



Proposed Mission

# CONQUERING CANCER: MISSION POSSIBLE

Report of the Mission Board for Cancer

Independent  
Expert  
Report



Research and  
Innovation

Proposed Mission

## Conquering cancer: mission possible

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**CONQUERING CANCER:**  
**MISSION POSSIBLE**  
*Report of the Mission Board for Cancer*

This document is the Mission Board's proposal to the European Commission for a Mission on Cancer.

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## CONQUERING CANCER: MISSION POSSIBLE

As an integral part of the Horizon Europe Framework Programme for Research and Innovation (2021-2027), a set of European Research and Innovation Missions aim to deliver solutions to some of the greatest challenges facing Europe. Cancer is one of these challenges. This Mission outline explains how a mission-driven approach can save and improve the lives of millions of European citizens exposed to cancer and its risk factors. It sets out the goal of the Mission on Cancer and makes recommendations on how to achieve this goal.

In designing the Mission on Cancer, the European Commission invited a Board of European experts – covering cancer research, innovation, policy, healthcare provision and practice – (hereafter Mission Board) to define an ambitious and measurable goal with a substantial impact on and relevance for society and citizens of Europe. The Commission also asked the Board to propose a coherent set of actions to achieve this goal in a set timeframe. These actions will be implemented through Horizon Europe and other instruments of the European Union (EU) and its Member States, and aligned with other initiatives at EU and Member State level.

In finalising this Mission outline, the Board was assisted by the Cancer Mission Assembly, inputs from a wide network of experts and organisations (academic, private sectors, and advocacy groups). In addition, the Board received input from the 27 Member States, members of the European Parliament and several Directorates-General of the European Commission, as well as a number of consultation and engagement sessions with EU citizens, including cancer patients and survivors (see Annex IV) organised in their countries and native language or in online meetings with participants from across the entire EU.

This Mission outline will be used as a basis for further stakeholder and citizen engagement activities in the remainder of 2020, and define a broad strategy for the Horizon Europe Framework Programme. Synergies will be developed with national cancer plans and other programmes of Member States, with other Horizon Europe Missions and research and investment programmes, as well as with other EU policies and actions, in particular the Europe's Beating Cancer Plan. The final Mission on Cancer report, due in December 2020, will feed the work programmes of Horizon Europe.

As President of the European Commission Ursula von der Leyen said, we need to build a stronger European Health Union, a Union where we are united in diversity and adversity, where we work together to overcome our differences and where we build today the healthier, stronger and more respectful world we want our children to live in tomorrow. With respect to tackling cancer, the Mission on Cancer and the Europe's Beating Cancer Plan, the Commission services will therefore now explore policy options and use of financial instruments to initiate a gradual and synergised implementation of both initiatives, in close cooperation with Member States.

## 1 Cancer: a growing challenge for Europe

Cancer is an umbrella term for more than 200 diseases. These have in common the uncontrolled growth and spread of abnormal body cells, affecting tissues and organs. Considering that Europe has a quarter of all cancer cases and less than 10 % of the world's population<sup>1</sup>, it is evident that cancer is a huge threat for Europe's citizens and health systems. Each year, 2.6 million people in the EU-27 are diagnosed with cancer<sup>2</sup>. This number is expected to increase rapidly because of ageing populations, unhealthy lifestyles and unfavourable environmental conditions. Almost three quarters of all cancers in the EU occur in people aged 60 or above.<sup>3</sup> Without strong action, the number of cancer cases in Europe will increase by 25 % by 2035.<sup>1</sup> Although survival rates of several cancer types have improved over the last decades, cancer still kills 1.2 million people in the EU-27 each year.<sup>4</sup> The probability of receiving a timely diagnosis of cancer and of surviving the disease differs substantially across Europe because of major inequities in access to cancer knowledge, prevention, diagnostics, treatments and care. The chances of surviving cancer also depend highly on the type of cancer, as some cancers are still not well understood, including several childhood cancers.

The current COVID-19 pandemic puts high pressure on health systems' capacities and resources. This is a severe threat to cancer prevention, detection and treatment. It may also impact funding for cancer research, innovation and care, as countries may reset their priorities and reallocate resources. However, the Mission on Cancer has lost none of its urgency, considering that the challenges of cancer have increased due to the COVID-19 crisis. At the same time, the COVID-19 pandemic has also shown health systems' and society's resilience and potential to adapt rapidly to changing circumstances, as it has accelerated the development and acceptance of new technologies as well as built strong collaborations across sectors and borders. The lessons learnt from the COVID-19 crisis will be applied in the Mission to develop genuine solutions to the challenges arising from cancer and beyond (see Annex V).

Increasing survival proportions result in more Europeans living with and after cancer. There are more than 12 million cancer survivors in Europe.<sup>5,6</sup> Being

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<sup>1</sup> Bray F, Ferlay J, Soerjomataram I, et al. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: a cancer journal for clinicians* 2018; 68: 394-424.

<sup>2</sup> ECIS (European Cancer Information System): Estimates of cancer incidence and mortality in 2018, for all cancer sites

<sup>3</sup> Cancer Surveillance Section, IARC ([csu@iarc.fr](mailto:csu@iarc.fr))

<sup>4</sup> Eurostat: Causes of death - deaths by country of residence and occurrence (last update 30-04-2020)

<sup>5</sup> Living within 5 years of a diagnosis; the term "survivor" throughout this Mission outline refers to survivors as well as people living with cancer

<sup>6</sup> Global Cancer Observatory (<https://gco.iarc.fr/>)

cancer-free does not however mean being free of the cancer experience.<sup>7</sup> Many survivors experience side-effects from treatment, which may only become apparent years after completing treatment and may intertwine with other comorbidities as survivors get older. Physical and mental health problems significantly impact their quality of life, affecting the ability to play a full role in society and the workforce. In addition, many survivors experience stigmatisation. This is reflected in difficulties in getting a job or having a career, and in obtaining health insurance or other financial products (e.g. life insurance for a mortgage). This all generates a substantial burden for cancer survivors and their families, but also for countries' health systems and society in general.

## **2 Conquering cancer calls for an EU-wide mission**

Given that the challenges that arise from cancer for European citizens and countries are vast, conquering cancer in Europe calls for multiple actions by many stakeholders, both at the national level and EU level. At EU level, citizens, cancer patients, survivors and their family members and carers may benefit from bundling of cancer knowledge, sharing of expertise and exchange of data. The EU could offer large scale for research on less prevalent cancers by providing a platform for sharing knowledge and data, for exchanging experience from best practices and innovations in countries. Previous EU Research and Innovation Programmes and other actions have addressed various challenges in cancer research, prevention and care. However, the increasing burden of cancer in Europe, and the rapidly increasing costs of cancer for health systems and society require collaboration on an ambitious European scale, innovating and integrating fundamental, translational, clinical and interventional research, underpinned by supportive policy and legislation, as well as a strong commitment from Member States to break barriers across Europe.

The Mission on Cancer will address the whole cancer control continuum, i.e. from prevention of risk factors to survivorship support and end-of-life care, for all ages and cancers, including rare and poorly understood cancers<sup>8</sup>, cancers in children, adolescents/young adults and the elderly, cancers in socially or economically vulnerable families and among people living in remote areas, across all Member States. While the Mission provides directions and objectives for research and innovation, it will also generate evidence on factors that limit effective policy and support actions to conquer cancer. In this regard, the Mission's actions will be able to make an important contribution to the Europe's Beating Cancer Plan.<sup>9</sup> Vice-versa, the Cancer Plan will provide opportunities to complement the Mission on Cancer.

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<sup>7</sup> Rowland JH. Cancer survivorship: a new challenge in cancer medicine (pp. 909-916). In: Bast Jr RC, Croce CM, Hait WN et al. (Eds) Holland-Frei Cancer Medicine. 9th Edition. Hoboken, NJ: Wiley, 2017.

<sup>8</sup> Cancers for which knowledge on their molecular characteristics is lacking. (this outline)

<sup>9</sup> <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan>

### **3 The goal of the Mission on Cancer**

The overall goal of the Mission on Cancer has been formulated as: “By 2030, more than 3 million lives saved<sup>10</sup>, living longer and better”. This is consistent with UN Sustainable Development Goal (SDG) 3: Ensure healthy lives and promote well-being for all at all ages. The target of this SDG for non-communicable diseases<sup>11</sup> for 2030 is “to reduce by one third premature mortality through prevention and treatment and promote mental health and well-being.”<sup>12</sup>

### **4 Achieving the goal: areas for action**

Given the high level of ambition, a comprehensive plan of bold actions supported by all Member States and stakeholders – including patients, survivors, carers and the wider public – is required to achieve the Mission’s goal. Figure 1 illustrates that five effective interventions are needed to improve 1. prevention, 2. diagnostics and treatment of cancer, 3. the quality of life of cancer patients, survivors, and their families and carers, as well as 4. equitable access to all the aforementioned areas. As such, these areas are considered the main intervention areas of the Mission. Effective interventions in these areas all require a thorough understanding (5<sup>th</sup> intervention) of cancers, causal factors and mechanisms, and their impact on cancer; therefore, understanding is considered the basis for actions. Furthermore, effective policy measures are needed and resources should be allocated to ensure that citizens and other stakeholders in all Member States have equitable access to high-quality prevention, diagnostics and treatment, care and support, including access to research funding and knowledge. Finally, as underscored in the Mazzucato report “Governing missions in the European Union”<sup>13</sup>, the success of the mission-oriented process will lie in novel flexible governing structures to correctly balance with an effective portfolio management enabling cross-sectoral and cross-institutional coordination.

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<sup>10</sup> The Mission on Cancer aims to avert more than 3 million additional premature deaths over the period 2021 – 2030, by accelerating progress of cancer prevention and control programmes and creating more equitable access to these programmes. This goal was set based on an analysis of avoidable deaths by the International Agency for Research on Cancer (IARC).

<sup>11</sup> [www.who.int](http://www.who.int)

<sup>12</sup> <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>

<sup>13</sup> [https://ec.europa.eu/info/publications/governing-missions-governing-missions-european-union\\_en](https://ec.europa.eu/info/publications/governing-missions-governing-missions-european-union_en)



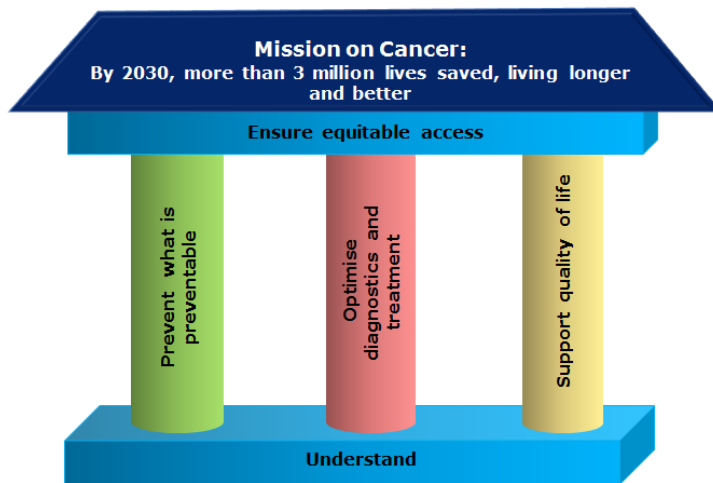


Figure 1. Intervention areas for action

## Understand cancer, its risk factors and impact

Understanding is a key starting point for effective actions to save lives and improve the quality of life of persons with and after cancer, their families and carers. What we do not understand, we cannot address effectively.

Understanding the biological processes in the human cell is crucial for diagnosing cancer and developing effective treatment. Despite developments in cancer treatment, some cancers are still resistant to all available therapies, and some well-known targets are still untreatable with current drugs. A special focus is deemed necessary on anti-cancer medication innovation for childhood cancers, cancers in adolescents and young adults, and cancers in the elderly, as these populations have distinct age-related biological and clinical characteristics.

Understanding the complexity of cancer and the role of factors and determinants (e.g. lifestyle, environment, workplace exposure, but also sex/gender and age) is important for developing effective preventive measures. Some factors are known to play a role in the development of cancers but their precise impact is not clear, whereas other causal factors remain to be discovered. Moreover, changing human behaviour has proven to be a challenge. Therefore, more understanding is needed of how people perceive health threats and cancer risks, how they behave accordingly and how unhealthy behaviours can be sustainably changed.

Furthermore, there is an urgent need to obtain a better understanding of the impact of cancer treatment on patients, both to optimise treatment and improve quality of life. Many people experience physical and mental health problems even years after their cancer diagnosis and initial treatment. Understanding how each individual reacts to treatment and how treatment affects mental health is crucial for developing more effective care and support for patients and their carers.

**🔗 Recommendation 1: Launch UNCAN.eu – a European Initiative to Understand Cancer**

Despite tremendous progress in deciphering the genetic and biological basis of cancer, our understanding of the molecular processes at the cancer cell level and the interactions of the tumour and its host is still very limited. This holds in particular for cancers for which understanding is lacking and rare cancers. The potential for increasing our understanding in this area is demonstrated by the significant benefit obtained through targeted therapies and host immune activation against some tumours. Recent technological developments and European collaborations provide an excellent opportunity for realising this potential through obtaining a comprehensive and dynamic view of how certain cancers initiate, develop and spread in the context of the host.

This requires a new level of investment in innovative research, including high-potential/high-risk projects. Therefore, the Mission Board proposes a Europe-wide platform, UNCAN.eu, utilising relevant research infrastructure and investing in the development of new models and technologies interrogating the interactions of cancers and their host. UNCAN.eu would encompass relevant stakeholders and enable integration of innovative models and technologies with longitudinal patient data, samples and biomarkers for identification and translation to patients. UNCAN.eu would provide breakthroughs in understanding how cancers initiate, develop and spread in the context of the host and thereby provide a basis for saving millions of European citizens' lives in synergy with actions related to recommendations 2-6 and 11-12 of this Mission outline as well as actions related to the Europe's Beating Cancer Plan and other EU Research and Innovation Missions (see Annex I).

## ☞ Recommendation 2: Develop an EU-wide research programme to identify (poly-)genetic risk scores

This action aims to assess the individual cancer risk with refined algorithms based on newly identified polygenic risk scores (PRS). Based on an increased understanding of individual cancer risks, education activities and counselling could be improved.

Sampling and data collection would be harmonised to enable sharing on an existing European Research Infrastructure<sup>14</sup> (e.g. BBMRI-ERIC<sup>15</sup>, EATRIS-ERIC<sup>16</sup>, ELIXIR<sup>17</sup>). The proposed research programme<sup>18</sup> would foster the implementation of genomic and informatics infrastructures for (GDPR<sup>19</sup>-compliant) data collection and dissemination, taking advantage of Digital Health Europe<sup>20</sup> and the initiative of the EU Member States “towards access to at least 1 million sequenced genomes in the EU by 2022”<sup>21</sup>. The Mission on Cancer could also contribute to achieving the objectives of this initiative. In addition, the research programme would promote clinical validation of the PRS, educational activities on the clinical relevance of polygenic risk scores in all citizens whatever their age and solicit public debate on their usage and control.

The proposed research programme would be carried out in all Member States to overcome existing inequity in access to cancer research and knowledge. In addition, the research programme would be extended to other disease areas, and as such contribute to increased understanding of other life-threatening or disabling non-communicable diseases.

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<sup>14</sup> A facility that provides resources and services for a research community to conduct research and foster innovation. A Research Infrastructure can be used beyond research, e.g. for education or public services. It may be single-sited, distributed, or virtual. A Research Infrastructure may include: scientific equipment or sets of instruments; collections, archives or scientific data; computing systems and communication networks; any other research and innovation infrastructure of a unique nature which is open to external users. ([https://ec.europa.eu/info/research-and-innovation/strategy/european-research-infrastructures\\_en](https://ec.europa.eu/info/research-and-innovation/strategy/european-research-infrastructures_en)).

<sup>15</sup> A European Research Infrastructure for biobanking. BBMRI-ERIC brings together researchers, biobankers, industry and patients to boost biomedical research. It offers quality management services, support with ethical, legal and societal issues, and a number of online tools and software solutions. (<https://www.bbmri-eric.eu/>)

<sup>16</sup> <https://eatris.eu/>

<sup>17</sup> <https://elixir-europe.org/>

<sup>18</sup> A coherent set of research and innovation actions undertaken by a community of researchers in co-creation with stakeholders, based on common definitions, assumptions, methods and goals. (this Mission outline)

<sup>19</sup> General Data Protection Regulation (<https://gdpr-info.eu/>)

<sup>20</sup> <https://digitalhealtheuropa.eu/>

<sup>21</sup> <https://ec.europa.eu/digital-single-market/en/news/towards-access-least-1-million-genomes-eu-2022-1-year>

- **Beating cancer requires a comprehensive approach: understand the link between the environment and health in general.**
- **Save time by optimizing current practices and resources; it should be at the basis of the mission.**
- **Understand patients and their whole cancer journey better.**
- **Raise awareness and educate the wide public about cancer, health and environment, and risk factors. The more the public knows about cancer, the easier it is for patients to go through treatment and recovery.**
- **The EU is seen as a reliable source of information and standardisation of information for citizens.**

## Prevent what is preventable

Despite improvements in cancer detection and treatment, there is a need for cancer prevention and health promotion to remain a very high priority. Lifestyle is a risk factor for many cancers and, although persistent, a modifiable factor. Around one third of deaths from cancer are due to the five leading behavioural and dietary risks: tobacco use, alcohol use, high body mass index, low fruit and vegetable intake, and lack of physical activity, as described in the European Code against Cancer.<sup>22-23</sup> Furthermore, cancer is the leading cause of work-related deaths. The International Labour Organization estimated that over 106,000 cancer deaths in Europe in 2017 were attributable to occupational causes.<sup>24</sup>

Early detection of cancer can improve cancer treatment outcomes and prevent or reduce deterioration of health and wellbeing. Early detection can be achieved by screening, creating awareness of suspicious signals among the population and screening patients at risk of cancer. Despite the Council Recommendation on cancer screening<sup>25</sup> adopted unanimously by the Health Ministers of the EU in 2003, in most Member States cancer screening is still not fulfilling the criteria set for population-based, organised programmes.

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<sup>22</sup> WHO (2018, November 12). Cancer. Retrieved May 19, 2020, from <https://www.who.int/news-room/fact-sheets/detail/cancer>

<sup>23</sup> Schüz J, Espina C, Villain P, et al. European Code against Cancer 4<sup>th</sup> edition: 12 ways to reduce your cancer risk. *Cancer Epidemiol* 2015; 39 Suppl 1: S1-S10. (<https://cancer-code-europe.iarc.fr/index.php/en/>)

<sup>24</sup> <https://www.wsh-institute.sg/-/media/wshi/past-publications/2017/global-estimate-of-occupational-injuries-and-workrelated-illnesses-2017.pdf>

<sup>25</sup> <http://data.europa.eu/eli/reco/2003/878/oj>

The area of prevention is particularly suited for creating synergies with other EU Research and Innovation Missions (see Annex I), as well as with the European Green Deal<sup>26</sup>, the Farm to Fork Strategy<sup>27</sup>, the European Health Data Space<sup>28</sup> and the Europe's Beating Cancer Plan.

**☞ Recommendation 3: Support the development and implementation of effective cancer prevention strategies and policies within Member States and the EU**

Preventing cancers calls for effective policy underpinned by excellent research. The Mission Board proposes to establish a research programme to identify effective cancer prevention strategies and methods to provide up-to-date knowledge to EU institutions and countries for designing and implementing effective cancer prevention measures at EU- and national level, tailored to local needs and conditions. Initial areas of research would focus on alcohol, food and sugar sweetened beverages and tobacco consumption, as well as commercial determinants<sup>29</sup> of health. These would be supplemented with research on exposures to workplace carcinogens, including emerging causes of cancer, air pollution, interactions of behavioural risk factors and comorbidities, as well as prevention strategies along the entire cancer continuum.

The research programme would also provide multi-disciplinary support for the prevention of other non-communicable diseases, and build research capacity and train young researchers across the EU in prevention and implementation research. The added value of an EU-wide approach also lies in its potential to create a large evidence base, including evidence from health economic evaluations, of preventive interventions and measures.

To support the implementation of effective prevention strategies within Member States, the Board also recommends the creation of a Policy Support Facility, for example to enhance knowledge sharing to support the implementation of cancer-related education tools in children and young citizens<sup>30</sup>. This would be aligned with the proposed research programme and research initiated by other EU Research and Innovation Missions (Annex I), as well as flagship EU policy initiatives, such as the Europe's Beating Cancer Plan,

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<sup>26</sup> [https://ec.europa.eu/info/strategy/priorities-2019-2024/european-green-deal\\_en](https://ec.europa.eu/info/strategy/priorities-2019-2024/european-green-deal_en)

<sup>27</sup> [https://ec.europa.eu/food/farm2fork\\_en](https://ec.europa.eu/food/farm2fork_en)

<sup>28</sup> <https://www.efpia.eu/news-events/the-efpia-view/blog-articles/a-european-health-data-space-a-small-step-or-a-giant-leap/>

<sup>29</sup> Factors that influence health which stem from the profit motive. (see <https://www.who.int/bulletin/volumes/97/4/18-220087/en>)

<sup>30</sup> A service offering practical support to EU Member States and countries associated to the Horizon Europe Programme to design, implement and evaluate reforms that enhance the quality of their research and innovation investments, policies and systems. The Policy Support Facility provides best practice, independent high-level expertise and guidance at the request of Member States and Associated Countries through a number of services: peer reviews, mutual learning exercises and specific support to countries. The Policy Support Facility responds to the strong need to offer more customer-oriented services to support evidence-based policy making. (adapted from: <https://rio.jrc.ec.europa.eu/policy-support-facility>)

the European Green Deal and the Farm to Fork Strategy.

This recommendation will also join an important cross-cutting theme and recommendation, i.e. the reduction of inequity in knowledge and access to effective cancer prevention and implementation research and programmes between and within Member States. It will also promote a whole-of-government approach to achieving a major breakthrough in cancer prevention.

#### **☞ Recommendation 4: Optimise existing screening programmes and develop novel approaches for screening and early detection**

To improve cancer screening in all Member States, the Mission Board proposes establishment of an EU-wide research programme to identify obstacles, optimise existing screening programmes and develop new approaches for screening and early detection of cancers. Studies will be designed together with citizens and other stakeholders, and support the development and implementation of innovative screening methods for cancers for which a reliable screening tool is lacking or for which current screening methods are suboptimal (as recommended by the Joint Action CanCon<sup>31</sup>); this also includes individualised approaches to screening. To optimise screening impact, effective and easily accessible communication strategies should be developed to enhance citizens' understanding of cancer risks and screening, including in difficult-to-reach geographical areas and populations.

Advances in new low-cost, non- or minimally invasive tests as well as new diagnostic technologies (e.g. liquid biopsies, volatolome testing, imaging biomarkers including radiomics, genetic risk scores, fluid markers, etc.) should be taken into account. Big-data analysis and machine learning methods could be integrated in screening and early detection programmes to generate new insights into risks and risk factors. Decision-making on screening and early detection strategies and programmes in all Member States should include cost-effectiveness modelling.

For continuous monitoring of screening quality, the Mission Board proposes development of a quality assessment tool, which could be implemented in all Member States. Exchange of good practices and twinning of high- and low-performing countries to reduce inequity in access to high-quality screening should also be supported.

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<sup>31</sup> <https://cancercontrol.eu/archived/>

- ***Raise awareness of cancer and its risks but correct perception of cancer as deadly, as it undermines health-related behaviour and screening participation.***
- ***Both governments and citizens have a role. Governments and the EU should ensure that environmental risks are reduced and international guidelines are adhered to. Citizens must adopt a healthy lifestyle, based on reliable information and education.***
- ***Behaviour change can be supported by a mix of measures such as bans, taxation, information on risk factors and nudges, including cancer-related education at high schools, but participants also stress the importance of making a healthy lifestyle affordable for all.***
- ***Primary care physicians should play a bigger role in informing and motivating patients to participate in screening***

## Optimise diagnostics and treatment

Many lives have been saved and the quality of life of patients and survivors has improved because of early diagnosis and better treatments. However, many cancers are still diagnosed at an advanced stage, are very aggressive and/or resistant to all therapies currently available.

An improved understanding of the aetiology, development and spread of poorly understood cancers could provide new biomarkers for diagnostics and new targets for therapies for all cancers. This would include highly lethal and rare cancers as well as cancers occurring in children, adolescents/young adults and the elderly with distinct age-related biological and clinical characteristics for which currently no effective treatment is available.

The translation from the development of breakthrough diagnostic technologies and from the identification of new targets for treatment into clinical trials is still too long. This requires further development of improved methodological validations and rapid implementation in cancer care.

A mission-driven approach aims to translate research breakthroughs into improved diagnostics and effective treatments, and to support equitable, timely access to optimal cancer diagnosis and treatment for each patient in all Member States.

### **☞ Recommendation 5: Advance and implement personalised medicine approaches for all cancer patients in Europe**

Personalised medicine offers the promise of maximally effective therapies with minimal harm, both for patients and society. While considerable efforts are being made (e.g. ERA PerMed<sup>32</sup>, ICPeMed<sup>33</sup>), many cancer patients still do not benefit from personalised medicine approaches. This recommendation aims to advance, scale, implement and optimise current personalised medicine approaches for cancer, deepening our understanding of cancer complexity, i.e. the role of the host, the impact of the outer environment on cancer initiation, and the evolution of cancer over time, to increase the number of patients for whom effective personalised approaches can be found.

As increased precision in cancer management will rely on large datasets for learning as well as advanced methods and standards, this recommendation encourages large-scale inter-sector and EU-collaboration and advanced data analyses in personalised medicine.

The uptake of personalised medicine is currently hampered by lack of understanding and adapted implementation measures and, in consequence, access to personalised therapies remains limited. This recommendation therefore aims to advance the methodology into outcome-based personalised medicine programmes, building on – but surpassing – initiatives such as PERMIT<sup>34</sup>, in close collaboration with clinical and HTA<sup>35</sup> decision-makers. At the same time, personalised medicine for cancer should expand in scope to achieve optimal and person-centred care, i.e. including additional tools for personalisation, such as imaging, but also patient preferences and individual risk/benefit trade-off.

### **☞ Recommendation 6: Develop an EU-wide research programme on early diagnostics and minimally invasive treatment**

With increased and more effective screening, it is expected that many cancers will be detected at an earlier, less advanced stage. At the same time, the increasing implementation of effective preoperative treatment (such as radiotherapy, systemic and immunotherapy) for both localised and advanced cancers has shown phenomenal and sometimes even complete responses. This raises the question of whether, in the very good responders, mutilating surgery is still justified. Minimally invasive treatment strategies (such as organ preservation in rectal-, oesophageal- or prostate cancer) and minimally invasive treatment technologies (such as interventional radiological, image-

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<sup>32</sup> ERA-Net (European Research Area Network) on personalised medicine ([www.erapermed.eu](http://www.erapermed.eu))

<sup>33</sup> International Consortium for Personalised Medicine (<https://www.icpermed.eu/>)

<sup>34</sup> PERsonalised MedicIne Trials (PERMIT) project (<https://www.ecrin.org/activities/permit-project>)

<sup>35</sup> Health Technology Assessment



guided surgical or endoscopic technologies) are advancing rapidly, yet research is still highly needed. These treatments use imaging to efficiently target the tumour and spare normal tissue. Hence, minimally invasive treatment has the potential to cure while providing the patient with a better quality of life. With the launch of effective minimally invasive therapies the role of diagnostic methods that can accurately detect tumours at early stage, accurately predict response to treatment and early detect tumour regrowth during active surveillance is becoming increasingly important. Research in minimally invasive and diagnostic technologies is therefore crucial to speed up the implementation of minimally invasive therapies in clinical practice.

Integration of diagnostic markers driven by AI, combining imaging, pathology, genetic, liquid biopsy and clinical biomarkers ('integrated diagnostics'), has the potential to increase the accuracy of prediction models of outcome and reduce the use of inefficient diagnostic tools, hereby enhancing personalised medicine. Hence successful research in the development of effective early diagnostic tools, integrated and driven by AI, as well as in minimally invasive treatment strategies and -technologies may lead to more cure and a better quality of life.

- ***Cancer treatment varies within/across EU countries.***
- ***Make knowledge widely available to patients and medical staff via the EU***
- ***Fasten access to treatment and decentralize health care facilities.***
- ***Ease access to clinical trials and innovative therapies.***
- ***Tailor treatment to patient's needs, e.g. paediatric patients have other needs than adults.***
- ***Personalised medicine is a good but costly concept. All involved need accurate and up-to-date information to avoid unrealistic expectations and misunderstanding.***
- ***A health passport with all relevant patient information is appreciated, but not sufficient to improve shared decision making.***

## Support quality of life

Increasing incidence and survival rates will result in many more EU citizens in the near future who will need to find a way to live a good life with or after cancer. Therefore, an important part of the Mission's goal is to achieve the best possible quality of life for everyone in the EU who is exposed to cancer in some way and in some phase of their lives.

Supporting the quality of life of people exposed to cancer requires a thorough understanding of their cancer-related problems. For patients and survivors these may be (late) side-effects of cancer treatment, symptoms, comorbidities and functional disability (which will increase with age), mental health and reproductive health problems. Many cancer survivors experience difficulties in returning to work because of persistent side-effects but also due to ignorance, stigma and hesitation on the part of employers. Obtaining health insurance or other financial products may also be difficult or expensive. This may also hold for individuals with a known family history of certain (hereditary) cancers or polygenic risks. Special attention should be paid to survivors of childhood cancer, as they are particularly vulnerable due to early life disruption. Two thirds of childhood cancer survivors experience adverse effects in adulthood.<sup>36</sup> This negatively impacts career opportunities, income, social relationships and starting a family. It is important to support carers for cancer patients, among others in terms of psychosocial support, as well by offering practical and financial assistance when needed.

The Mission on Cancer aims to contribute to a better understanding of (late) treatment side-effects, symptoms, comorbidities, functional disability and psychosocial needs, to relieve symptoms, improve palliative care and survivorship support. The Mission also aims to improve access to quality of life and survivorship support in all Member States. Besides research and innovation, this calls for policy and support actions, adjustment of legal frameworks and close collaboration with EU citizens, cancer patients and survivors, as well as their carers. Fundamental for all actions is that they be co-designed, -implemented and -evaluated with those for whom they are of concern.

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<sup>36</sup> Haupt R, Essiaf S, Dellacasa C, Ronckers CM, Caruso S, Sugden E, Zdravec Zaletel L, Muraca M, Morsellino V, Kienesberger A, Blondeel A, Saraceno D, Ortali M, Kremer LCM, Skinner R, Roganovic J, Bagnasco F, Levitt GA, De Rosa M, Schrappe M, Hjorth L, Ladenstein R; PanCareSurFup, ENCCA Working Group; ExPo-r-Net Working Group. The 'Survivorship Passport' for childhood cancer survivors. *Eur J Cancer*. 2018 Oct;102:69-81. doi: 10.1016/j.ejca.2018.07.006

**☞ Recommendation 7: Develop an EU-wide research programme and policy support to improve the quality of life of cancer patients and survivors, family members and carers, and all persons with an increased risk of cancer**

The Mission Board recommends developing an EU-wide research programme to improve the quality of life of all cancer patients, survivors and their carers, and all citizens with an increased risk of cancer. This research programme should start by gaining a comprehensive understanding of the holistic needs of all (subgroups) exposed to cancer. Together with this, appropriate methods and metrics should be developed to capture key elements of quality of life from the perspective of those affected by cancer, based on their personal life goals and values. Based on the results of these first actions, research should be conducted to develop innovative effective interventions. This includes high-quality research to limit the (late) side-effects of cancer treatments, to relieve pain and improve palliative care, home care therapy models as well as interventions in other sectors, such as regulatory and social interventions.

Apart from research and innovation, there is a need for supportive policies to identify and monitor physical and mental health problems among patients and survivors life-long by implementing a health passport for people living with and after cancer, and to help survivors achieve their personal life goals (e.g. related to work, family life). It is therefore recommended that countries be supported to develop and implement policies and strategies to help cancer survivors assert the 'right to be forgotten', counteract discrimination and strengthen the legal position of individuals with a family history of cancer, cancer patients, survivors and carers. Support should also be offered to improve access to health promotion, mental health and social care for each of these groups in all Member States.

The research programme and policy support will both link to actions resulting from recommendations 5, 6, 9 and 13, while also feeding the proposed European Cancer Patient Virtual Centre (recommendation 8) and providing evidence and support to the Europe's Beating Cancer Plan.

**☞ Recommendation 8: Create a European Cancer Patient Digital Centre where cancer patients and survivors can deposit and share their data for personalised care**

This recommendation involves the creation of a European Cancer Patient Digital Centre (ECPDC), i.e. a virtual network of patient-controlled (national) health data infrastructures, in which cancer patients and survivors can deposit their health data provided by their medical care providers (e.g. imaging, genetics, blood markers, clinical and lifestyle data) in a standardised, ethical and interoperable manner. The repository would include a summary of treatments and integrate patient-reported outcomes useful for the cancer patient own use and everyday life data provided by patients and survivors themselves.

The creation of the ECPDC would rely on a patient-driven roadmap and governance document, drawing on existing expertise at the EU and national level and on EU- and Member State-tailored data-sharing procedures. The ECPDC (with due regard for the GDPR) will provide people living with and after cancer with a health passport, including information on treatments and follow-up recommendations, and foster a (long-term) personalised care plan. For patients and carers, the ECPDC will be a global centre of knowledge on cancer, cancer prevention and health promotion, diagnostics, treatment and supportive care. For survivors and their families, the ECPDC will also be a global point of contact, offering guidance and support on returning to work, addressing financial issues and asserting survivors' rights.

Data within the ECPDC will serve as a valuable resource for research to improve understanding of cancer and its impact on patients' and survivors' lives, thus contributing to the development of improved diagnostics, treatment, care and quality of life support (recommendations 1 and 2, 4 to 7, 9, 13). In line with the European data strategy put forward by the European Commission<sup>37</sup>, the ECPDC will give a voice to patients and survivors, enable them to enforce their rights, and increase their confidence in sharing their data for cancer research, innovation and policy development.

## Ensure equitable access

One of the core values across the European Union is the shared commitment to universal access to high-quality care financed on the basis of equity and solidarity. Unhindered access to prevention and care is often under pressure within health systems broadly, and in the field of cancer in particular, due amongst others to widely shared pressures on limited resources. This impacts all areas of the Mission, making it a cross-cutting challenge that should be addressed in order to reach the Mission's goal.

According to recent European Commission reports<sup>38</sup>, Europe is characterised by inequitable access to cancer prevention and timely, high-quality diagnostics and treatment. These are the result of geography and socio-economic disparities between and within countries, which have a profound impact on cancer incidence and survival. With no assurance of equitable access to preventive measures, new diagnostics and treatments, achievements in the field of cancer research and innovation will not be distributed evenly within Europe and among

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<sup>37</sup> [https://ec.europa.eu/info/sites/info/files/communication-european-strategy-data-19feb2020\\_en.pdf](https://ec.europa.eu/info/sites/info/files/communication-european-strategy-data-19feb2020_en.pdf)

<sup>38</sup> State of Health in the EU Companion Report 2019. Publications Office of the European Union, 2019, State of Health in the EU Companion Report 2019: [ec.europa.eu/health/sites/health/files/state/docs/2019\\_companion\\_en.pdf](https://ec.europa.eu/health/sites/health/files/state/docs/2019_companion_en.pdf)

its most vulnerable populations. Equitable access implies access to education, amongst others, to improve citizens' (digital) health literacy, to expertise (e.g. training for care professionals) and to research and innovation resources.

Improving access within Member States requires a better understanding of why some policy tools have not been implemented effectively and what could be done to address inequity in access to prevention, diagnostics, treatment and quality of life support for anyone exposed to cancer. In addition, empowering patients should make it possible for them to gain more control over their care and life, and to act on issues of high value to them personally.

Hence, achieving equitable access calls for 1. a strong commitment from Member States, 2. availability and optimal use of research and clinical data (see recommendations 1-8), 3. strong promotion of research and innovation, supported by the establishment of at least one Comprehensive Cancer Infrastructure (CCI) in each Member State (see recommendation 10), and 4. EU-wide acknowledgment of the urgent need to transform the culture around cancer (see recommendation 13).

**☛ Recommendation 9: Achieve Cancer Health Equity in the EU across the continuum of the disease**

Substantial inequities exist in access to and quality of cancer prevention, screening, early detection, treatment, care and survivorship support between Member States and among different socio-economic and demographic groups (age, gender) within Member States.

The causes of these inequities should be analysed and strategies should be developed to overcome them. This requires an in-depth understanding of their underlying factors at all levels of the health system. In addition, more knowledge is needed to better understand interactions between (multiple) behavioural and environmental risk factors and the impact on successful prevention initiatives of socio-economic and health inequities.

Apart from research, policy support and interventions are needed to overcome existing inequities across and within Member States. These might include, amongst others, an annual public health promotion and cancer education programme to raise awareness and increase cancer knowledge by distributing messages through different channels with a particular focus on disadvantaged groups; policy support to countries to agree on a minimum set of high-quality screening programmes; policy support and facilitation of collaboration to accelerate and monitor access to new diagnostics, treatments and drugs; policy support to improve access to health promotion, effective return-to-work policies, mental health and social care for patients, survivors and their families, asserting the 'right to be forgotten' (in line with recommendations 7 and 8).

- **Improve access to screening and treatment in countries that are lagging behind.**
- **Improve geographical accessibility to screening, e.g. using mobile screening systems.**
- **Improve clinical trial access via legislation, mobility and expenses reimbursements.**
- **Remove inequities between health systems across the EU.**
- **Improve coordination and knowledge exchange between EU Member States.**

**☞ Recommendation 10: Set up a network of Comprehensive Cancer Infrastructures within and across all EU Member States to increase quality of research and care**

The current situation in the EU is characterised by substantial differences in the standards of care, research and education between Member States, and even within a country: patients receiving care from hospitals in more remote areas often do not have access to interventions that are offered only in the context of clinical studies. Uniform quality criteria set by accreditation standards are expected to decrease current inequities.

To ensure that each EU citizen or cancer patient has access to and could benefit from high-quality cancer research and care, it is proposed to support establishing a strong network of Comprehensive Cancer Infrastructures<sup>39</sup> (CCIs) within and across EU Member States. EU citizens or cancer patients should have access to an accredited CCI in their own country (at least one CCI in each Member State), albeit through a national access point to an accredited CCI in another country, if relevant. The network will contribute to sharing experiences and harmonising standards of care and research implementation. Each CCI should take into account the structure, governance, and geographical context – drawing, when possible, on EU-accredited care, teaching and research standards; liaise with the (EU-wide, national or regional) cancer and screening registries and with the European Reference Networks dealing with cancer (EURACAN<sup>40</sup>, EuroBloodNet<sup>41</sup>, Genturis<sup>42</sup> and PaedCan<sup>43</sup>); and integrate data collection to allow quality assurance and data consolidation. CCIs are expected to liaise also with biobanking facilities, and to build strong partnerships with research institutes and universities, as well as

<sup>39</sup> National or regional infrastructures that provide resources and services to support, improve and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/carers. Different formats of Comprehensive Cancer Infrastructures are possible, including existing Comprehensive Cancer Centres or Care Networks. (this outline)

<sup>40</sup> European Reference Network Rare Adult Solid Cancers (<https://euracan.ern-net.eu/nl/start/>)

<sup>41</sup> European Reference Network Hematological Diseases (<https://www.eurobloodnet.eu/>)

<sup>42</sup> European Reference Network on Genetic Tumour Risk Syndromes (<https://genturis.eu/l=eng/Home.html>)

<sup>43</sup> European Reference Network for Paediatric Oncology (<https://paedcan.ern-net.eu/>)

with an extensive international network. Newly established infrastructures should preferably align with existing initiatives within countries to ensure sustainability. Twinning arrangements with existing CCIs could facilitate the establishment and performance of new CCIs.

- ***The concept of quality of life is differently understood across countries (Eastern vs Central Europe).***
- ***Include mental health and psychological support in default treatments as psycho-social issues need more attention.***
- ***Attention for family of cancer patients and survivors is needed, not only psycho-social but also practical (time from work) and financial***
- ***Discrimination of survivors when taking out insurance or mortgage, or applying for a job must be banned.***
- ***EU-wide programme to improve the quality of life should be based on broad research among experts by experience.***

## Cross-cutting recommendations

The Mission Board proposes several (other) cross-cutting actions below to maximise the impact of the Mission on Cancer.

### **☞ Recommendation 11: Childhood cancers and cancers in adolescents and young adults: cure more and cure better**

Cancer is the leading cause of death in Europe in children above one year of age. This cancer patient population is characterised by multiple types of rare cancers, unique to this population with specific epidemiological, biological and clinical features. Whereas cancers in adults typically result from long-term processes, paediatric cancers develop early in life and over a much shorter period, suggesting that fewer but stronger events play a causal role. In addition to cancers that develop in early childhood, cancers in adolescents and young adults also require special attention, as their biological characteristics are distinct from (early) childhood cancers (and from cancers developing later in life). Given that incidence rates have been increasing continuously over the last decades, it is obvious that we need to increase our understanding of how cancers in children and adolescents/young adults initiate and develop.

Current survival rates come at a high price with a late effect burden from

treatment of up to 60 %, which is related to old off-patent, off-label drug supply<sup>44</sup>. Of all cancer medicines developed in the last decade (>150), only 6 % (9) were approved for children. Improving survival requires well-tested novel anti-cancer drugs tailored to specific tumour entities and age groups. A synergistic mission drawing on existing ambitious EU networks and aligned with the Europe's Beating Cancer Plan, focusing on the complex needs of paediatric cancer patients, survivors and their families could boost the transformation of paediatric cancer care and generate the evidence needed to advance diagnostic, treatment and survivorship support.

**☛ Recommendation 12: Accelerate innovation and implementation of new technologies and create Oncology-focused Living Labs to conquer cancer**

This recommendation aims to provide new ways for traditional and non-traditional innovators to contribute to cancer understanding, prevention, diagnostics and treatment, and quality of life support. For this purpose, it is proposed to create Oncology-focused Living Labs<sup>45</sup> to conquer cancer in its broadest sense. These will collate best practices of multi-stakeholder collaborations, distilling principles for successful joint working. It will position the EU as the home of collaboration and research to tackle cancer in order to attract stakeholders across different sectors and disciplines to work on cancer challenges within the EU. Activities will entail horizon-scanning and trend forecasting across all relevant technologies to inform a holistic cross-sector approach to conquering cancer.

The Oncology-focused Living Labs will enhance cross-sector research, knowledge-sharing and implementation of new technologies. Through increasing mutual understanding, and creating efficient and effective collaborative approaches to driving innovation, job creation and industrial competitiveness in healthcare and health-related industries, innovation will be steered (e.g. facilitated, protected and rewarded) in the direction of solving the societal challenge of the cancer burden, as well as generating economic growth, wellbeing and technological spill-overs.

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<sup>44</sup> Haupt R, Essiaf S, Dellacasa C, Ronckers CM, Caruso S, Sugden E, Zdravec Zaletel L, Muraca M, Morsellino V, Kienesberger A, Blondeel A, Saraceno D, Ortali M, Kremer LCM, Skinner R, Roganovic J, Bagnasco F, Levitt GA, De Rosa M, Schrappe M, Hjorth L, Ladenstein R; PanCareSurFup, ENCCA Working Group; ExPo-r-Net Working Group. The 'Survivorship Passport' for childhood cancer survivors. *Eur J Cancer* 2018;102: 69-81. doi: 10.1016/j.ejca.2018.07.006.

<sup>45</sup> User-centred, open innovation ecosystems based on a systematic user co-creation approach integrating research and innovation processes in real-life communities and settings. In practice, Living Labs place the citizen at the centre of innovation, and have thus shown the ability to better mould the opportunities offered by new ICT concepts and solutions to the specific needs and aspirations of local contexts, cultures, and creativity potentials. (JRC: <https://s3platform.jrc.ec.europa.eu/living-labs>)



### **☛ Recommendation 13: Transform cancer culture, communication and capacity building**

It is proposed to develop a coherent set of cross-cutting, cross-sector actions to enable citizens, clinical practitioners (including nurses, primary care physicians), researchers, other stakeholders (e.g. policy-makers, health insurers, employers and trade unions) and communities within all Member States to rethink cancer and challenge cancer culture in all its dimensions. Increased understanding of cancer has substantially improved cancer prevention and treatment over the last decades, with many more people living with and after cancer who are willing and able to live a meaningful life and participate in society as much as possible. However, thinking and communicating about cancer in research, healthcare and society has not substantially changed in the same way. In cancer research and innovation, co-design and co-creation with patients and survivors are still limited, but should become common practice. In cancer care, as in healthcare in general, a paradigm shift is needed towards person-centred, rather than disease-centred, care. This calls for individualisation and co-creating health and wellbeing with patients and their carers. European citizens and societies still hold on to traditional views on cancer, reflected in stigmatisation and discrimination of patients and survivors, and resulting in substantial preventable disease burden.

To support the uptake of accurate and up-to-date knowledge about cancer (joining on going efforts, such as for example JRC's Cancer Knowledge Centre), and stimulate communication and understanding on current scientific insights, it is proposed to develop and exploit an EU-wide Cancer R&I Dissemination and Communication Facility<sup>46</sup> using accessible language and citizen-/stakeholder- adapted communication tools.

Furthermore, it is recommended that national and EU-wide capacity building be developed and supported in order to adapt the skills and competences of all stakeholders in the changing field of cancer. This includes training all stakeholders and education programmes/campaigns to raise awareness among the general public including children and adolescents in line with up-to-date scientific knowledge on cancers, their symptoms, risk factors, preventability, treatment options and impact on patients, survivors, their families and carers, and citizens with an increased risk of cancer.

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<sup>46</sup> A service offering practical support to EU Member States and countries associated to the Horizon Europe Programme to disseminate accurate and up-to-date knowledge about cancer in lay language and to stimulate communication in line with current scientific knowledge about cancer. (this outline)

## ANNEX I: OVERVIEW OF RECOMMENDATIONS

Recommendation		Potential synergy with other EU Research and Innovation Missions
1	Launch UNCAN.eu – a European Initiative to Understand Cancer	Missions on Soil health and food; Climate-neutral and smart cities; Adaptation to climate change including societal transformation
2	Develop an EU-wide research programme to identify (poly-) genic risk scores	Missions on Soil health and food; Climate-neutral and smart cities; Adaptation to climate change including societal transformation
3	Support the development and implementation of effective cancer prevention strategies and policies within Member States and the EU	Missions on Soil health and food; Climate-neutral and smart cities; Adaptation to climate change including societal transformation
4	Optimise existing screening programmes and develop novel approaches for screening and early detection	
5	Advance and implement personalised medicine approaches for all cancer patients in Europe	
6	Develop an EU-wide research programme on early diagnostic and minimally invasive treatment technologies	
7	Develop an EU-wide research programme and policy support to improve the quality of life of cancer patients and survivors, family members and carers, and all persons with an increased risk of cancer	Communication to citizens together with other Missions
8	Create a European Cancer Patient Digital Centre where	

	cancer patients and survivors can deposit and share their data for personalised care	
<b>9</b>	Achieve Cancer Health Equity in the EU across the continuum of the disease	
<b>10</b>	Set up a network of Comprehensive Cancer Infrastructures within and across all EU Member States to increase quality of research and care	
<b>11</b>	Childhood cancers and cancers in adolescents and young adults: cure more and cure better	
<b>12</b>	Accelerate innovation and implementation of new technologies and create Oncology-focused Living Labs to conquer cancer	
<b>13</b>	Transform cancer culture, communication and capacity building	Communication to citizens together with other Missions

## ANNEX II: FROM RECOMMENDATIONS TO SPECIFIC ACTIONS

This Mission outline describes the overall goal of the Mission on Cancer as identified by the Board based on the expertise of the Board members and valuable inputs from the members of the Cancer Mission Assembly, Member States, other experts, representatives of citizens and patients and from Foresight workshops<sup>47</sup>. To achieve this goal, the Board has made a number of recommendations for actions.

Each of these recommendations has been briefly described in this Mission outline, separately from one another for the purpose of clarity and simplicity. But it should be noted that these recommendations form a coherent framework of proposed actions, as visualised in Figure 2.

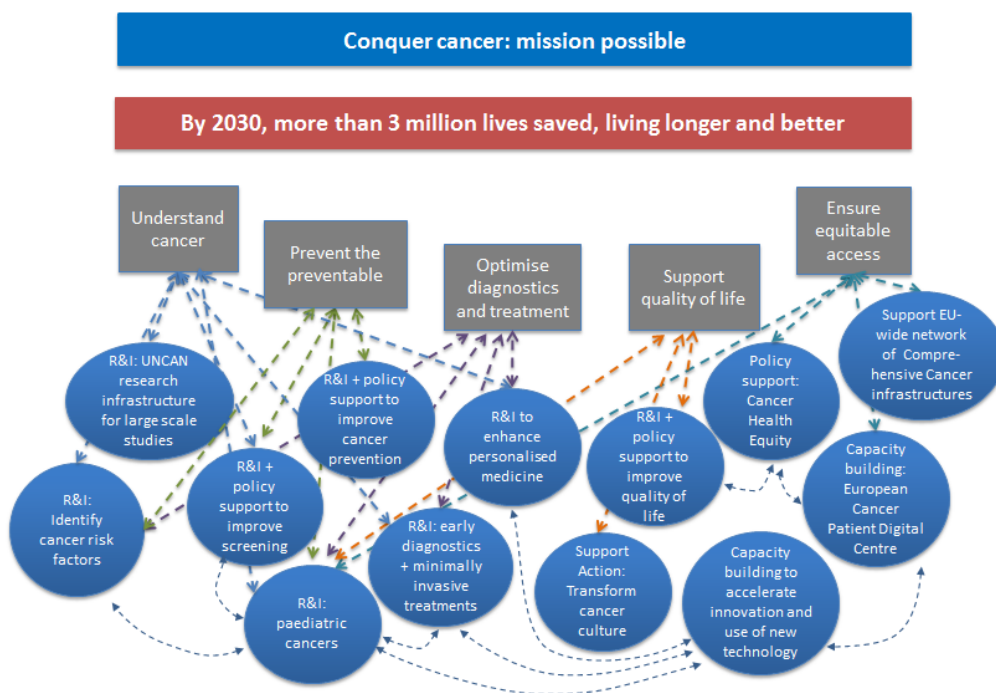


Figure 2. Relationships between Mission's goal, areas of action and recommended actions

The recommendations described in this Mission outline will be further developed in the remainder of 2020. They will be combined and specified in a proposal for specific actions, each with an ambitious and measurable objective, a tight but

<sup>47</sup> Reports of Foresight activities are reported on separately for all five Missions, see [https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme/missions-horizon-europe\\_en](https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme/missions-horizon-europe_en)

realistic timeframe, identified key performance indicators to measure progress towards its objective and identified actors. This will be done together with the members of the Cancer Mission Assembly and all stakeholders, for whom several stakeholder engagement activities are being planned for autumn 2020. To strengthen the impact of the Mission, synergies will be created as much as possible with national cancer plans and other actions of Member States as well as of other Horizon Europe Missions, research and investment programmes and other EU policies and actions, in particular the Europe’s Beating Cancer Plan.

To prepare this next step, the Board has started to draft a number of specific actions based on its recommendations, which will be discussed with all stakeholders in Member States and at EU level, to ensure maximal impact of the Mission with optimal use of available resources.

Figures 3 and 4 highlight some examples of how the Board’s recommendations could be further developed in specific actions with measurable objectives, identified actors and synergies with related initiatives.

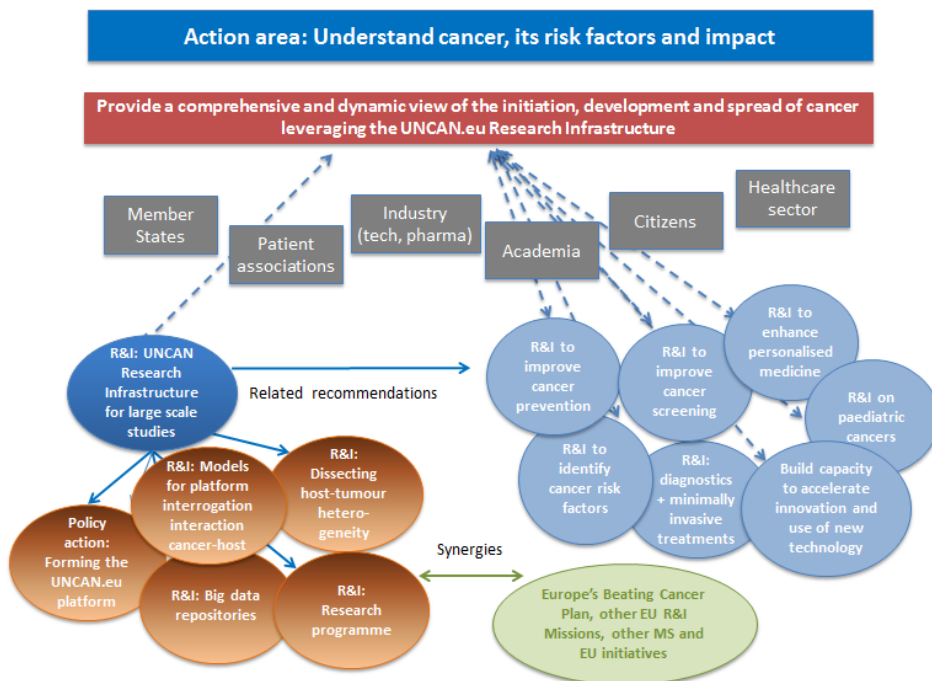


Figure 3. Example of action area 'Understand cancer, its risk factors and impact'

**Action area: Prevent what is preventable**

By 2030, all EU Member States will have implemented comprehensive cancer prevention strategies, resulting in a reduction of preventable cancer cases of at least 25 %

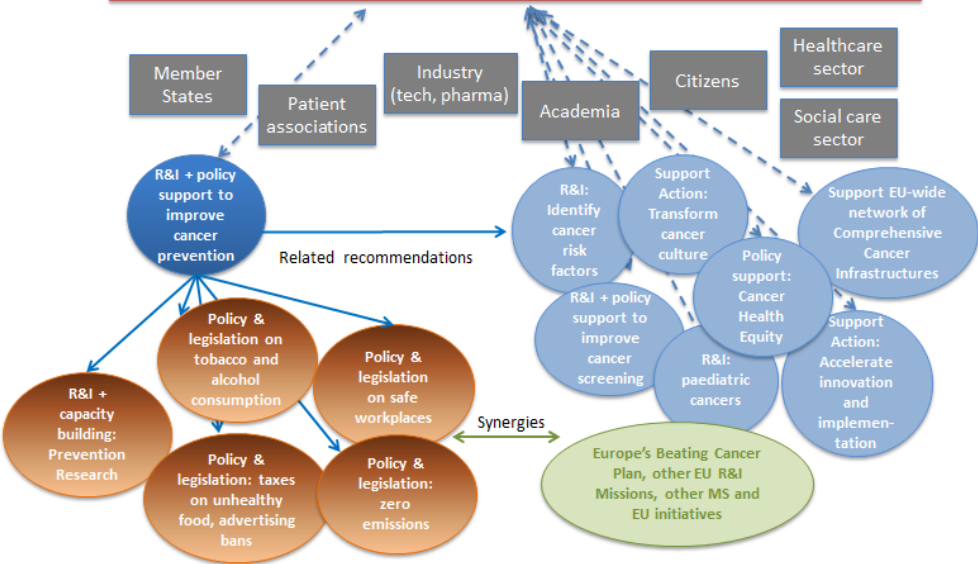


Figure 4: Example of action area 'Prevent what is preventable'

## ANNEX III: CITIZEN ENGAGEMENT ACTIVITIES

### Box 1 Overview of citizen engagement activities

To ensure that the voices of citizens and patients are heard at all stages of the development and implementation of the Mission, a number of citizen engagement activities around the Mission Against Cancer have been organized. Because of the outbreak of Covid-19, most activities were organized online and a mixture of types of focus group discussion was used. Two meetings took place as so-called **asynchronous focus groups** (one in May and one in August/September). Group members consisted of citizens from different (in total 26) European countries, and discussions were moderated in English through a secure online platform on which participants could respond to questions and engage in a dialogue over a course of 2 weeks, among others reflecting on the proposed Mission's goal, areas for action and recommendations for cancer prevention and screening, treatment and care, and quality of life and survivorship support. These same topic areas were also addressed in a number of national level events, facilitated by a local moderator in the national language. For all meetings, the aim was to involve as many different citizens as possible. Both younger and older participants were represented, and many of them were experience experts such as patients, survivors and their families. Some participants were also professionally involved, e.g. working in patient advocacy. Although other citizens did not have personal experiences with cancer, it became clear that all were able to draw from experiences and observations from their personal networks, showcasing the fact that cancer is something that affects all citizens in the EU.

In addition to the aforementioned citizen engagement meetings, Board members organised Ambassador activities, both in their own countries and in other Member States. Some of these meetings took place with expert audiences, such as Ministries of Health and/or Science, Members of Parliament, and clinical plus research audiences. While many of these meetings had the participation of patient organisations, Ambassador activities also took place as dedicated events with patients and other citizens, and the main lessons from those latter activities are incorporated in this Annex on citizen engagement. Similar to the above mentioned consultation meetings, these events varied in size and composition, among others with smaller face to face meetings at different locations or larger online meetings with close to 100 participants.

Consultation and Ambassador activities are also scheduled to take place for the continuation of the Mission preparations, and will be reported on more extensively in the final Mission on Cancer report, due in December 2020 (see also footnote 48, providing reference to citizen events and other mission conferences for all five Missions).

## Introduction

The Mission on Cancer aims to generate a substantial impact on the lives of all European citizens exposed to cancer. Therefore, it is of utmost importance that the Mission is being developed together with citizens and cancer patients, survivors and their families or carers. To ensure that the voice of citizens and patients is heard in all phases of Mission development and implementation, several patient representatives are members of the Mission Board and the Mission Assembly. Moreover, members of the Board are taking the role of ambassadors to engage citizens and patients in their home countries in the developmental process. In the sections below, we report on the main results of the discussions which served as inputs for refining the present outline of the Mission on Cancer. (For a description of engagement activities and the methods used, see Box 1).<sup>48</sup> Box 2 provides an overview of messages and recommendations per area from these focus groups.

It is important to note that the composition of the group of participants and the format of the meetings varied, as well as the topics that were discussed and the exact questions asked. Hence, the report below provides an overview of the subjects that are relevant to citizens, but no quantitative statements or conclusions can be made.

## Mission goal

Participants expressed strong support for the **overall goal** identified for the Mission. Cancer concerns all European citizens. There was appreciation for the fact that the goal is not only on saving lives, but also on improving the lives of those exposed to cancer. Participants felt that there is still a strong need for awareness raising in many countries, and emphasized that all EU citizens should have equal access to up-to-date scientific knowledge about cancer, education about cancer and cancer symptoms, and to prevention and treatment. The more the public knows about cancer, the easier it is for patients to go through treatment and recovery.

Regarding the identified areas for action – Understand, Prevent, Treat, Support Quality of life – participants felt these were logic and all important. To the extent that preferences were given, participants emphasised the importance of cancer **prevention**, as they felt that actions in this area would have the potential to save and improve many lives while also being relatively inexpensive (compared to cancer treatments). However, especially patients with cancer also put strong emphasis on **early detection** of cancer.

The area of cancer **treatment** was also strongly supported, as participants felt that many cancer patients had their hopes pinned on new drugs and therapies.

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<sup>48</sup> Information on Ambassador activities for all five Missions is also available at: [https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme/missions-horizon-europe/citizen-events-and-specialised-missions-conferences\\_en](https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme/missions-horizon-europe/citizen-events-and-specialised-missions-conferences_en) and <https://missions-get-involved.ec.europa.eu/>



In addition, participants emphasised the need for more attention to the **quality of life** of people exposed to cancer and their families and for cancer survivors. Young people and children may need extra attention. In general, it is important that the taboo on cancer disappears, as this is still prevalent in some societies.

There was a consensus that the **EU has a role to play** because cooperation and shared knowledge are important. Participants perceived the EU as a credible source of standardised information. One suggestion was to set up an "official EU platform, containing not only medical research, studies and cures, but also facts about nutrition, lifestyle, social programs, resources for information, projects and non-governmental organisations in each country. Basically creating a guided network of support."

## Understanding

In general, little attention was paid in the discussions to **understanding** the factors leading to cancer. If mentioned, participants referred to e.g. cancer genetics, for example for hereditary and childhood cancers. In general, participants put more emphasis on the importance of **understanding patients** rather than understanding cancer alone, i.e. being more patient-centred and understanding patients' whole cancer journey. They also perceived a need for all EU citizens to have a better understanding of cancer. There is a need to "de-mystify cancer", as "Cancer should not be taboo." The perception of this aspect of understanding included empowering patients by giving them greater knowledge.

## Prevention

**Cancer prevention** was considered a shared responsibility of citizens and governments. Participants pointed to people's own responsibility for healthy living (e.g. nutrition, physical activity, smoking and alcohol intake), but also indicated that national or **EU-wide policies** were important to support this, for example by enabling access to affordable healthy food, increasing knowledge and raising awareness through regular public campaigns and health education at schools about cancer and risk factors, and by enabling cancer screening. Specifically for health education at schools some participants suggested to include cancer-related education to the educational curricula in high schools across the EU. Similarly, some participants encouraged partnerships between government, public hospitals, communications agencies and schools, to disseminate effective information campaigns and curricula to inform people on the importance of healthy diet, quit smoking and physical exercise to prevent cancer. The EU also has a potential role by providing a platform to share promotional materials and comprehensive information to support cancer patients, family members and the wider public.

Participants were also very concerned about **air pollution and pesticides** and frustrated that economic interests always weigh more heavily than health and environmental rules and standards. They think that the **EU can work together** by ensuring adequate funding, especially for lower income countries, good research and guidelines, and holding all Member States accountable for

compliance. Taxes and bans to reduce smoking, overweight and alcohol consumption were considered a way to go, but not by all participants. Some think it is better to **make healthy food affordable** for every citizen instead of taxing unhealthy food.

Participants suggested putting more effort into health promotion and **education starting at school age**, research into personalised advice and taking account of personal characteristics and circumstances in developing tailored lifestyle interventions. Information about and **equal access to cancer screening** was felt highly important. In some countries there is room for improvement as it concerns proximity for screening, especially in some rural areas, and waiting lists for diagnosis and treatment, especially for people who are dependent of public health care. In many countries, family doctors should communicate better and more personalised with their patients about the pros and cons of screening. There was support for more **personalised prevention**, based on assessment of individual risk based on big data.

Citizens favoured more EU policy in this area, while also pointing to the responsibility of countries for offering high-quality cancer screening. There is support for a **European Cancer Patients Data Centre**.

The hope was that European guidelines, standards and recommendations will be followed by the Member States.

## Cancer treatment and care

While evaluating the **quality of available cancer treatment and care** in their country, differences were observed between countries in the access, affordability and level of person-centeredness of cancer care. In some countries, there are **wide disparities in care** between public health care that is reimbursed but has long waiting lists and expensive private care. Health services and specialists are mainly available in urban centres, making it harder for people from the rural areas to have access to adequate care and support. More decentralization is necessary and more state funds should be directed to the public health care system. Accommodation facilities for patients and their family should be provided by the state when they need to travel for medical purposes.

Some participants mentioned that cancer care in their country focused exclusively on the medical treatment, providing little opportunity for obtaining mental healthcare, quality of life and survivorship support. Although **shared decision making was felt important**, many participants think that it is hindered by the lack of adequate patient information in cancer treatments. To strengthen the position of patient in shared decision making they should also have easy access to their own health data. In the meetings were this was addressed, there was **support for a Health passport** that not only contains relevant information on patients clinical history and received treatments, but may also serve as an educational tool. For senior patients such a passport might be difficult to use and also concerns were raised about the security of such a database.

Although most participants had a **positive attitude on personalised medicine** for cancer and about a dedicated European research programme, there were concerns about the high costs which entails that personalised medicine will not be readily available to every citizen. In addition, several participants emphasized that informing citizens about personalised medicine must be done with caution, as long as so much is still unknown and there is a risk of unrealistic expectations being created.

**The voice of cancer patients must be heard.** Several participants emphasised the importance of patient involvement in designing and evaluating cancer treatments and cancer care in general. Access to participation in clinical trials should be improved. In addition, the role of cancer patient associations at the national and European level is vital and non-governmental organisations should have access to funding.

Participants see a **role for the EU** to make a unified plan how to invest financial and political resources efficiently in research, prevention, screening, diagnosis and treatment (including personalised treatment) and development of guidelines for the benefit of cancer patients. The EU should support countries which have the most need of better cancer treatments, to make sure that all EU citizens have access to efficient prevention and treatments of cancer. Some participants feel that the EU is not doing enough to support Member States in their fight against cancer (both financially and in terms of information campaigns).

## Quality of life

In the action area of **quality of life and survivorship support** concrete aspects of patients' and survivors' daily life were addressed. Aspects important to improving everyday life are frequently unseen, such as the need to facilitate access of cancer patients to oncofertility clinics, to cryopreservation and reconstruction surgeries, which in many health systems are yet to be supported. But also mental problems that arise from having cancer or undergoing treatment do not always receive attention in some European countries.

Participants suggested a number of specific actions they felt to be important, such as peer-to-peer support, support from patient-experts, support from a cancer patient navigator, psychosocial support for family members (including support for siblings of children with cancer), financial support and time for work for family members who take care for their relatives with cancer and research to reduce and better manage (late) side-effects of cancer treatment.

For cancer survivors, **support to return to an active and normal life has priority**, including reintegrating to work, adapted or not, access to insurances and other financial products and economic support to guarantee the basic need as good living conditions. A unified **EU plan** can lead national plans to ensure that health care systems support the needs of cancer survivors. This plan should be based on broad research into the experiences and needs of cancer patients and among family and friends. Special attention is needed for young people and children and cancer patients without relatives and friends. The EU

could also play a role by creating European support groups and platforms to share experience.

Some participants also mentioned that person-centredness of cancer care needed attention and that patients should be considered as partners in care. They also emphasised the need to put effort into **educating the social environment and society in general** on cancer survivors' physical and mental health issues, and related challenges for personal and social life. In many of their responses, participants mentioned the importance of **equity**. For example, they pointed to standardisation of cancer care across and within countries, and equitable access to cancer drugs and knowledge, which would be a role for the EU.

It was suggested that the EU should encourage the involvement of non-governmental organisations as they can provide, through adequate funding, information campaigns and psychological and practical support for patients and their family.

## Box 2 Main messages per area of action

<p><b>Understand</b></p> <ul style="list-style-type: none"> <li>• Beating cancer requires a comprehensive approach: understand the link between the environment and health in general.</li> <li>• Save time by optimizing current practices and resources; it should be at the basis of the mission.</li> <li>• Understand patients and their whole cancer journey better.</li> <li>• Raise awareness and educate the wide public about cancer, health and environment, and risk factors. The more the public knows about cancer, the easier it is for patients to go through treatment and recovery.</li> <li>• The EU is seen as a reliable source of information and standardisation of information for citizens.</li> </ul>	<p><b>Prevent</b></p> <ul style="list-style-type: none"> <li>• Raise awareness of cancer and its risks but correct perception of cancer as deadly, as it undermines health-related behaviour and screening participation.</li> <li>• Both governments and citizens have a role. Governments and the EU should ensure that environmental risks are reduced and international guidelines are adhered to. Citizens must adopt a healthy lifestyle, based on reliable information and education.</li> <li>• Behaviour change can be supported by a mix of measures such as bans, taxation, information on risk factors and nudges, including cancer-related education at high schools, but participants also stress the importance of making a healthy lifestyle affordable for all.</li> </ul>	<p><b>Treat</b></p> <ul style="list-style-type: none"> <li>• Cancer treatment varies within/across EU countries.</li> <li>• Make knowledge widely available to patients and medical staff via the EU</li> <li>• Fasten access to treatment and decentralize health care facilities.</li> <li>• Ease access to clinical trials and innovative therapies.</li> <li>• Tailor treatment to patient's needs, e.g. paediatric patients have other needs than adults.</li> <li>• Personalised medicine is a good but costly concept. All involved need accurate and up-to-date information to avoid unrealistic expectations and misunderstanding.</li> <li>• A health passport with all relevant patient information is appreciated, but not sufficient to improve shared decision making.</li> </ul>
<p><b>Support quality of life</b></p> <ul style="list-style-type: none"> <li>• The concept of quality of life is understood differently across EU Member States.</li> <li>• Include mental health and psychological support in default treatments as psycho-social issues need more attention.</li> <li>• Attention for family of cancer patients and survivors is needed, not only psycho-social but also practical (time from work) and financial</li> <li>• Discrimination of survivors when taking out insurance or mortgage, or applying for a job must be banned.</li> <li>• EU-wide programme to improve the quality of life should be based on broad research among experts by experience.</li> </ul>	<p><b>Ensure equitable access</b></p> <ul style="list-style-type: none"> <li>• Improve access to screening and treatment in countries that are lagging behind.</li> <li>• Improve geographical accessibility to screening, e.g. using mobile screening systems.</li> <li>• Improve clinical trial access via legislation, mobility and expenses reimbursements.</li> <li>• Remove inequities between health systems across the EU.</li> <li>• Improve coordination and knowledge exchange between EU Member States.</li> </ul>	<p><b>Overall</b></p> <ul style="list-style-type: none"> <li>• Connect citizens from all paths of life, make cancer a societal problem.</li> <li>• Involve youngsters via EU Youth Programmes.</li> <li>• Make the mission visible</li> <li>• More education and information for citizens is needed on a range of issues.</li> <li>• Encourage cooperation across Member States with the EU in a leadership role.</li> <li>• Citizens and patients need to be more involved in research and developing interventions.</li> <li>• An EU-based platform should collect and share promotional materials and comprehensive information to support patients, family members and the wider public.</li> </ul>

## **ANNEX IV: COVID-19 AND CANCER**

COVID-19 may – in a foreseeable future – possibly be prevented by vaccines or effectively treated, while cancer will not.

The COVID-19 crisis has negatively affected cancer care at an unprecedented speed. Its aftermath poses significant threats to prevention and treatment, as well as to research and innovation critical for improvements. In this exceptional situation, the Mission on Cancer – in alignment with other European efforts – offers an excellent opportunity to address these threats, as detailed in this Annex and in the main text of this Mission outline. The ambitious Mission on Cancer aims to improve cancer prevention, diagnostics, treatment and quality of life of people exposed to cancer through a new level of research and innovation. The investment will also provide an important stimulus to European healthcare and its economy, and thereby contribute to societal recovery from the COVID-19 crisis. The Mission on Cancer is an essential and fundamental element in providing a coherent vision and detailed instruments for action to achieve the ambitious goals of the Europe’s Beating Cancer Plan.

### **Implications for the delivery of the Mission on Cancer**

- The goals of the Mission on Cancer are more relevant than before the COVID-19 crisis.

The COVID-19 (SARS-COV-2) disease and the ongoing response by European health systems captured the immediate attention of citizens, healthcare professionals and political decision-makers. The speed of the spread of SARS-COV-2, and the current absence of effective vaccines or treatment created unprecedented uncertainties. This does not, in any way, decrease the burden of other diseases<sup>49</sup>, nor change the historical trend of cancer becoming the first cause of mortality in every European country unless effective cancer control measures are found and implemented in the near future. Thus, the Mission on Cancer’s long-term objectives, as conceptualised before the COVID-19 pandemic, remain largely unchanged but need to be re-weighted in light of the current situation. It is fundamental that cancer patients continue to receive the treatment and care that they need in the aftermath of the most acute phase of the COVID-19 epidemic in Europe. The Mission provides an overarching framework to provide solutions and achieve the goals of the Europe’s Beating Cancer Plan.

- Availability of public and private funding

The crisis caused by the COVID-19 pandemic stressed all sectors of the global economy, including healthcare and research. There is the risk that public

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<sup>49</sup> [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)31067-9/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)31067-9/fulltext)

funding for research from Member States as well as private investment will decrease in the near future. The decisions by the European Commission to put a special effort into improving cancer prevention and care through the Mission on Cancer and the Europe's Beating Cancer Plan – and the recently expressed commitment of Commissioner Kyriakides (27 May 2020 webinar) that cancer remains a priority – provide a unique opportunity in this regard. The risk of the increased attention – and budget investment on issues related to COVID-19 is alleviated by e.g. the expected new EU4Health programme: this responds to COVID-19 and provides support for addressing long-term health challenges, including cancer. To reach the ambitious but tangible goals of the Mission on Cancer, it is essential that the required funding be made available as was planned before the COVID-19 pandemic.

- Engaging citizens

The prominent role of prevention and early detection that is critical in reducing the cancer burden requires an active role of citizens. COVID-19 has brought the importance of health to the forefront of citizens' minds and should be used: a shift to health and personal care seems to be taking on momentum.

- Accelerated acceptance of new technologies

The COVID-19 crisis has rapidly led to a willingness to embrace new technologies and approaches by both governments and citizens, an opportunity which it is important to leverage. On the care providers' side, the more intense use of telemedicine, reorganisation of teamwork and task shifts, and new and extended roles of health professions, offer experiences and possibilities that can be of use in cancer care. The Mission on Cancer aims to initiate implementation of its work at the beginning of 2021 with several actions to develop new technologies providing a niche in Europe for adopting new technologies in cancer prevention, early detection, personalised medicine and minimally invasive technologies. The Mission on Cancer proposal is also suited to taking advantage of the rapid development of telemedicine and remote interactions, where earlier resistance from several sources (patients, healthcare professionals, and payers) has been overcome.

- Need for communication

The dominance of COVID-19 in the media requires special attention for the Mission on Cancer. It highlighted once more how much citizens rely on the media and social networks for information, the importance of evidence-based decision-making and clear lay communication of research results, methodologies and uncertainties. The crisis has also compromised the mission's outreach programme as citizens' focus shifted from cancer to COVID-19.

## Implications for the relevance of the Mission on Cancer

The relevance of the Mission on Cancer is emphasised by the impact of COVID-19. The impact of the COVID-19 crisis has been immediate and dramatic, illustrated by a 25 % drop in cancer diagnoses in the Netherlands<sup>50</sup>, and a 50 % delay in treatments in the UK<sup>51</sup>, suspended prevention and early detection programmes and halted research activity. Thus, the COVID-19 pandemic is significantly aggravating the cancer crisis in Europe and amplifying the current shortcomings of health systems. A heavy toll in terms of cancers is expected due to the need to redirect precious healthcare resources to tackle the COVID-19 crisis. After the immediate shock wave dissipates, three broad challenges to health systems will be added: first, to overcome citizens' and patients' uncertainty regarding the safety of accessing healthcare facilities; second, to learn and apply lessons learned from this period to induce permanent changes in healthcare delivery, while thirdly dealing with increasing resource constraints.

The Mission on Cancer will induce innovations in several areas, as mentioned in the recommendations. The strong emphasis on principles of data collection, data sharing and data use by citizens will require innovative solutions in IT tools that can be used elsewhere in the economy. The COVID-19 pandemic generated a massive movement towards use of remote work. Privacy and security of data was already a concern in healthcare, and innovations in this area can benefit many other fields of economic activity. The development of the required IT tools will also create a demand for specialised work, creating jobs and companies that may extend their reach beyond cancer. The development of new technologies for testing will contribute further to the creation of high-skilled job opportunities in Europe. One of the economic lessons from the COVID-19 pandemic was the need for European supply lines. This will also be true for medical equipment (of all sorts), meaning that products used in cancer prevention, treatment and post-treatment will hopefully be produced within the European Union.

A major threat to the relevance of the Mission on Cancer would be an imbalanced response from the European Commission to the COVID-19 crisis with resources redirected to this single epidemic, leading to an unprecedented health crisis due to other big killers<sup>1</sup>, including cancer.

## Ways in which the Mission on Cancer supports European economic and societal recovery

COVID-19 has demonstrated, beyond doubt, the critical importance of health for any society. While usually only accounted for on the cost side, the recent pandemic clearly shows that the absence of health leads to severe economic,

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<sup>50</sup> <https://www.thelancet.com/action/showPdf?pii=S1470-2045%2820%2930265-5>

<sup>51</sup> <https://www.nature.com/articles/s41591-020-0874-8>



political and societal consequences for Europe. COVID-19 has also laid bare critical insufficiencies in healthcare system preparedness, adaptability and resilience.

While the COVID-19 pandemic is unprecedented in terms of incidence and mortality, it is foreseeable that – with determination, political will, and based on rapid scientific and technological advances – both vaccines and effective treatments will be found. Unfortunately, this will not be the case with cancer, which will remain one of the major killers in Europe.

The Mission on Cancer will be a major driving force to apply the lessons from the current COVID-19 crisis to find solutions to the cancer challenge and beyond. We have seen an unprecedented willingness in technology adaptation, collaboration across sectors and borders, including extensive data sharing, genuine communication and alignment between healthcare and research, remarkably shortening the implementation of research findings and the ability to mobilise and allocate considerable funding resources at short notice.

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The EU Open Data Portal (<http://data.europa.eu/euodp/en>) provides access to datasets from the EU. Data can be downloaded and reused for free, for both commercial and non-commercial purposes.

Under the Horizon Europe Framework Programme for Research and Innovation (2021-2027) five *Missions* aim to deliver solutions to major challenges for Europe. They include a Mission on Cancer. Many more people in Europe are living with cancer as the result of an ageing population, unhealthy lifestyles, and unfavourable social, environmental and working conditions. This is generating a huge burden for citizens, cancer patients, survivors and their families, and for health systems and society at large. To deliver concrete solutions, the Board for the Mission on Cancer is proposing an ambitious goal: "By 2030, more than 3 million lives saved, living longer and better". The Board's Mission outline with the input of citizens, patients and Member States' stakeholders, now presents 13 recommendations for bold actions to understand cancer, its risk factors and impact; to prevent what is preventable; to optimise diagnostics and treatment; and to support the quality of life of people living with and after cancer, while ensuring equitable access for all. The Board will use its Mission outline as the basis to continue engaging with stakeholders and citizens across Europe to define the actions and strategies required to achieve this goal.

*Studies and reports*

