of Rights*, and modelled on *the European Code Against Cancer*, the forthcoming European Code of Cancer Practice will aid the achievement of Quality Cancer Care by empowering all cancer patients with a concise tool for understanding and expressing the rights they are entitled to expect after receiving a cancer diagnosis.

The Essential Requirements for Quality Cancer Care

The Essential Requirements for Quality Cancer Care (ERQCC) papers are organizational specifications, not clinical guidelines, and are intended to give oncology teams, patients, policy-makers and managers an overview of the elements needed in any healthcare system to provide high quality care throughout the patient journey. References are made to clinical guidelines and other resources where appropriate, and the focus is on care in Europe. Written by European experts representing all disciplines involved in cancer care, as well as patient representatives, the ERQCC papers provide roadmaps to high quality multidisciplinary cancer care for a specific tumour type.

European Cancer Summit resolution on combating financial discrimination against cancer survivors

Stakeholders from the cancer patient, healthcare professional, commercial provider, research and other communities came together at the ECCO 2018 European Cancer Summit to form and pass a resolution calling for the French 'right-to-be-forgotten' legislation to be enacted across Europe.

European Cancer Organisation response to the EU Pharmaceutical Strategy Roadmap consultation

Emphasized: the need for an ambitious pharmaceutical strategy that helps to remodel incentive structures and support innovation in all areas of treatment and care. The strategy should also help to:

- resolve the current political impasse on the HTA cooperation proposal;
- leverage data and new tools in a more coherent and powerful way; and
- reduce bureaucracy in the clinical trial landscape, and urgently address the medicines shortages crisis.

European Cancer Organisation commentary on the EU4Health Programme, July 2020

Emphasized:

- The role the EU4Health Programme could play in supporting non governmental organizations as the agents of effective on-the-ground delivery of core EU health objectives, including those of the forthcoming Europe's Beating Cancer Plan;
- The potential value of an EU-supported European Cancer Dashboard to support core delivery of the Beating Cancer Plan aspirations by engendering ongoing reporting on performance and access covering such matters as screening, medicines, radiotherapy, oncology surgery, supportive care, pathology, imaging, specialist cancer nursing, oncology pharmacy, interventional radiology, nuclear medicine, palliative care, and psycho-oncology; and
- The opportunity the EU4Health Programme could play in supporting greater patient empowerment and engendering of health systems with a strong sense of patient rights.

European Cancer Organisation commentary on WHO Europe 2020–25 Workplan

Emphasized the need for WHO Europe to play a role in coordinating efforts across Europe towards achieving the WHO Global Strategy for the Elimination of Cervical Cancer.

Also encouraged WHO Europe to provide a guiding role with its member countries on such matters as:

- combating the negative impact of fake news on public health, including in deterring vaccination;
- overcoming the challenges associated with medicines shortages and securing a long-term resolution of the problem;
- achieving successful disease prevention strategies and effective early detection strategies (e.g. in respect of tobacco control, alcohol misuse, physical activity, diet, sunbed use, screening programmes, etc.);
- preparing health systems to best utilize and prepare for opportunities provided by the fourth industrial revolution, including artificial intelligence, and big data;
- understanding opportunities to achieve greater efficiencies in healthcare provision; and,
- making all of Europe a dynamic environment for excellent health research.

The Nine Focused Topic Networks of the European Cancer Organisation

On behalf of its Member Societies and Patient Advocacy Groups, the European Cancer Organisation convenes interested stakeholders around nine important topics. Led by co-chairs from our Member Societies, these Networks have been established to facilitate consensus and joint projects in our Strategy 2020–2023. The nine topics are: Health Systems and Treatment Optimization; Quality Cancer Care; HPV Action; Digital Health; Workforce; Inequalities; Prevention; Survivorship and Quality of Life; and the impact of Covid-19 on cancer.

Some further commentary about:

The need for unifying, galvanizing ambitious goals

In any arena of life, setting goals can push things forward. In healthcare and other policy areas, targets help to break down barriers between political groupings, government agencies, professions, other stakeholders and interest groups as all work towards a shared aim. Clear goals energize and make actions measurable with respect to the impact being achieved.

Potential goals suggested by the European Cancer Organisation include:

- the European Cancer Concord's recommendation of achieving 70% long-term survival for patients with cancer by 2035;
- doubling survival for intermediate and poor prognosis tumours; and
- the 2019 European Cancer Summit resolution for the EU to eliminate HPV-caused cancers as a public health problem.

The case for a European Cancer Dashboard

Early in the public discussions about the potential beneficial content of the Europe's Beating Cancer Plan was the floated concept of creating a 'European Cancer Dashboard'. In its March 2020 response to the Roadmap consultation on the Plan, and in reference to the above stated challenges for access to high quality cancer treatment and care, compromising all essential requirements, the European Cancer Organisation recommended that such a Dashboard include simple measures to report on the access cancer patients have across Europe to essential components of treatment and care. Elements to monitor and report upon in this respect could include access to screening, medicines, radiotherapy, oncology surgery, supportive care, pathology, imaging, specialist cancer nursing, oncology pharmacy, interventional radiology, nuclear medicine, palliative care and psycho-oncology.

Bolstering the power of European Reference Networks to drive change

The establishment of European Reference Networks has opened a great range of possibilities for meaningful pan-European collaboration in the field of rare cancers. ERNs have proven instrumental in addressing the scarcity of clinical expertise in rare cancers and improving treatment and care of rare cancer patients, via sharing of clinical cases, rationalization of patient referral and improved rare cancer management in small countries. Numerous further potential roles for ERNs have been identified, including fostering the production of clinical practice guidelines for rare cancers, facilitating biobanking, achieving efficiencies of scale in clinical trials, and improving access to potentially practice-improving data. However, the continuation of ERNs' role and their further development is critically reliant on their support by long-term funding. In the newly published landmark study 'Strengthening Europe in the fight against cancer', the European Cancer Organisation provides strong support to recommendations from the EU-funded Joint Action on Rare Cancers and unanimous calls from the European rare cancer community for securing long-term funding of ERNs and thereby ensuring the sustainability and capacity of these networks, as part of the Europe's Beating Cancer Plan.

Genetic testing

Hereditary cancers, due to cancer-causing germline genetic mutations, significantly contribute to the European cancer burden, accounting for 5–10% of cancer cases. The management of these cancers is critically reliant on the identification of individuals at high risk of cancer through the provision of genetic germline testing and associated genetic counselling. These individuals can thereafter be directed to risk-adapted primary prevention and early detection strategies, ultimately contributing to decreasing the cancer burden and improving cancer outcomes. In spite of its benefits, proven cost-effectiveness and dropping costs, access to genetic germline testing is not yet routine across Europe and significant inequalities subsist in the provision of risk-adapted interventions to those tested positive. In its newly published landmark study 'Strengthening Europe in the fight against cancer', the European Cancer Organisation recommends that the Europe's Beating Cancer Plan provides specific attention to increasing the access to genetic germline testing and associated genetic counselling. Specifically, these parameters should be measured as part of a European Cancer Dashboard and the EU should assist in the establishment and endorsement of clear guidelines, ensuring that European citizens benefit from the best clinical and ethical standards at national level. See also the work of the European Tumour Hereditary Group (EHTG), member of the European Cancer Organisation, in this respect.

The breadth of the inequalities issue

The European Cancer Organisation has recently constructed a new Network of its members, patient representatives

and others to help bring focus to the issue of inequalities in cancer care and to promote timely policy recommendations to assist in ameliorating inequalities. Early considerations of the Network have indicated the breadth of the issue, with inequalities highly evident not only in respect to geographical/country differences in Europe, but also inequalities between age groups and social groups. Inequalities are also evidenced in all areas of the cancer care continuum, including in respect of prevention, screening and early detection, treatment (including all modalities), survivorship and follow up care. Further outputs from the Network will be made before the end of 2020, but in the meantime, the multi-faceted and broad nature of inequalities should be well noted and, we hope, reflected within the Beating Cancer Plan. https://www.europeancancer.org/topic-networks/7:inequalities.html.

The Professional Qualifications Directive

Europe's Beating Cancer Plan, in driving for powerful change across Europe in respect to cancer policy, must, by its very nature, draw upon wide areas of EU competence, and not only those within the field of DG Sante. An example of an area of legislative competence of the EU that could play a very strong role in driving improvement in cancer care, but that is outside DG Sante's remit, is the field of professional qualification recognition. Presently, regulations such as the Professional Qualification Recognition Directive are applied through a Single Market focused lens, i.e. the Commission tends to take up a case for helping a qualification to be recognized at the European level usually after a single market-related problem has been identified, i.e. a barrier in labour mobility. However, professional qualification harmonization and mobility are not only a benefit to single market operation. In respect to healthcare and cancer care, a coordination of training and education requirements can open up wholly new avenues for elevating professions, and the level of care they provide, across many countries. We would therefore recommend that the role of the EU in assisting and promoting coordination of professional qualification, education and training requirements be considered an aspect for inclusion in Europe's Beating Cancer Plan. All relevant departments of the European Commission should be drawn into the shared battle to combat cancer together.

European Cancer Prevention (ECP)

1 ***Evaluation of cancer policies***

Primary key performance indicators remain cancer mortality and incidences per organ and per region. From these figures we know that cancer mortality in the EU, France, Germany, Italy, UK, USA and Japan have declined by almost 50% in the last 25 years. Never in history have we experienced a similar triumph over deadly diseases. But other intermediate key indicators should be considered as well:

- Diagnostic and therapeutic adherence to international guidelines;
- Off-label use of drugs that were accepted for small range indications but have the potential to increase cure rate and survival in other cancers;
- Acceptance of drugs that are not provided by the pharmaceutical industry but have proved to be effective (e.g. no patent applicable); and
- Measurement of quality of cancer care by quantitative measures.

2 ***Cancer prevention***

Primary cancer prevention should prevail in all circumstances because it is highly effective at reasonable costs. History has learned important lessons:

- Availability of non-contaminated drinking water to all citizens: this means network of drinking water supply;
- Preservation of food by freezing: this means electricity to all EU citizens and the availability of food freezers. Preservation by pigments, salts, smoking should not replace freezing;
- Preservation of hygiene: by allowing every EU citizen to have a daily bath (means electricity and water supply);
- Continued lifestyle education such as smoking cessation, alcohol, drugs, etc., that prevent adequate nutrition;
- Nutritional guidelines for the next generations (high caloric foods, fast (white) sugars, fats, beverages, etc.). In particular, for children;
- Guidelines on physical activity (minimal activity guidelines for children and adults);
- Vaccination for virus related cancers;
- Monitoring of primary preventive measures on an individual level (personalized); and
- More EU funded research on primary prevention.

3 ***Early diagnosis and screening***

Cancer screening is still a matter of debate. The most important reasons for this debate are differences in basic medical care (the higher the care, the less important screening is) and the absence of a personalized approach (not everybody has the same risk of getting cancer). Molecular biology might be a great way to classify individuals at different risk.

- Breast cancer detection for high risk women (based on polymorphisms, lifestyle, mutation status, etc.);-
- Lung cancer detection in smokers by navigational techniques that offer cure during the same intervention;
- Colon cancer detection in family members of cancer patients;
- Stomach cancer (see STOP project) in individuals with Helicobacter infections and lifestyle characteristics; and
- Cervical cancer: non-vaccinated women with risks from lifestyle.

4 ***Inequalities in quality of care***

The accreditation mechanism should go from bottom up:

- Oncologists (qualified training, focused on cancer (100% cancer care job), at least five years' experience, training in communication, scientific education and affiliation with research center;
- Oncology department: comprehensive or focused means different accreditations
- Hospital: comprehensive or focused;

- University hospital: with emphasis on education and clinical studies – no competition for regular cancer care – forced to collaborate with first and second admission centres;
- Regulatory instances in line with European accreditation programmes; and
- Governmental issues: identification of the Ministry that communicates with the healthcare system and EU for a transparent quality system. Commitment to provide financial means for high quality cancer care.

5 ***Collaboration***

Horizontal networking (between similar levels of care across borders) and vertical networking (primary, secondary, university levels of admission) should be integrated for expanding knowledge, guidelines, participation in clinical trials, concentrating expertise, integration of various specialties (medical oncology, radiotherapy, ablative systems, molecular biology, interventional radiology).

6 ***Data sharing***

Data sharing should make available knowledge more transparent and should not complicate decision-making and research.

7 ***Creation of human resources***

Human resources are part of the resources that should be created by governments (see above). More important is that the healthcare worker is appreciated, that somebody who works as a nurse is as important as a physician, professor, researcher, etc. There must be a free flow from healthcare workers based on specialty, knowledge and experience.

8 ***Person-centredness***

The first goal of the cancer patient is cure, no matter what this takes. A government that denies access to life-saving treatments because of, for example, high costs is not worthy to participate in the European dream.

For patients for whom there is no cure, their hope is to live life, if possible, in a comfortable way. This means the right products and techniques to provide tumour control, the coaching to keep mental health to the highest level, and maximal control over side-effects and symptoms.

9 ***Research and innovation***

Most new ideas come from start-ups by researchers that want to take risks to provide answers to unmet needs. Even the brightest ideas may fail because:

- Inadequate financing techniques, e.g. banks consider young enterprises as regular business (e.g. restaurant business) and ignore the long investment periods that are necessary to bring an innovative idea to the market;
- Financing medical companies is a delicate and risky endeavour. There should be a kind of accreditation towards companies, individuals, banks, etc., that are in this market;
- Inadequate cost-structures: a small enterprise for example needs to pay the same registration costs as a multinational;
- Approval of medicines and medical devices is complex. For some an easier way might be essential; and
- Too many intermediates: notified bodies, national representatives, controlling bodies, regulatory labs (certification processes), ISO standardization costs, etc.

10 ***Costs, HTA and independent evaluations***

Cost mitigation is indeed a most important and critical issue. Too many instances are involved that claim to be inevitable for reducing risk, increasing quality, etc., but create costs for inventors and healthcare workers.

The huge profits of international pharmaceutical and medical device companies eventually are used to create more profits and steer the healthcare system. Indications for use are created with the sole goal to increase revenues and profits. Delegates of these larger companies have a permanent seat in the healthcare providing system in various countries.

11 ***Other points***

Personalizing oncology means special attention to individuals or groups that share similar characteristics. Geriatric patients indeed are such a group as well as children, socially deprived people, single parents, etc. The local care system should provide alternatives for these classes.

Families of cancer patients deserve attention: for example, husbands of breast cancer patients, partners of impotent prostate cancer patients and children of cancer patients. Cancer patients come from a social environment and this environment status needs to be incorporated in the comprehensive care.

The above remarks are general and need to be worked out per item but also in concert with the remarks made in other aspects of cancer care. The main departing view in cancer care comes from the individual with cancer. The care system has to be built upon every aspect of the biological, psychological, social and environmental health of the individual.

European Organisation for Research and Treatment of Cancer (EORTC)

In general, the EU should build on existing organizations and support optimizing existing solutions which have delivered therapeutic progress for patients. The EU should, therefore, look at the track records of organizations which are hands-on for topics of interest and relevance and have already delivered and continue delivering multidisciplinary therapeutic improvement for cancer patients. The EU should discuss today the actual needs for the oncology of tomorrow with such organizations. Active, fit-for-purpose organizations which are on the top of current issues such as evolving biology and generating new types of datasets should be given a specific role according to their competences and based on what they can deliver. Delivering new types of knowledge should drive the process of changing policy for access to treatments in the EU for cancer patients. This can only be achieved by implementing patient-centred research into healthcare systems. Taking forward and enabling priority clinical questions for cancer patients and developing the appropriate research to answer those questionswould be seen as major achievements, complementing the mostly drug-centred systems which exist today in Europe.

Additional information:

OERTC (2020). Treatment Optimisation and Health Systems https://www.eortc.org/app/uploads/2020/05/Manifesto-29052020.pdf.

2.4 Public health organizations

Stakeholder organisations:
Association of Schools of Public Health in the European Region (ASPHER);
EuroHealthNet;
European Health Management Association (EHMA);
European Network for Health Technology Assessment (EUnetHTA);
European Public Health Alliance (EPHA);
European Public Health Association (EUPHA);
International Association of National Public Health Institutes (IANPHI);
Non-Communicable Disease (NCD) Alliance

Key points:

1 **Overarching policy approach to strengthen public health and primary prevention**

- Focus on the overarching policy approach to strengthen the roots of public health, in which the EBCP is framed.
- Develop the principles outlined in article 168 of the EU Treaty with a 'Health-in-All-Policies' approach. This should be done both by means of structural approaches for providing the right environment for protecting and promoting health, along with behavioural approaches for improving lifestyles. Prevention of NCDs in general will have impact on preventing cancer.
- Articulate stronger regulations on tobacco and alcohol control (including cigarette prices, uniform tax policies, alcohol industry is still being promoted via agricultural incentives), environmental regulation (reducing air pollution, carbon emissions and plastic – Green Deal) at the European level.
- Transition to the Green Deal needs to be done in a socially just way – without disadvantaging vulnerable populations.
- EU-level policy development on cross-border marketing and advertising, including digital, provides an important opportunity for synergies across alcohol, tobacco and food, especially also with a view on protecting children and young people (in line with the EU's agenda on children's rights). The EU has taken measures in the past, but more can be done on obesity, inactivity. Next steps could involve development of policy toolkits to support MS in implementation of effective measures in these areas, e.g. with a view to designing and implementing sugar taxation policies; assisting municipalities with guidance on the implementation of urban planning policies for fast-food outlet density in a way that is compatible with EU law; assisting municipalities with the development of active and clean transport policies, etc.
- European Programme of Work could be used to maintain momentum and work in synergy.
- European public health groups can contribute with advocacy actions.
- Strengthening of vaccination programmes.
- Health is political will – EU can lead and encourage decision-makers in MS.
- EU-led process to encourage health system reforms towards prevention (e.g. through European Semester).
- Budget for public health/prevention across the EU is still very small in terms of share of health expenditure (around 3%), and budget for public health research.

2 **Health inequalities are one of the biggest challenges in the EU**

- Address the different dimensions related to reduction in health inequalities. The drivers of these inequalities include socioeconomic and commercial determinants of health, and factors such as risk behaviours (e.g. tobacco, alcohol, food-related) and can be addressed by policies at the EU level that focus on the creation of health-enabling societal conditions and living environments to empower and facilitate healthy living.
- Inequalities in access to cancer treatments (affordability and capacity of the systems to deploy integrated care models) are important challenges that the EBCP should tackle.
- Practical ways to minimize unjustified diagnostic and therapeutic variability, and its consequent inequalities, involves a commitment to ensure that clinical practice guidelines and the evaluation of biomarkers and medical devices are established at a European level, promoting digital technologies that are truly useful.
- All countries have vulnerable groups that are also more at risk of cancer and with less capacity to deal with its consequences.

3 **Investment in training and education towards capacity building in public health**

- Investment in public health skills, advocacy, next generation of public health professionals.
- Training of professionals who can help navigate patients with complex needs through care pathways.

4 **Strengthening research and collaboration**

- Research strengthening and research funding at EU level should include epidemiology and prevention, implementation, clinical, economic, outcomes, and organizational research, as well as funding on knowledge translation for policy-making. Research for policy development and innovation is needed to facilitate MS' prevention policy efforts.
- At the same time, a lot of existing knowledge, particularly on prevention, is not implemented.
- EU added value could be in exchange of best practices; EuroHealthNet can support this initiative and contribute. The EC initiative on breast cancer (ECIBC) model, which includes an evidence-based approach and good communication with MS, as well as providing updated guidelines, harmonization of lab measures/indicators (ISO standards), could be developed for other cancers.
- Health policy platforms could be used more for communication with the Commission and across MS.

5 **Cancer, multimorbidity and integrated models of care**

- The number of cancer patients with multimorbidity is increasing, and so is the number of geriatric cancer patients. This requires integrated models of care that could be highlighted more in the EBCP.
- Use of B3 maturity model.
- Mental health support is not reflected enough in the EBCP; it is important at all stages and needs to be integrated into pathways.

6 **HTA should be promoted to give rationality and European coherence to decision-making**

- Ensure access to the best treatments and diagnostics for the patients. National HTA bodies need better evidence and transparency on medicines and clinical interventions. EU could also support collaboration and cooperation between HTA bodies.
- There is a need for availability of scientific data on both positive and negative results, particularly for HTA agencies – a move which could be supported by the EC.
- The EU could play a larger role in transparency on pricing of medical products and information sharing, although it is recognized that pricing decisions are ultimately in the remit of MS.
- There is a need to develop EU-level economic evaluation strategies.
- Patient involvement in decision-making, including for HTA.

Table 4 *Further comments added by public health organizations*

European Public Health Alliance (EPHA)

EPHA supports the recommendation in the Mission Board for Cancer report 'Conquering Cancer: Mission possible' about the creation of a 'Policy Support Facility' (see Recommendation 3). Such a facility could prove instrumental in supporting MS with the effective development, implementation, enforcement, monitoring and evaluation of some of the prevention policies mentioned above, and those included in the WHO 'Best Buys and other recommended interventions for the prevention and control of NCDs'.

EPHA (2020). Prevention at the heart of Europe's Beating Cancer Plan – joint statement.

https://epha.org/wp-content/uploads/2020/02/prevention-at-the-heart-of-europes-beating-cancer-plan-joint-statement-17-2-2020.pdf.

2.5 Industry

Stakeholder organizations:
European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry (COCIR);
European Federation of Pharmaceutical Industries and Associations (EFPIA);
MedTech Europe.

Key points:

1 **Reducing barriers to accessing cancer care**

- Modernization of the infrastructure and incorporation of innovations (e.g. medical software, medical devices) happens at very different pace across the MS, leading to barriers in accessing care.
- The COVID-19 pandemic has also prompted the need for infrastructure for remote access to services.
- An obviously important parameter for the industry to monitor is the time-to-patient-access (TTPA). There are a number of issues to be improved in terms of process, reimbursement (e.g. taking into consideration the value of diagnostic information for diagnostics as well as the barriers to access in interventional oncology), health system readiness; evidence requirements; novel endpoints; sufficiency of evidence; fast access to patients.
- Regulatory issues – medical technologies are regulated at the EU level. There are sometimes frictions between pharma and other technologies – hiccups in the regulatory system; the needs of patients and healthcare providers need to be also clearly taken into account.
- Measures at the EU level that could help to reduce barriers to accessing services are:
  - EU leadership in scaling-up best practices;
  - Support of Cancer mission;
  - Work on implementing public-private partnerships in health care, e.g. through a pan-European multi-stakeholder forum;
  - research and innovation solutions can help, but there are regulatory barriers;
  - Initiatives to improve access across the EU are ongoing (e.g. EFPIA + LSE – published in September 2020);
  - enabling the implementation of value-based healthcare and cross-sectoral partnerships on health innovation to accelerate access to integrated care along the continuum of care;
  - promoting fast track funding/reimbursement models for innovative solutions; and
  - bridging resource constraints in countries with limited resources (via structural and cohesion funds).

2 **Cancer data**

- There was common understanding that there should be better use of data and the information they could provide. Better data sharing, efficient use and analysis of data, facilitating sharing of data are needed. The following points were proposed:
  - Support for the concept of a dashboard was strongly expressed by all. It is seen as a self-standing tool in order to inform the Europe's Beating Cancer Plan to understand the progress and priority areas now and in the future. Dashboard as a solution for demonstration of status, disease burden as well as societal responsibility. It is important how we develop the measurement, reliability;
  - The dashboard could be a stand-alone tool for the EU Cancer Plan to understand progress and priority areas now and in the future; and
  - In the cancer debate participants operate with different incidence and mortality data; if we were to get better quality and reliable clinical data across Europe, this would be the baseline for planning and evaluating.
- It is clear that there are certain challenges to be overcome with sensitivities over health data but some successful examples of implementation can serve as proof of the room that exists in spite of the GDPR limitations.
- There is a need for a Pan-European cancer e-registry that would help to monitor multiple aspects of cancer care and outcomes across the EU.
- Common initiatives could help to overcome existing fragmented approaches to collection of cancer data across the EU.

3 **Prevention, early detection and diagnosis**

- It is important to have an integrated approach to cancer care management focused on improving quality of life and overall patient outcomes.
- Prevention activities must be better supported. Screening programmes need to be structurally reviewed and revised. A good example is the work of JRC on breast cancer screening and their recommendations. COCIR also believes that there is a strong case for a priority focus on lung cancer screening, based on the existing scientific evidence as well as the gravity of the disease. MedTech Europe suggested that screening programmes and guidelines would be important also for liver and pancreatic cancer, while developing diagnostic technologies that can detect other cancers early through the use of biomarkers would also be critical.
- EU funding programmes (structural/cohesion funds as well as Next Generation EU, EU4Health and Digital Europe) could delegate funds in the development of innovative technologies that can enhance the resilience of healthcare systems.
- There was strong support given to a better view of environmental/work-related factors (occupational health and safety).

4 **Change in service delivery models**

- MedTech Europe explicitly put forward the issue of changing delivery models, moving towards a value-driven delivery model, where even before the COVID pandemic there had been a clear movement towards the home-settings. There are advances in improving technologies, removing barriers – regulatory barriers, which could be successfully overcome.
- E-health initiatives in the EU are particularly important, but they often suffer from limited implementation.
- As more and more cancer patients not only survive but overcome cancer, there are co-morbidities developing. It would be very important to address them ahead of time.
- Better patient monitoring and ensuring continuity of care. Equally, there is a need for better coordination of collecting patients' input on how care should be delivered and moving to a more integrated value-driven delivery of care. One example would be through patient reported experience data.

5 **Other challenges**

- European environment should be more conducive to personalized medicine: regulations, recommendations on genome testing, creating a precision medicine network with the ERNs.
- There is need to involve both the industry as well as patients in the consultations and reviews prepared by the JRC.
- Patient safety issues – managing co-morbidities, AMR and hospital-acquired infections, medication errors, mechanism to better coordinate, taking into account patient experiences.
- There are clear limitations as to the extent of the EU activities given the limited competencies on regulating healthcare.

Table 5 *Further comments added by industry organizations*

European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry (COCIR)

COCIR commends and fully supports the European Commission, with the Europe's Beating Cancer Plan initiative to contribute to the EC dialogue with the stakeholders, and responded to all related consultations and questions received.

COCIR represents the leading voice for industry sectors such as imaging, radiotherapy and digital health, which are sectors critically contributing to cancer care, both prevention, early diagnostic, screening, treatment and after care, and continues to innovate to contribute to better patient care, for equal access to the best support and treatment, as part of a patient-centred approach.

COCIR is also very active at the international level via DITTA which is a global association in official relations with WHO. We just finalized our triennial work programme (2021–2023) agreed with WHO, and cancer is part of it.

At the EU level, COCIR has always been a partner on IPAAC and previous cancer initiatives. Last year we mandated Science Business to work on a study (1) on breast cancer. Moreover, this year, we did the following:

- In the context of COVID-19, we issued a call for action on 28 May to ensure cancer treatment (2); and
- on 2 July COCIR organized its Annual General Assembly Open Session as a virtual event (3) on how we can beat cancer together in partnership with ECL and organized through multi-stakeholder panels. In addition, we launched that day our industry

paper (4) with pragmatic industry recommendations for consideration.

We continue to communicate intensively through social media to also share the value of our sectors and their pragmatic contribution to cancer care. Cancer care remains a critical priority for COCIR for 2020 and onwards, and we are happy to continue to organize a series of webinars on various cancers in partnership with other stakeholders. Cancers under focus will be breast cancer, lung cancer and cervical cancer.

References:

https://www.cocir.org/fileadmin/Publications_2019/SB_COCIR_The_Life_Saver_Repor_-_June_2019_0.pdf.

https://www.cocir.org/fileadmin/Position_Papers_2020/COCIR_Call_for_Action_-Ensuring_cancer_treatment_in_COVID_times_28_May_2020_-_Final.pdf.

https://www.cocir.org/media-centre/events/article/cocir-annual-general-assembly-beating-cancer-together.html.

https://www.cocir.org/fileadmin/Position_Papers_2020/COCIR_Paper_on_Cancer_-_2_July_2020_-_final.pdf.

European Federation of Pharmaceutical Industries and Associations (EFPIA)

The EFPIA Oncology Platform identified three key points which should be reflected by Europe's Beating Cancer Plan:

1. **Touching on the broader context, the cancer plan should also assess the investment in cancer care and take a societal perspective on cancer, including cancer literacy**
   - a. Cancer is set to become disease burden #1; however, European countries invest between 4 and 7% of their health expenditure in cancer; and
   - b. Cancer incidence increased by 50% in the past 20 years; the expenditure on cancer as a share of healthcare expenditure remained the same over the past 20 years.

➡ Europe's Beating Cancer Plan should have a holistic approach and include a chapter about investing in cancer and put a stronger focus on the role of citizens and patients in improving cancer outcomes (cancer literacy).

2. **Science is evolving and the regulatory framework should adapt to this development to ensure timely and equal patient access to innovation in cancer care**
   - a. 118 cancer medicines have been approved between 1995 and 2018 alone, including 164 indications.
   - b. Over 300 antibodies are currently under development.
   - c. Since 2006, nearly 3,000 trials have launched and are still active (as of 2019) examining PD-1/PD-L1 mAbs alone or in combination with other treatments. 76% of the active trials focus on testing combination therapies of these inhibitors with other cancer therapies, including targeted therapies, chemotherapies, radiotherapies, and more. 295 drug targets are currently being tested in combination with PD1/PD-L1 inhibitors, an increase of 136 targets in 2 years (1).
   - d. Many new cancer treatments are used in the curative setting, i.e. before or after surgery, with the expectation of cure. Current regulatory HTA as well as P&R systems are based on assessment criteria (OS) which are not applicable to (neo)adjuvant treatment (surrogate endpoints for example).

➡ Europe's Beating Cancer Plan should ensure that regulatory frameworks reflect evolving science and allow for more tailored pricing and reimbursement models for cancer medicines.

3. **Europe's Beating Cancer Plan should include a EU Cancer Dashboard to ensure that progress is measured**
   - a. Europe's Beating Cancer Plan should set realistic goals in the areas of prevention, screening, treatment and survivorship and social rights. To ensure impact, EFPIA together with the European Cancer Organisation (ECO) and the European Cancer Patients Coalition (ECPC) proposed a European Cancer Dashboard which would include some key performance indicators (2).
   - b. The proposed KPIs were:
     - i. Clinical: Incidence, mortality, five-year survival, disability adjusted life years gained, recurrence;
     - ii. Financial: Public expenditure/investment in oncology, efficiency of screening/diagnosis, technology in different stages, diagnostics, treatment and care, cost-effectiveness of public spend, % of access to innovative oncology treatments; and
     - iii. Patient: Time from first referral to treatment, patient experience of care, return to work rates, improved capacity of reintegration into society, palliative care, patient-reported outcomes, cancer literacy.

➡ Europe's Beating Cancer Plan should include a European Cancer Dashboard to ensure that progress is measured.

References:

1. Hodge J (2020). A closer look at PD-1/PD-L1 inhibitors. How trial innovation is pushing treatment boundaries for rare and hard-to-treat cancers; IQVIA. https://www.iqvia.com/blogs/2020/08/a-closer-look-at-pd-1-pd-l1-inhibitors.

2. See EFPIA (2019). A European Cancer Plan – For better, more equal access to cancer care. https://www.efpia.eu/news-events/the-efpia-view/blog-articles/a-european-cancer-plan-for-better-more-equal-access-to-cancer-care/.

2.6 International agencies

Stakeholder organizations:
European Centre for Disease Prevention and Control (ECDC);
European Medicines Agency (EMA);
International Agency for Research on Cancer (IARC);
Organisation for Economic Co-operation and Development (OECD);
WHO Regional Office for Europe (WHO-Europe);
World Health Organization (WHO)

Key points:

1 **Assessing and recognizing the value of prevention**

- It is essential that we move towards the systematic assessment of the value and impact of cancer prevention interventions (foster outcome research for cancer prevention, including economic assessment to convince policy-makers to invest in prevention). This should also include better risk communication to the public and long-term realism of cancer prevention among policy-makers through provision of long-term data and evidence, e.g. projections.
- Beyond existing EU activities contributing to the fight against cancer we should improve implementation science of ongoing activities and continue or strengthen regulation and intervention on smoking, alcohol (including on alcohol pricing, alcohol marketing, alcohol labelling) and high bodyweight as risk factors; in addition, environmental factors which could affect the risk of cancer should also be prioritized. The EU could encourage countries to implement WHO NCD 'best buys' (i.e. evidence-based policies to improve NCD prevention).
- Healthy and sustainable diets – in connection with the Green Deal and the Farm to Fork EU Policy – are a blueprint to cancer prevention; policies and interventions need to be prioritized.
- The concept of the value of vaccinations that are effective needs to be reinforced, along with supporting a gender-neutral approach to HPV vaccination, and counteracting anti-vaccine movements and fake news in the field. Synergy with international organizations can and should be encouraged in this field.

2 **Early diagnosis and screening programmes need to be strengthened and standards set across the EU**

- Secondary prevention (early diagnosis and screening) need to be strengthened. The large proportion of patients diagnosed at a late stage shows that early diagnosis of symptomatic cancers needs to be improved across the EU. The EU could encourage countries to develop early diagnosis programmes as part of their NCCP.
- Screening can improve outcomes for few types of cancer, but in many EU countries it is not well organized or adequately quality assured. Better monitoring and evaluation, as well as quality improvement systems for screening programmes, are needed.
- Non-evidence-based screening practices are increasing in the EU (e.g. out-of-screening-age mammography, screening for prostate cancer, stomach cancer, etc.) driven by market forces, and call for adequate regulation.
- The EU may have a particular role in fostering evidence-based best practices focusing on quality and equity, notably for early diagnosis, setting thresholds and standards of care, and serving as a model of good standardization for quality. Regulation is also important for efficient interaction between academia and biotech partners to limit the market-driven biases.
- Research to better understand risk stratification and targeted interventions for screening and prevention is needed; that also relies on putting individuals at the centre of care.
- There was a view that the EC could support further research to identify biomarkers for early detection of cancer through coordination of large population cohorts; investing in infrastructure for population cohort research; promoting efficient interaction between academia, biotech and population cohorts; and working to ensure promising biomarkers for early cancer detection are brought forward into practice. However, this was contested by the position that there is no early detection biomarker that is eligible for large population cohort yet. This would mean that such research may divert resources from other important areas (e.g. implementation research of early diagnosis programmes). There was a strong view against supporting investment in biomarkers

for early detection and new screening technologies, and in favour of putting resources into early diagnosis of symptomatic cancer (i.e. better services).

- The EC could support the MS to have efficient systems of data collection across the screening programme care continuum and to use data to estimate quality indicators and ultimately improve quality of screening programmes. This will minimize the harms of screening and maximize the impact. An EU-wide monitoring programme (now and during the following years) will be useful to motivate and assess the efficiency of interventions directed at early diagnoses and screening programmes.
- Consequences of earlier cancer diagnoses should be taken into account for healthcare system directions and cancer research (e.g. changes to clinical trial populations, possibly types of outcome endpoints, patients having exhausted all effective treatments will remain important even if possibly less frequent).

3 **Achieving more synergies between European initiatives as well as within EU policies**

- Synergies between a number of existing international initiatives, such as updating of the European Code Against Cancer (ECAC) (IARC), work on the EBCP (EC), iPAAC Joint Action, JRC (EC), Cancer Mission Board, etc., should be strengthened.
- Steering role of the EC in fostering political will of MS to tackle determinants, adopt HiAP, in a consistent manner with EU policies and WHO recommendations.
- Across the initiatives, it is important to foster more successful implementation and evaluation, adapt them to different target populations, and improve dissemination.
- Policy coherence across the EU is important (e.g. alcohol-related policies) – applying HiAP across the board (agriculture, food, environment, etc.).

4 **Data collection, management and use; generating knowledge**

- Registries should be promoted, supported and guided. EC-Santé, ENCR (European Network of Cancer Registries via EC JRC secretariat), EMA (including HMAs) and WHO-IARC should be working jointly in this endeavour.
- There is a need to appreciate register landscape across Europe – 20 registries, 120 sub-registries, and a great divide between countries.
- Harmonization of data on screening is also essential to improve quality of national screening programmes. Data linkage with population registries would assist in assessing the benefits of cancer screening on outcomes.
- Standards and guidance should be developed to facilitate the direct capture of data from electronic health records, to improve the efficiency, quality and quantity of data reporting.
- The improvement of information systems is needed to systematically use interoperable metrics, and ensure inequalities can be assessed. Need to go beyond traditional outcomes (mortality and survival) and include differentiation by stage, co-morbidities, socioeconomic levels, performance status, response indicators, etc.; as well as person-centred outcomes (PROMS, PREMS).
- The EU could support and promote research of European population cohorts, including investing in joint infrastructure – for broader NCD (including cancer) prevention and population risk stratification.
- Work of JRC could be more proactive to support MS in their development of quality cancer registries.
- A synergy is needed among the various efforts being made at EU level to develop artificial intelligence (AI)-based algorithms in cancer prevention, early detection and cancer management. AI requires large repositories of data, images and biospecimens. The EC should take a lead in developing such a repository addressing all ethical, legal, equity and technological issues.
- Generating knowledge and collecting data require support, facilitation and funding, also for cancer clinical trials, for observational studies and for translational research since registry data cannot be enough for evaluating new interventions and treatment strategies/sequences. This is a large topic area where some alignment of stakeholders (academia, pharma, HTA, EMA) is needed with respect to goal-setting, data sharing and practical collaboration.
- Generation of knowledge aiming to optimize treatment in the post-marketing phase is a neglected area of research that could generate

significant information for optimizing treatment allocation to patients who are likely to benefit the most, optimize treatment schedules to maximize benefits and minimize harms, etc. A framework to conduct academically conducted independent trials, involving multiple stakeholders (e.g. patients, health-economic organizations, medicines regulators), and independent evaluation of the data, would be essential to achieve treatment optimization.

5 **Value-based care**

- More research is needed for understanding and precisely articulating the value to patients and various stakeholders, as well as cost-effectiveness of therapeutic interventions, notably for high-cost treatments.
- Equity should be ensured and the high price of medicines, the need for standardization, and the value-based care assessment methods, et., need to be tackled.
- The EU could encourage adherence to evidence-based practices (prevention and intervention), discourage practices with no evidence on effectiveness.

6 **Empowerment and patient-centredness**

- This point is consistent with all of the above and is a recommendation to make more explicit something that we all share implicitly.
- Transform cancer patients' role into active partners, governing their health data, choosing options for medical care and research engagement, fostering and maximizing patient autonomy and informed benefit-risk decisions through optimal information and decision analysis tools. Dedicated projects should be inititated to support patients and to advance their role.

Table 6 *Further comments added by international agencies*

WHO Regional Office for Europe (WHO Europe)

Prevention

- The EU needs to encourage/enforce countries to implement WHO recommended policies, so-called **'NCD best buys' (1)** for all cancer risk factors, including alcohol. WHO Europe can help with extended guidance and expertise.
- The EU needs to support zero pollution ambition for a toxic-free environment (EU Green Deal). **WHO can support in:**
  - Strengthening capacities to quantify the health impacts of air pollution, through deploying tools, such as the AIRQ+ software and trainings;
  - Supporting the revision of the EU Air Quality Policy, taking into account the forthcoming publication of the updated WHO global Air Quality Guidelines; and
  - Developing case studies and assessments on the effectiveness of different policy options to reduce air pollution.
- The Europe's Beating Cancer Plan needs a part about **tackling vaccine hesitancy**; WHO Europe can **help with extended guidance** about:
  - How to implement HPV and Hepatitis vaccination; and
  - How to best communicate about vaccination and respond to vocal vaccine deniers.

Secondary prevention

- The EU could **set standards** for early diagnosis as has been done already for screening. Standards for patient pathways, with standards in maximum waiting time allowed for various procedures as has been done in countries like Denmark, for example.
- WHO has published essential guides for early diagnosis and for screening (WHO Europe short guide on screening 2020, WHO guide to cancer early diagnosis 2017; WHO module on Early Detection 2007). WHO Europe has a strong and unique expertise in supporting European countries (notably Eastern ones) with early detection and can provide countries with all the guidance they need to:
  - Assess their priorities in term of early diagnosis and screening programmes; and
  - Implement these programmes properly.

Achieving more synergies

- The Europe's Beating Cancer Plan should align with the WHO global initiatives on cervical cancer, paediatric cancer and breast cancer (this latter will be launched soon). All EU countries can achieve the targets proposed: cervical cancer elimination initiative: 90% of girls fully vaccinated when reaching age 15; 70% of women screened with an HPV test; 90% of patients receive treatment for pre or invasive cancer.
- Paediatric cancer initiative: ensuring at least 60% survival for children with cancer, and reducing suffering for all.
- WHO is keen to collaborate with the EU (DG Sante, research, NEAR, Europaid) to advance further those initiatives and create synergies. WHO can help in strategy development and provide expertise for country support.

Value-based care

Since the resolution WHA70.12 on Cancer prevention and control in the context of an integrated approach adopted in 2017, WHO has worked a lot on the issue of access and affordability of cancer medicine and has notably produced a strong report on Pricing of cancer medicines and its impacts (2); WHO can provide expert advice on the benefits and consequences of various pricing approaches and on options for improving the availability and affordability of cancer medicines in the EU.

References:

1. Tackling NCDs: 'best buys' and other recommended interventions for the prevention and control of noncommunicable diseases: https://apps.who.int/iris/handle/10665/259232.

2. Technical report on Pricing of cancer medicines and its impacts: https://www.who.int/medicines/areas/access/Improving-affordability-effectiveness-of-cancer-medicines/en/.