



CONSULTATION RESPONSE

Europe's Beating Cancer Plan

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12. POINTS TO HELP ENSURE A HIGH IMPACT EUROPE'S CANCER PLAN

The following 12 points of advice were developed with members of the European Cancer Organisation during 2019 prior to publication of the Europe's Beating Cancer Plan consultations in February 2020.

They are expanded here as quick response to the short deadline Roadmap consultation (deadline 3rd March 2020). Further representations from the European Cancer Organisation will follow with additional concrete suggestions for inclusion in the plan in respect to the now identified four pillars of the plan: Prevention, Diagnosis, Treatment and Survivorship and Follow-up Care. In this respect, we consider this submission as the opening of an ongoing dialogue.

1. Set ambitious and unifying goals

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

The stimulating impact of clear goals can be seen in many policy areas. Commonly known examples including the UN Sustainable Development Goals¹, and the pursuit of international climate change goals, such as the Paris Agreement². An impactful Cancer Plan and Mission must be underpinned by a significant sense about what measurable purpose its actions are being directed towards.

As well as many sub-goals we suggest be taken up in specific areas of the plan, the European Cancer Organisation recommends some substantial over-arching goals to the Plan. These should capture the public imagination and engender deep political will in all EU Member States. Some early suggestions include: the European Cancer Concord's recommendation of achieving 70% long-term survival for patients with cancer by 2035³; the OECI recommendation of doubling survival for intermediate and poor prognosis tumours⁴; the SIOP Europe aspiration of halving of

deaths and late effects from childhood cancer by 2030⁵; and the European Cancer Organisation call for the EU to eliminate HPV caused cancers as a public health problem⁶.

Other major and worthy goals for the Cancer Plan will undoubtedly be suggested to the Cancer Plan authors. As just one example, the European Society for Radiotherapy and Oncology (ESTRO) have outlined how potentially as much as 1 million lives could be saved in Europe by 2035 through improved access to radiotherapy⁷.

All should be considered with reference to such issues as: their achievability, their possible application to help break down persistent barriers to progress, and their possibility to inspire actors across the policy spectrum to go further faster.



The stimulating impact of clear goals can be seen in many policy areas.

2. Involve all stakeholders in the development of the Plan

The immediate launch of two consultations, and commitments from the Commissioner for Health and Food Safety to pursue a bottom up philosophy to construction of the Plan already indicate a good approach in respect to working with stakeholders and experts in the cancer community. We urge continuation in this regard.

Solid reasons for conducting such an open and engaging approach towards construction of the plan include:

- **Getting things right first time**

Unintended disruption to implementation of the plan can be achieved by ensuring proposals in the Plan have benefited from 'road-testing' with the cancer community, who hold the experience of what has worked, and has not worked, to date.

- **Avoiding 're-inventing of the wheel'**

There are decades of European and international level collaborations on cancer that can be learnt from and built upon, including those conducted by the European Cancer Organisation's member societies and members of its Patient Advisory Committee.

- **Ensuring the widest possible buy-in and political will**

In this sense, it will be important to provide strong opportunities in the development stage of the Plan for:

- Engagement with the FULL European cancer community.

The European Cancer Organisation underlines the importance of the Cancer Plan authors seeking direct interaction with relevant cancer stakeholder organisations for matters specific to their respective activity areas to the greatest extent that this can be possible within the timeframe for completing the Plan. Nevertheless, as an umbrella Federation of 28 European and international level cancer organisations, working closely with 17 European level patient organisations, the European Cancer Organisation can offer itself as a means for the Commission to reach a wide number of

stakeholders at one time. This could be via bespoke physical meetings (such as half or day long fora) and/or virtual means of connection, potentially of a subject focused nature e.g. Prevention and the Cancer Plan; Diagnosis and the Cancer Plan etc.

We especially urge that efforts are taken to ensure connection is made with all societies with expertise and experience to offer the Commission, including associations who may not have independent Brussels-based resource for representation. The European Cancer Organisation would be delighted to facilitate connection in this sense.

- Connection to professionals and cancer stakeholders at national levels

Beyond this, we urge regular webinar update on developments, and outreach efforts to national parliaments to help bring about strong levels of support for the Plan's achievement within national political capitals.

3. Give focus to the quality of cancer care patients receive

The Quality of Cancer Care that patients receive matters. The management of cancer care is complex. To achieve best results for the patient, coordination and cooperation between disciplines is essential. Each profession brings unique skillsets and insights to the decision-making process on individualised patient treatment. It is multidisciplinary and multiprofessionalism that ensures such teamwork occurs, and is therefore a central component of what quality cancer care consists of.

To play its role in helping to advance quality cancer care, the European Cancer Organisation is currently developing a series of charters that advocate for improvements in patient care, entitled 'The Essential Requirements for Quality Cancer Care' (ERQCCs). The ERQCCs provide checklists and explanations of organisations and actions that are necessary to give high quality care to patients who have a specific tumour type. The ERQCCs sit alongside other European level quality cancer care initiatives such as clinical guidelines in specific areas, and approaches for raising quality cancer care in centres, such as the OECl Accreditation and

Designation Programme⁸, the MASCC Designated Centers of Excellence in Supportive Care in Cancer certification⁹, as two examples.

ERQCCs are now published for sarcoma, colorectal cancer, oesophageal-gastric cancer, melanoma and will be published soon for breast and prostate cancer, with lung cancer, pancreatic cancer and glioma following thereafter. An ERQCC document¹⁰ has also been published to outline the role of primary care in achieving Quality Cancer Care.

In respect to ways in which the Beating Cancer Plan could support the achievement of quality cancer care in the European Union, this could include:

- **Creating a European Cancer Dashboard to monitor and report on the quality of cancer care being delivered across Europe**

This could 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 to¹¹ screening,

medicines, radiotherapy, oncology surgery, supportive care, pathology, imaging, specialist cancer nursing, oncology pharmacy, interventional radiology, nuclear medicine, palliative care, and psycho-oncology.

Such monitored and reported information should then be a spur to considered discussions about where improvements in cancer care in Europe can be best achieved, and how planning of healthcare services in Europe can better optimised. We refer to work by the ESTRO HERO project in this respect, which through such a mapping of access discovered that at least one in four people in Europe needing radiotherapy does not receive it¹².

- **Developing an agreed set of core standards and evidence-based indicators (based on processes and patient outcomes) to evaluate the quality of cancer services in the EU.**

We refer the Cancer Plan authors to both a resolution¹³ of the ECCO 2018 European Cancer Summit on this subject and ongoing work by the Organisation of European Cancer Institutes (OECI)¹⁴ in this area. OECI will soon publish a set of Core Standards for Cancer Centres, developed

with 10 other European cancer societies that might be embraced in respect to the above recommendation. See also the OECI Accreditation and Designation Programme¹⁵.

- **Setting an objective for Comprehensive or large Clinical Cancer Centres in every geography**

Such comprehensive networks mean that all hospitals diagnosing and treating cancer in a defined area work together. Experience in some Member States demonstrates that this reduces inequalities. We refer the Cancer Plan authors to the consultation submission of OECI for further information on game-changing improvement such centres can make to improving delivery of cancer care and achieving the realisation of cancer treatment delivered by high functioning multidisciplinary teams.

OECI recommends that Europe needs one Comprehensive Cancer Centre or large Clinical Centre per 5-10 million of the population and at least one in small Member States, fully networked to other hospitals.

4. Provide attention to the quality of life and survivorship needs of patients

It is pleasing to see 'Quality of Life' featuring as a specific consideration for the European Beating Cancer Plan. This indicates an holistic approach that recognises the distinct needs of the growing numbers of citizens who survive cancer as well as a requirement for more focus on such matters as palliative care.

In respect to concrete policy proposals that we recommend be included in the Europe's Beating Cancer Plan, these include achieving a target of "the right to be forgotten" for cancer survivors being legally codified in all EU countries by 2025.

In line with the ECCO 2018 European Cancer Summit resolution¹⁶, this should mean the right of cancer survivors not to declare their cancer 10 years after the end of the active treatment and 5 years if they had cancer under 18 where financial services are

concerned. This is in line with legislation already in place in France and Belgium.

In combatting the financial toxicity of cancer for citizens more widely, among other recommendations, the recently published Vision paper of the Association of European Cancer Leagues (ECL) makes a good case for strengthening the capacity of the European Agency for Health and Safety at Work (OSHA) to identify and work towards the implementation of best practices in national legislation providing security and flexibilities for cancer patients and their caregivers at the workplace (including gradual return to work)¹⁷.

Furthermore, the European Commission can play helpful roles in respect to advancing access to supportive care for cancer patients and their families, by including these matters within

monitoring of quality cancer care delivery in Europe. Neglected supportive care needs for cancer patients include the prevention and management of the adverse side effects of cancer and its treatments, including but not limited to, pain management, psycho-social support, sexual counselling, palliative care, occupational therapy rehabilitation, pain management and sexual counselling and palliative care.

In respect to palliative care specifically, the Cancer Plan authors should familiarise with work and conclusions of the Lancet Oncology Commission investigating the Integration of oncology and palliative care¹⁸. Among its summary findings include: *"The absence of international agreements on the content and standards of the organisation, education, and research of palliative care in oncology are major barriers to successful integration. Other barriers include the common misconception that palliative care is end-of-life care only, stigmatisation of death and dying, and insufficient infrastructure and funding."* These are all areas where EU initiative conducted under the aegis of the European Beating Cancer Plan could help to achieve important progress.

The EAPC Atlas of Palliative Care in Europe 2019¹⁹ is a recommended further resource for understanding in this area, including country by country breakdowns of the current situation for palliative care in every European country.

We refer the Cancer Plan authors to the European Cancer Organisation's members such as the European Association for Palliative Care²⁰, the International Psycho-Oncology Society²¹, and the Multinational Association of Supportive Care of Cancer²² for additional inputs on these topics.

Every cancer patient in Europe should expect to receive a Survivorship Care Plan when completing treatment. A Survivorship Care Plan is a detailed plan given to a patient after treatment ends, that contains a summary of the patient's treatment, along with recommendations for follow-up care. A survivorship care plan may include schedules for physical exams and medical tests to see if the cancer has come back or spread to other parts of the body. Getting follow-up care also helps check for health problems that may occur months or years after treatment ends, including other types of cancer. A survivorship care plan should may also include information to help meet the supportive

care aspects of survivorship such as emotional, social, legal, and financial (e.g., financial toxicity) needs of the patient. It may should also include referrals to specialists and recommendations for a healthy lifestyle, such as changes in diet and exercise and quitting smoking.

Assurance that a Survivorship Care Plan is being provided to patients can be achieved by adherence to the OECl accreditation and designation programme, which includes survivorship care planning as an essential part of its qualitative standards²³.

Every cancer patient in Europe should expect to receive a Survivorship Care Plan when completing treatment

Pursuing elements such as those suggested by the EORTC Treatment Optimisation manifesto²⁴ and and the SIOP Europe – CCI Europe Manifesto for the paediatric population²⁵ within the Beating Cancer Plan will also assist in improving understanding about long term impacts of certain treatments upon cancer patients, including their quality of life and long term side effects.

We also refer the Cancer Plan authors to the excellent initiative of the paediatric oncology community in respect to developing 'survivorship passports' for childhood cancer survivors²⁶.

Attention should also be provided within the Beating Cancer Plan on how EU mechanisms can be better deployed to create a more supportive environment for cancer survivors and return to work. We refer the Cancer Plan authors to the 2017 Joint Statement of the European Chronic Disease Alliance (ECDA)²⁷ for suggestions on this.

We also refer the Plan authors to the laudable work of the Dying to Work EU campaign²⁸ which highlights the surprising lack of legal protections for terminally ill employees under EU law. This should be an important area for DG Employment, Social Affairs and Inclusion to have engagement and responsibility in the Cancer Plan.

5. Better integrate primary care into the cancer care pathway

There is a growing recognition of the depth and value of the roles primary care healthcare professions can provide in respect to advancing the quality of cancer care and outcomes, including in areas such as prevention, early diagnosis, management of co-morbidities and long-term follow up care. This comes in part as health systems seek ways to deliver more healthcare in the community setting, a preference often shared by patients themselves, and being supported by increased use of oral chemotherapy and other home-based treatment and care options.

Ways in which the Beating Cancer Plan could support the elevation of primary care roles in the cancer care pathway include by:

- Encouraging all national cancer plans in Europe to contain ambitious measurable goals and actions to improve the integration of primary care healthcare professionals and informal carers within multidisciplinary care to patients;
- Reporting on the extent to which primary care is integrated in the delivery of cancer care in European health systems within health system

monitoring exercises such as the 'State of Health in the EU', 'Health at a Glance' and the European Cancer Information System (ECIS);

- Publishing best practice guidelines to EU Member States on the means by which better integration of cancer care can be achieved. This can be informed by, among other sources, existing European Commission best practice collections on integration of healthcare, the findings and recommendations of the State of Health in the EU exercise, and the work of several EU Health Programme funded Joint Actions on Cancer Control.

See ECCO 2018 European Cancer Summit resolution on Integrated Cancer Care²⁹.

We also refer the Cancer Plan development team to the recently published European Cancer Organisation's Essential Requirements for Quality Cancer Care: Primary Care³⁰.

6. Meaningfully address inequalities in cancer care

(Inequalities in respect to the delivery of Quality Cancer Care are also referenced in Section 3 above)

Levels of health inequality between countries and regions in respect to cancer prevention, control, access to treatment and survival are both wide and varied³¹. The situation is particularly challenging in Eastern Europe, with survival for many cancers below the European average. Western and Northern European countries also show inequalities in cancer care. This is reflected in lower survival from lung, colorectal and ovarian cancers in the UK and Denmark when compared to Norway and Sweden³².

Inequalities also occur within countries, between regions and between social groups. For example,

in respect to cancer, it is often observed that more privileged groups record better outcomes because they have fewer risk factors for cancer, can take advantage of new interventions and screening programmes more quickly, have easier access to health services, and can minimise the social and financial consequences of cancer when it occurs.

The European Cancer Organisation also points out to the Cancer Plan authors the particular needs patient cohorts such as children and young adults, and older patients, who can often be overlooked or neglected by health system planners. This is another important source of inequalities for consideration. We refer the Beating Cancer Plan authors to the expert perspectives of the European Society

for Paediatric Oncology (SIOP Europe)³³ and the International Society of Geriatric Oncology (SIOG)³⁴ in these areas.

We also urge the Cancer Plan authors to be mindful of the needs of other hard to reach groups in respect to cancer control such as migrant workers, undocumented migrants, refugees and Roma populations. Specific outreach should be made to stakeholder organisations representing these communities in the process of finalising the Cancer Plan.

In terms of the ways in which the Beating Cancer Plan could address inequalities, this include by:

- **Setting significant and ambitious European-wide goals for the Beating Cancer Plan that will drive actions towards reducing health inequalities**

This could include such suggestions from the cancer stakeholder community as: achieving 70% average long term survival in cancer across the EU by 2035³⁵; the OECI recommendation of doubling survival for intermediate and poor prognosis tumours³⁶; the SIOP Europe aspiration of halving of deaths and late effects from childhood cancer by 2030³⁷; and the European Cancer Organisation call for the EU to eliminate HPV caused cancers as a public health problem in Europe³⁸. See section 1 on goals above.

To get even close to achieving such goals will logically and inevitable require providing attention to how to address the underlying causes of disparity

across Europe in respect to incidence, mortality, access to optimal treatment and quality of life.

Inequalities occur within countries, between regions and between social groups and survival are both wide and varied

- **Creating a European Cancer Dashboard to monitor and report on inequalities**

Building on existing exercises of this nature conducted by the European Commission, such as the European Cancer Information System, and the State of Health in the EU series. The suggested dashboard could monitor potential areas of inequality such as 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.

7. Support the education and mobility needs of the cancer care workforce

A high performance Beating Cancer Plan should break down silos across Europe by engendering a motivating sense of common purpose between professionals, patients, the public, political decision makers and many other stakeholders. This silo breaking need applies as much to the Commission itself as elsewhere. All relevant Directorate Generals (DGs) and Units should be invoked by the Plan, and this includes DGs and Units with responsibility for Education, Professional Mobility and Qualification Recognition, and Health System Workforce Planning.

We recommend that the Beating Cancer Plan include elements aimed at:

- **Stimulating recognition of professions and harmonisation of specialist oncology professional training at the European level**

This will help professionals in keeping pace with rapid developments in science impacting treatment and care for patients, and encourage mobility of talent and skills across Europe, with

accompanying spread of good practice.

The European Cancer Organisation can refer to societies such as the European Oncology Nursing Society (EONS), European Society of Surgical Oncology (ESSO) and European Society of Oncology Pharmacy (ESOP), among others, for direct experience and perspectives in this area, including where improvements in the EU framework for professional qualification recognition could be achieved.

- **Promoting multiprofessional team working in cancer care in its fullest sense**

As well as through promotion of the Quality Cancer Care agenda referenced in Section 3 above (see Essential Requirements for Quality Cancer Care),

Europe's Beating Cancer Plan could assist this area of need by providing attention to such matters as the extent to which common curricula and training requirements at the European level promote and achieve multiprofessionalism, and otherwise undertaking report on the matter.

- **Understanding emerging and pressing cancer workforce needs**

Workforce shortages are a problem increasingly reported to the European Cancer Organisation in respect to daily problems encountered in cancer care across Europe. As just one concerning illustrative example, a recent survey by the European Society for Radiotherapy and Oncology Health Economics in Radiation Oncology (ESTRO-HERO) project has found that 11 countries in Europe still fall below internationally recommended staffing levels for radiation oncologists.

A European level review on this topic could therefore include the development of recommendations to help Member States address identified shortages in the cancer workforce.

8. Create an improved EU environment for better use of evidence and data

The EU has an impactful role to play in improving the EU environment for better use of evidence and data. This includes:

- **Achieving a further elevation of cooperation between cancer registries in the EU**

Cancer registries are the fundamental source of objective cancer data, and thus are indispensable for the evaluation of the cancer burden and for design of effective cancer control plans. The role of registries goes further than only epidemiological research, but also to exploration of the causes of cancer, to health economics, from the evaluation

of mass screening programmes to monitoring the quality and outcomes of health services, from addressing the inequalities in access to healthcare, to patients' quality of life analyses, from treatment safety to the development of biomarkers³⁹.

However, in Europe, cancer registration remains challenged by significant disparities in the quality and coverage of registries, by insufficient harmonisation and comparability of procedures and data, by heterogeneous legislation that limits registries abilities for networking, collaboration, and participation in research⁴⁰.

The European Beating Cancer Plan should include attention to resolving these remaining registry disparities in areas such as data quality standards and comparability.

Experience of projects such as the EURECCA initiative of the European Society of Surgical Oncology should also be referred to in this area⁴¹.

- **Resolving reported barriers to research invoked by GDPR regulations**

We urge continual dialogue with the European

cancer research community, including the European Organisation for Research and Treatment of Cancer (EORTC) in respect to the impact on cancer research from legal obligations brought into being by General Data Protection Regulation (GDPR), and close attention to opportunities for overcoming these.

The Association of European Cancer Leagues (ECL) have recently recommended that the European Data Protection Board (EDPB) work together with EU Member States and supervisory authorities to achieve a better harmonised understanding of the application of GDPR regarding roles and relations when sharing data for research purposes within and outside of the EU (including EEA and the UK)⁴²

- **Embrace Treatment Optimisation as an agenda**

Current mechanisms in the EU for regulatory approval and market access of new treatments in cancer, especially for medicines, are well established in respect to the requirements in for providing evidence of safety and efficacy from clinical trial stages. However, the possibilities for achieving a better understanding of the real world use of treatments (i.e. after approval and market access) are underexploited. The European Cancer Organisation therefore refers the Cancer Plan authors to the widely endorsed EORTC manifesto on Treatment Optimisation (EORTC)⁴³. This points to how EU approaches could be amended to greatly improve knowledge on how to optimise treatments already in use. This includes potential for generating better understanding on matters such as dose, sequence, combination and duration of treatment.

Recommendations stemming from the Treatment Optimisation manifesto include:

- establishing Treatment Optimization research as an official and mandatory step in the treatment access path to market;
- developing international approaches to treatment optimisation research; and,
- creating funding opportunities for treatment optimisation research within the Horizon research programme.

The EU has an impactful role to play in improving the EU environment for better use of evidence and data.

Attention should also be provided to where, and how, EU data initiatives can be supportive for purposes of advancing access to non-systemic treatment innovation, such as in respect to radiotherapy

and surgery. To see reflections of an European Cancer Organisation convened collaboration, *'Towards an evidence-informed value scale for surgical and radiation oncology: a multi-stakeholder perspective'*⁴⁴.

9. Be bold on primary prevention

Principal risk factors for adult cancers are well known, including tobacco, alcohol, obesity, physical activity, diet, UV radiation, and vaccine-preventable viruses such as HPV and HBV. The European Beating Cancer Plan should include measures on all, including:

- Sustained investment in health literacy efforts at the European level, including long term commitment to promotion of the European Code Against Cancer
- Ongoing review of tobacco control legislation at the European level for improvement opportunities, including in respect to novel tobacco and nicotine products

- Further consideration of how to enhance Europe's approach to food and alcohol labelling to help consumers make healthier life choices
- Evaluation of approach in respect to European regulation of artificial tanning devices ('sunbeds')

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and surgery. To see reflections of an European Cancer Organisation convened collaboration, *'Towards an evidence-informed value scale for surgical and radiation oncology: a multi-stakeholder perspective'*⁴⁷.

The European Cancer Organisation also advocates that the European Beating Cancer Plan matches with WHO ambitions on cervical cancer elimination⁴⁸ and adopts an inspiring global leadership position in this area, by formally seeking the elimination of HPV caused cancers as a public health problem in Europe.

With EU legal competency in respect to workplace health and safety legislation well established, including exposure to carcinogens in the workplace, we urge the European Cancer Plan to take

cognisance of an ongoing study being conducted for the European Commission on tackling hazardous drug exposure in healthcare environments (e.g. cytotoxics and cytostatics). We also strongly recommend the Cancer Plan authors be closely advised by the European Society of Oncology Pharmacy (ESOP) and the European Oncology Nursing Society (EONS), both of whom are engaged in important research and awareness activity in this area^{49,50}.

As an example, an important EU initiative in this area to be aware of, is the development of the ESOP yellow hand symbol, which aims to help all who handle medicines with carcinogenic, mutagenic and/ or reproductive toxicity properties, take appropriate safety action⁵¹. The Cancer Plan might provide opportunity to achieve its wider take-up.

Linkage with the EU Cancer Mission on Cancer Prevention

Linkage between the European Beating Cancer Plan and the EU Cancer Mission in respect to prevention will be of considerable importance. The Mission should include important focus on gaining better understanding of remaining 'known unknowns' in respect to causes of cancer.

We also recommend that the European Beating Cancer Plan and EU Cancer Mission create linkage on improving understanding about hereditary components of cancer. The European Cancer Organisation refers the Cancer Plan authors to the European Hereditary Tumour Group (EHTG)⁵² for further discussion on this.

Seeking the elimination of HPV caused cancers as a public health problem in Europe.

Finally, and importantly, we refer the Cancer Plan development team to:

- The strongly developed set of recommendations on primary prevention of cancer made by the Association European Cancer Leagues (ECL) in its recently published Vision Paper⁵³. These are set out thematically across areas such as: reducing

the use of tobacco and other nicotine products; promoting healthier lifestyles; tackling Europe's alcohol problem; decreasing Europe's skin cancer burden; protecting citizens from harmful exposure to carcinogens in the environment; and enabling population-wide access to vaccines; and,

- Activities and positions of the European Respiratory Society in respect to matters such as tobacco control⁵⁴ and air pollution⁵⁵.

10. Achieve greater health literacy in respect to cancer

Health literacy refers to the cognitive and social abilities that are determinants in the motivation and capacity of the individual to access, understand and use information for the care of one's own health. The needs for improved health literacy by the public in respect to cancer therefore includes not only the need to heighten citizens' understanding of modifiable risk factors and cancer (referred to above with reference to the European Code Against Cancer), but also the need to widen understanding in respect to such matters as: early warning signs of cancer; how to navigate healthcare systems; and patients' understanding of their rights.

Ways in which the Beating Cancer Plan can support the achievement of improved overall health literacy in respect to cancer includes by:

- **Continuing to support calls within Horizon Research, the Health programme and forthcoming Innovative Health Initiative in respect to health literacy**

This should include specific streams related to increasing public understanding of early warning signs of cancer; and,

- **Linking closely with DG CONNECT for well defined initiatives to improve digital health literacy;**

Further to the above recommendations, the European Cancer Organisation will soon be publishing a new 'European Code of Cancer Practice', a co-creation between healthcare professionals and patients, designed as an

augmentation to the European Cancer Patients Bill of Rights⁵⁶ and the European Cancer Organisation's Essential Requirements for Quality Cancer Care⁵⁷ series. This aims to provide a short 'one page', lay-friendly outline of what every cancer patient in

Europe should reasonably expect in relation to their treatment.

Modelled on the success of the European Code Against Cancer, we consider this Code of Cancer Practice as having potentially transformative impact in respect to cancer patients' understanding of their rights, and ability to navigate health systems effectively.

We therefore submit the Code of Cancer Practice concept to the Commission as a health literacy focused project that might be supported within the European Beating Cancer Plan.

EU actions to deter fake news in respect to vaccinations should be continued, elevated and referenced within the European Beating Cancer Plan.

With the possibility of eliminating HPV caused cancers in Europe in mind, EU actions to deter fake news in respect to vaccinations should be continued, elevated and referenced within the European Beating Cancer Plan.

11. Increase efforts towards early detection of cancer

Concrete policy proposals that we recommend be included in the European Beating Cancer Plan on Early detection and diagnosis include to:

- **Strengthen screening coverage targets**

In the press release of the European Commission on 4th February 2020, announcing the Roadmap consultation on the European Beating Cancer Plan, it was intimated: *“Measures to improve the chance of a better health outcome through early diagnosis could include increasing the coverage of the target population for cancer screening”*. The European Cancer Organisation supports this proposal ⁵⁸.

This may be especially relevant in the case of cervical cancer screening, where the World Health Organisation seeks all countries to achieve 70% coverage of screening (70% of women are screened with high-performance tests by the ages of 35 and 45 years)⁵⁹.

As part of the European Beating Cancer Plan, and in light of its global leadership role, the European

Concrete policy proposals that we recommend be included in the European Beating Cancer Plan on Early detection and diagnosis include to:

As part of the European Beating Cancer Plan, and in light of its global leadership role, the European Union could consider even exceeding this target, with accompanying support for its achievement.

- **Go further in ensuring best practice implementation in respect to screening**

It is known that while many countries in Europe have implemented cancer screening programmes, there remains great variability in the quality of the screening provided. Furthermore, the fundamental 2003 Council Recommendation, that all countries should implement screening in respect to Breast, Cervical and Colorectal cancer, is still not achieved in all EU countries.

The next European Beating Cancer Plan should therefore go further in promoting best practice uptake in respect to screening, with a suggested annual Cancer Screening Summit with an invited primary audience of member state government health departments. The main objectives should be both reporting of annual progress across Europe on

screening, as well as sharing of key learnings.

- **Bring about an update to the 2003 Council Recommendations on Screening**

In the 17 years that have passed since the 2003 Council Recommendation on Cancer Screening, enormous advances have been made in many areas, including in respect to screening technologies as well as trialling of screening for other cancers such as prostate cancer, skin cancers and lung cancer.

The European Beating Cancer Plan should therefore encourage EU Member States to conduct a review of the 2003 recommendations, taking account of the latest policy evidence.

Measures to improve the chance of a better health outcome through early diagnosis could include increasing the coverage of the target population for cancer screening.

The European Cancer Organisation recommends the Cancer Plan authors liaise specifically on these matters with medical societies with particular expertise in respect to tumour specific areas of cancer screening such as those represented within the European Cancer Organisation’s membership⁶⁰. Such medical societies include the European Association of Urology (EAU)⁶¹ in respect of prostate cancer screening, the European Respiratory Society (ERS)⁶² and European Society of Radiology (ESR)⁶³ in relation to lung cancer screening, the European Society of Coloproctology (ESCP)⁶⁴ with connection to colorectal screening, the European Society of Gynaecological Oncology (ESGO)⁶⁵ for cervical cancer screening, the European Society of Skin Cancer Prevention (EUROSKIN)⁶⁶ in connection to skin cancer screening, and the European Society of Breast Imaging (EUSOBI)⁶⁷ and European Society of Breast Cancer Specialists (EUSOMA)⁶⁸ in connection to breast cancer screening.

We also refer the Cancer Plan authors to the recommendation on screening contained within the

recently published Vision paper of the Association of European Cancer Leagues⁶⁹. This includes recommendations, among others, to:

- Create a permanent structure to continuously monitor and collect data from cancer screening programmes, which would be responsible for the periodic implementation reports on cancer screening in the EU (ensuring that the next implementation report on cancer screening is published before 2024); and,
- Develop an action plan for Member States in response to the WHO Guide to Cancer Early Diagnosis addressing health literacy, supporting implementation research, and fostering collaboration amongst Member States and neighbouring countries.

- **Increase health literacy in respect to the warning signs of cancer**

Just as the European Code Against Cancer has been a model initiative for improving public understanding about modifiable behaviours to reduce risk of cancer, so a European level project to improve health literacy Vis-à-vis citizens' ability to recognise potential early warning signs of cancer

could be of enormous value in improving early detection, and may be achieved at comparative modest cost.

The European Cancer Organisation recommends specific funding for such an exercise be ring fenced within the EU Health Programme.

- **Facilitate an acceleration in uptake of new diagnostic technologies**

Suggestions made to the European Cancer Organisation in this regard include an EU platform to facilitate rapid uptake of essential new diagnostic modalities. For further development of these suggestions, the European Cancer Organisation recommends specific engagement by the European Cancer Plan authors with societies representing experts in the cancer imaging and diagnosis fields, such as those within the European Cancer Organisation's membership⁷⁰.

12. Ensuring all patients benefit from access to meaningful innovation in cancer treatment

Adopting a balanced understanding of cancer treatment

A point the European Cancer Organisation wishes to emphasise to the Beating Cancer Plan authors is that cancer treatment must be understood throughout the plan in respect to its multi-modal nature. Forms of cancer treatment include, but are not limited to: oncology surgery, radiation therapy, treatment via pharmaceutical agents, nuclear medicine and interventional radiology.

We therefore recommend that the needs of professional-led services such as pathology, imaging, oncology pharmacy, cancer nursing, supportive care, psycho-oncology, and palliative care be considered within the 3rd Pillar of the European Cancer Plan: Treatment. The Treatment Pillar of the Cancer Plan should aim to encompass the full experience of patients when it comes to the treatment phase of cancer, including all of the healthcare professional services they need and encounter.

We therefore urge that throughout the development and implementation stages, the Cancer Plan authors understand the holistic nature of cancer treatment, and give attention to the opportunities to provide support for improvement in ALL areas of treatment.

We also refer and can provide connection to individual European Cancer Organisation's member societies present and engaged in separate treatment areas.

Helping countries improve resource allocation in respect to treatment

The European Union is already conducting useful roles in helping Member States better ensure best use of available health resource when it comes to cancer and the adoption of new innovations in treatment. This includes the current legal proposal on Health Technology Assessment (HTA)⁷¹ and the deliberations of the Expert Panel on effective ways of investing in health.⁷²

There is a “good news problem” in cancer care in respect to innovation. Over the last two to three decades, the field of cancer has seen improvements in the speed and accuracy of diagnostic procedures, the effectiveness of surgery, radiation therapy and medical treatments and the power of information technology. The growing adoption of Artificial Intelligence in areas such as radiology is another example in this regard. Development of clinical support roles such as those of specialist cancer nurses and oncology pharmacists and of multidisciplinary, specialist-led approaches to care have also played an important role in improving the care and treatment offered to cancer patients.

Investment in all these innovations is critical if we are to continue to improve the lives of cancer patients across all age groups in years to come. However, there is growing evidence of inequalities in, and complex barriers to access to, many innovations in Europe, as healthcare systems struggle to meet the associated challenges in respect to investment decisions.

Ways in which the European Beating Cancer Plan can assist in this regard, include by:

- Continuing to progress Health Technology Assessment (HTA) cooperation between EU Member States⁷³;
- Better harnessing the power of data collection and analysis at European level for understanding the real world impact of new treatments, including via greater harmonisation of cancer registry initiatives;
- Adopting the recommendations of the EORTC Treatment Optimisation Manifesto⁷⁴;
- Clarifying and communicating the ability of EU structural funds to be deployed for certain kinds of health system investment related to cancer (e.g. radiotherapy/radiosurgery); and,
- Providing Innovative Health Initiative, Health Programme and Horizon Programme funding to support real world data, outcomes research, healthcare spending efficiency, and value based healthcare related projects

In terms of building upon work already conducted in this area, we refer the Cancer Plan authors to initiatives such as:

- the ESTRO HERO project that has developed a

knowledge base and a cost accounting model estimating the national cost of radiotherapy⁷⁵ ;

-the work of the European Society of Radiology in advancing the concept of Value-Based Radiology⁷⁶

Advancing the use of digital technologies for the improvement of cancer care

The European Cancer Organisation advocates that DG CONNECT be a closely linked partner in authoring and developing the European Beating Cancer Plan, especially for areas within its remit that can have meaningful impact for cancer care and control, including in respect to the use of Artificial Intelligence in cancer care and electronic Health records.

Cancer treatment must be understood throughout the plan in respect to its multi-modal nature.

In respect to meeting other policy challenges connected to treatment improvement in cancer the European Cancer Organisation also refers the Cancer Plan authors to: the consensus statement: ‘Identifying critical steps towards improved access to innovation in cancer care: A European Cancer Organisation position paper’⁷⁷ and the SIOP Europe Position Paper on the Paediatric (Medicines) Regulation⁷⁸.

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