

# Public consultation on the Commission's Europe's Beating Cancer Plan (Online Questionnaire)

Fields marked with \* are mandatory.

## Introduction

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Cancer concerns all European citizens. 40% of us are likely to be affected at some stage in our life and we all know someone who developed the disease. This is why the President of the European Commission announced [Europe's Beating Cancer Plan](#) to be carried forward by the Commission, under the stewardship of the [Commissioner for Health and Food Safety](#).

Europe's fight against cancer is ongoing ([link](#)). But beating cancer requires everyone's involvement. The Commission wants to place European citizens at the centre of this plan. This is why we want to hear your views as we embark on this journey. Whether you are a concerned citizen, a patient or one of his/her relatives, a healthcare worker, a researcher, an employee in the pharmaceutical sector, or a policy maker, we want to hear from you. Share your experience. Tell us where you think Europe should focus its efforts.

We see the cancer problem as three-fold. First, cancer can cause huge suffering to individuals and their families. The citizen, and patient and his/her immediate family is the starting point and epicentre of Europe's Beating Cancer Plan. The second element is the burden that cancer imposes on society as a whole, stretching health systems. The third dimension is the significant inequalities that exist across Europe in terms of access to high-quality cancer-related services. Access to screening programmes varies significantly throughout Europe. And once diagnosed, patients don't always get access to the treatment that might make a vital difference for them.

With an estimated 40% of cancers being attributed to avoidable causes, we need to do better when it comes to cancer prevention. And as we get better at ensuring people survive cancer, our societies also need to do better at helping survivors with the problems they face subsequently. Therefore, the Commission intends to design the plan to cover the entire cycle of the disease. Actions should span all steps of the disease, including prevention, early diagnosis, treatment, and the social dimension of cancer (encompassing life after cancer, carers and palliative care). We published a roadmap describing this approach under this [LINK](#). Please let us know if you think we have missed something important, be it in terms of problems, objectives, or areas of EU action to explore.

Drawing on your input, the Commission will go on to complement this initial public consultation with further targeted interactions with specific stakeholder groups.

The contributions to this public consultation are not considered to relate to your own personal health situation but may relate to the health experience or situation of family and/or friends.

Thank you for helping us shape the European Cancer Plan!

## About you

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\* Language of my contribution

- Bulgarian
- Croatian
- Czech
- Danish
- Dutch
- English
- Estonian
- Finnish
- French
- Gaelic
- German
- Greek
- Hungarian
- Italian
- Latvian
- Lithuanian
- Maltese
- Polish
- Portuguese
- Romanian
- Slovak
- Slovenian
- Spanish
- Swedish

\* I am giving my contribution as

- Academic/research institution
- Business association
- Company/business organisation
- Consumer organisation
- EU citizen
- Environmental organisation
- Non-EU citizen
- Non-governmental organisation (NGO)
- Public authority
- Trade union
- Other

\* First name

\* Surname

debry

\* Email (this won't be published)

axel.debry@embl.de

Gender

- Male
- Female

Age

- 14 or less
- between 15 and 24
- between 25 and 39
- between 40 and 54
- between 55 and 64
- 65 or more

Highest degree obtained

- Basic education
- Secondary education
- Vocational training
- University degree

\* Organisation name

*255 character(s) maximum*

European Molecular Biology Laboratory (EMBL)

Postal address of your organisation

Meyerhofstrasse 1, 69117 Heidelberg

\* Country of origin

Please add your country of origin, or that of your organisation.

- |                                      |  |                                     |  |
|--------------------------------------|--|-------------------------------------|--|
| <input type="radio"/> Afghanistan    | <input type="radio"/> Djibouti           | <input type="radio"/> Libya         | <input type="radio"/> Saint Martin                     |
| <input type="radio"/> Åland Islands  | <input type="radio"/> Dominica           | <input type="radio"/> Liechtenstein | <input type="radio"/> Saint Pierre and Miquelon        |
| <input type="radio"/> Albania        | <input type="radio"/> Dominican Republic | <input type="radio"/> Lithuania     | <input type="radio"/> Saint Vincent and the Grenadines |
| <input type="radio"/> Algeria        | <input type="radio"/> Ecuador            | <input type="radio"/> Luxembourg    | <input type="radio"/> Samoa                            |
| <input type="radio"/> American Samoa | <input type="radio"/> Egypt              | <input type="radio"/> Macau         | <input type="radio"/> San Marino                       |
| <input type="radio"/> Andorra        | <input type="radio"/> El Salvador        | <input type="radio"/> Madagascar    | <input type="radio"/> São Tomé and Príncipe            |

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- Antarctica
- Antigua and Barbuda
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- Austria
- Azerbaijan
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- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
- Bonaire Saint Eustatius and Saba
- Bosnia and Herzegovina
- Botswana
- Bouvet Island
- Brazil
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- Falkland Islands
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- French Southern and Antarctic Lands
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- Georgia
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- Greenland
- Grenada
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- Guam
- Guatemala
- Guernsey
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Heard Island and McDonald Islands
- Honduras
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania
- Mauritius
- Mayotte
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Myanmar /Burma
- Namibia
- Nauru
- Nepal
- Netherlands
- New Caledonia
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norfolk Island
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Sint Maarten
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Georgia and the South Sandwich Islands
- South Korea
- South Sudan
- Spain
- Sri Lanka
- Sudan
- Suriname
- Svalbard and Jan Mayen
- Sweden
- Switzerland
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- Taiwan
- Tajikistan
- Tanzania
- Thailand
- The Gambia
- Timor-Leste
- Togo
- Tokelau

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- Cape Verde
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- Central African Republic
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- China
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- Clipperton
- Cocos (Keeling) Islands
- Colombia
- Comoros
- Congo
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- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Pitcairn Islands
- Poland
- Portugal
- Puerto Rico
- Qatar
- Réunion
- Romania
- Russia
- Rwanda
- Saint Barthélemy
- Saint Helena Ascension and Tristan da Cunha
- Saint Kitts and Nevis
- Saint Lucia
- Tonga
- Trinidad and Tobago
- Tunisia
- Turkey
- Turkmenistan
- Turks and Caicos Islands
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United Kingdom
- United States
- United States Minor Outlying Islands
- Uruguay
- US Virgin Islands
- Uzbekistan
- Vanuatu
- Vatican City
- Venezuela
- Vietnam
- Wallis and Futuna
- Western Sahara
- Yemen
- Zambia
- Zimbabwe

\* Organisation size

- Micro (1 to 9 employees)
- Small (10 to 49 employees)

- Medium (50 to 249 employees)
- Large (250 or more)

## Transparency register number

*255 character(s) maximum*

Check if your organisation is on the [transparency register](#). It's a voluntary database for organisations seeking to influence EU decision-making.

## \* Publication privacy settings

The Commission will publish the responses to this public consultation. You can choose whether you would like your details to be made public or to remain anonymous.

### **Anonymous**

Only your type of respondent, country of origin and contribution will be published. All other personal details (name, organisation name and size, transparency register number) will not be published.

### **Public**

Your personal details (name, organisation name and size, transparency register number, country of origin) will be published with your contribution.

In the interest of transparency, organisations and associations have been invited to provide the public with relevant information about themselves by registering in Transparency Register and subscribing to its Code of Conduct.

I agree with the [personal data protection provisions](#)

Please indicate if you have work experience in any of these areas

- Cancer care
- Pharmaceutical industry
- Social care sector
- Healthcare sector
- Education sector
- Health/social insurance sector
- Public administration

Are you a healthcare professional?

- Yes
- No

## General Questions

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**1. On a scale from 0 to 10, how present is cancer in your life? (0 is not at all present and 10 very present)**

*Only values between 1 and 10 are allowed*

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## 2. What do you think is needed to beat cancer?

- **What do you think citizens can do to help beat cancer?**

*600 character(s) maximum*

In order to be successful, fundamental research needs to be integrated with clinical data from cancer patients. Now more than ever, researchers can make sense of and utilize large data sets to better understand cancer and develop novel therapeutic approaches. Understanding the mechanisms of cancer at the individual patient level is important for personalised medicine, We therefore encourage citizens (cancer patients) to reach out to patient networks and research organisations/universities to understand how they could help in this aspect.

- **What do you think health professionals can do to help beat cancer?**

*600 character(s) maximum*

While health professionals cannot share medical and patients' data, it would really help patients and research alike if patients were informed about patient networks and ways to get involved in cancer research. Cancer patients often are not aware of how they can contribute to research. Cancer patients can then able to contribute to the global understanding of the disease, which can then support better diagnostics, treatments and management of the disease.

- **What do you think public authorities/national governments can do to help beat cancer?**

*600 character(s) maximum*

It would be in the best interest of citizens if national governments would align their efforts with those of their partners within the EU, and come together under a Europe-wide plan, on top of national initiatives. We would encourage national governments to increase spending on research and innovation and to support cross-border research projects. National repository of data shared by research, healthcare and industry, and suitable legal frameworks that enable optimal medical and research data sharing would be welcome, as currently, GDPR does not facilitate this.

## 3. Do you support the idea that the EU should do more to address cancer?

- Yes
- No
- I don't know

## In which areas do you think the EU should prioritise its efforts (choose top 3):

*at most 3 choice(s)*

- Prevention
- Screening and early diagnosis
- Treatment and quality of life of patients and carers
- Life after cancer

- Research and collection of information
- Other
- I don't know

Which actions would you consider most useful in the areas indicated below

## **STEP I: PREVENTION- Preventing cancer by addressing risk factors**

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Many things related to our lifestyle, and the environment around us may increase or decrease our risk of getting cancer. About 40% of cancer cases could be avoided through prevention measures that have proved to be successful.

Some of the most effective measures are:

- lifestyle changes (healthy diet, physical activity, reduction of obesity, avoidance of tobacco and alcohol consumption),
- vaccination against viruses that cause diseases such as cervical or liver cancer (Human papillomavirus, Hepatitis B),
- avoidance of excessive exposure to sunlight (including sunbeds)
- protection from exposure to certain chemicals that can cause cancer.

More recommendations are available in the [European Code Against Cancer](#), a joint initiative between the European Commission and the World Health Organization's International Agency for Research on Cancer.

### **4. Do you have enough information about how to prevent cancer?**

- Yes
- No
- I don't know

### **5. Which of the actions below do you think would have the biggest impact on your lifestyle habits (e.g. diet, physical activity, tobacco or alcohol consumption)? (choose top 3)**

- Measures on prices (including both taxation and/or incentives)
- Advertising
- Information campaigns
- Legislation
- Other

## **STEP II: EARLY DIAGNOSIS - Preventing avoidable cancer cases through cancer screening**

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An early cancer diagnosis can often significantly increase the chances of successful treatment. The European Union has issued [recommendations](#) for the screening of [breast](#), [cervical](#) and [colorectal](#) cancer.



**6. Do you think the EU should extend recommendations for screening of other types of cancer, beyond breast, cervical and colorectal cancer?**

- Yes
- No
- I don't know

**To which types of cancer in priority?**

- Lung cancer
- Gastric cancer
- Prostate cancer
- Ovarian cancer
- Other types of cancer

**7. What could influence your decision to take part in a cancer screening programme?**

- Information about the usefulness of screening and early diagnosis
- Convenience (proximity, ...)
- Cost
- Expertise and skills of healthcare workers
- The safety and quality of the equipment
- Other

**STEP III: TREATMENT - Best available care, treatment and quality of life for all cancer patients**

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Finding out you have cancer can be quite a shock. It can be difficult in these circumstances to decide how to approach your treatment. And then there is the question of whether you can get the treatment you need, and how much of it will be covered or provided by your health system. As with diagnosis, the best and most effective treatment should be available to all EU citizens. And, whilst our current treatments are indeed effective, new innovative treatments offer us even greater possibilities – yet this innovation can come at a very high cost.

**8. What could Europe do to ensure that cancer patients across Europe receive the best available treatment at an affordable price, independently of where they live?**

*600 character(s) maximum*

**9. Do you believe that you know where to find sufficient information about available cancer treatment services where you live?**

- Yes
- No

**10. Do you consider sufficient written information regarding cancer diagnosis and possible treatments is available to patients ?**

- Yes

- No
- I don't know

**11. Do you consider adequate support, both inside and outside of the healthcare setting, is available to cancer patients?**

- Yes
- No
- I don't know

**12. In your experience, do cancer patients receive treatment from a multidisciplinary team of health professionals (oncologists, researchers, psychologists)?**

- Yes
- No
- I don't know

**13. Do you consider that adequate means are available to help families and friends caring for cancer patients?**

- Yes
- No
- I don't know

#### **STEP IV: SOCIAL INTEGRATION - Quality of life with and after cancer**

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The good news is that the number of cancer survivors has increased substantially in the EU over the past decades. However, many of these survivors experience disabilities or long-term side effects of cancer treatment, including emotional distress.

In addition, cancer patients and cancer survivors often face hurdles in the workplace and in matters such as access to employment, insurance, or credit.

**14. In your country/region, do cancer survivors receive follow-up and support after treatment?**

- Yes
- No
- I don't know

**15. Do you consider that cancer survivors experience significant challenges in their daily life?**

- Yes
- No
- I don't know

**16. Do cancer patients and survivors receive psychosocial support during or after their treatment?**

- Yes
- No

I don't know

**17. Do you know or have experience of any particularly good practice in supporting cancer survivors, or do you have any suggestions as to how this could be done?**

*600 character(s) maximum*

## GENERAL QUESTIONS:

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**18. Tell us what a successful cancer plan means to you. 10 years after we implement the plan, what should have improved in the lives of European citizens?**

*600 character(s) maximum*

There is still a lot we do not fully understand about the disease, and while treatment and management are important, better understanding in order to make sure we can prevent it will be the key. Improving detection and prevention would make any future plan a success.

Therefore, a successful plan would demonstrate strong and sufficient funding of basic research.

**19. Provided it is securely managed and in full respect of data protection would you share your personal health data in order to help others and contribute to health improvements (tick all that apply)**

- With doctors?
- With researchers?
- With pharmaceutical industry?

**20. Have you received information on or been informed about the possibility to take part in clinical trials, including their benefits and risks?**

- Yes
- No
- Not applicable

**21. How can you (or your organisation) contribute to the EU plan on cancer?**

*600 character(s) maximum*

EMBL is involved in the Pan-Cancer Analysis of Whole Genomes project, a collaboration of over 1300 scientists and clinicians from 37 countries. It analysed over 2600 genomes of 38 different tumour types, creating a huge resource of primary cancer genomes, studying multiple aspects of cancer development, causation, progression. EMBL is planning new research areas that aim to uncover environmental factors that can contribute to cancer. Working with large datasets across Europe, EMBL will aim to use new statistical and AI approaches to understand the physical and genetic contributions to cancer.

**22. Is there anything else that you would like to add that has not been covered in this consultation?**

*600 character(s) maximum*

## Contact

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