

# 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

Ariane

\* Surname

WEINMAN

\* Email (this won't be published)

ariane.weinman@eurordis.org

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*

EURORDIS – Rare Diseases Europe (European patient organisation for rare diseases)

Postal address of your organisation

Fondation Universitaire, Rue d'Egmont 11, 1000 Brussels, Belgium

\* 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 |
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| <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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- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
- Bonaire Saint Eustatius and Saba
- Bosnia and Herzegovina
- Botswana
- Bouvet Island
- Brazil
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- Estonia
- Eswatini
- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
- Finland
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- French Guiana
- French Polynesia
- French Southern and Antarctic Lands
- Gabon
- Georgia
- Germany
- Ghana
- Gibraltar
- Greece
- Greenland
- Grenada
- Guadeloupe
- 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
- Syria
- Taiwan
- Tajikistan
- Tanzania
- Thailand
- The Gambia
- Timor-Leste
- Togo
- Tokelau

- Burundi
- Cambodia
- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- Christmas Island
- Clipperton
- Cocos (Keeling) Islands
- Colombia
- Comoros
- Congo
- Cook Islands
- Costa Rica
- Côte d'Ivoire
- Croatia
- Cuba
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- Ireland
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- Jamaica
- Japan
- Jersey
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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.

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## \* 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*

10

## 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*

Rare Cancers (RCs) account for 22% of all new cancer cases (incidence <6/100,000/year). Patients, families, carers become expert of their disease due to its rarity, their search for scarce information and treatments. Engagement from RC patients, families and patient organisations is crucial and has positive impact on health outcomes. It must be supported in research projects, patient registries, biobanking, clinical trials, collection of PROMs/PREMs, developing clinical guidelines and lay versions, quality of life's guidelines, training for health professionals, patients, families

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

*600 character(s) maximum*

RC patients require a high level of expertise, multidisciplinary care and a good referral system embedded in national HC systems, like any rare diseases. Health professionals who are not part of specialised RC centres need to be made aware that these centres exist for different types of RCs and need to know how to contact them. ERNs for RCs who provide virtual expertise can be contacted by non-ERN members, incl. GPs, via the CPMS provided by the EC. A good networking among health professionals is crucial to beat RCs. Participation in virtual trainings, conferences should be facilitated

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

*600 character(s) maximum*

Improving EU and national cancer plans, integrating specific provisions for RCs in children and adults, and covering all issues pertaining to research and care. Plans must be adequately budgeted and implemented. In RCs, mapping out specialised expertise and implementing appropriate referrals from the GP up to highly specialised care units will ultimately improve access to timely diagnosis and treatments. ERNs must be financially supported and well-integrated in healthcare systems. HTA and pricing mechanisms to ensure equal access to orphan drugs, innovative treatments must be harmonised

## 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

If you chose "Other", please describe it

*600 character(s) maximum*

All areas deserve to be equally tackled from research to screening, equal access to timely diagnosis and adequate treatments, quality of life of patients and carers during and after treatment. Efforts should cover all types of cancers including RCs whose incidence is <6/100,000/year. RCs include all paediatric cancers and RCs in adults. The EU funded project RARECARE estimates 200 types of RCs grouped into 12 families. They make 22% of all new cancer cases in Europe. The specificities of RCs, like all rare diseases, single them out as a unique domain of very high EU added-value

**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

### **What information would you need?**

*600 character(s) maximum*

Based on current scientific knowledge, modifiable risk factors are not well established in the field of RCs. Europe's Cancer Plan should include in its section on research, a specific focus on understanding the underlying causes of RCs through fostering epidemiological, biological, genetic research, making the best use of big data and advanced technologies, including Artificial Intelligence. Current and new registries are to be developed and sustained. Secondary prevention is also crucial to halt the progress of a high number of RCs



**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

Please describe

*600 character(s) maximum*

It is mostly unknown at present if changes of lifestyle can help prevent RCs in children, adolescents and adults. This is largely due to the lack of knowledge on causative factors of those cancers. All types of research need to continue, be organised and funded to establish clearer causative factors and help prevent or make early accurate diagnosis. Healthcare professionals need to be further trained on RCs and the public better informed to help detect early symptom

## **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

Other types of cancer

*600 character(s) maximum*

Cancer screening should be provided wherever possible. All hereditary cancers, rare cancers where applicable as well as rare diseases giving rise to tumours should be included in screening programmes. The list can be established with relevant ERNs. Identifying patients at risk, irrespective of their age, can enable

good surveillance and appropriate clinical management. Expanding screening programmes to this population at risk in all EU MS will contribute to decrease healthcare costs on the long term and ensure better health outcomes for these people

## 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*

Due to major disparities in access to RC treatments it is crucial to: Adopt common HTA assessments across EU; Enable adaptive licencing; Provide resources to ERNs for collecting, analysing real word data. Establish transparent, mutually agreed process to determine prices; Create EU-level mechanisms for MS collaboration (e.g. a voluntary “European Table for Negotiation” for joint price negotiation, joint purchasing) & a EU fund to co-finance generation of post-marketing evidence for high-uncertainty rare disease therapies; Work out solutions for off-label use of drugs and shortage of medicines

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

- Yes
- No

How can this be improved?

*600 character(s) maximum*

RC patients face great difficulty accessing an accurate and timely diagnosis with often too long delays. Establishment of ERNs are a response to gathering scattered expertise but they should be better known. EU MS must identify specialised centres on their territory, ensuring their connection with ERNs' centres and

provide information on access to these centres on their public health websites. GPs, secondary care health professionals should be able to connect to national and ERN centres for advice. Partnerships between specialised centres and patient organisations have to be implemented

**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

**What additional support do you consider could be made available?**

*600 character(s) maximum*

Psycho-oncologists are needed throughout the patient journey up to palliative care for both the patient and his/her family, carer(s). Case managers responsible for each patient are needed to plan the necessary examinations, help patients navigate the system, interpret the results from the different specialists, discuss and plan the treatment options together with the patient and/or family of the patient. To have the same person in charge of a patient creates an important feeling of routine, safety and trust. Case managers must have the opportunity to participate in trainings and conferences

**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

**What additional support do you consider could be made available?**

*600 character(s) maximum*

Patient organisations also provide significant support and information on medical treatments and access, health insurances, integration at work, at school. They provide training programmes and often team up with specialised medical centres. Their action of general interest should be better recognised and supported by EU and national institutions. A better collection and use of PROMs/PREMs, with the support of patient organisations, should be put in place to further improve patients' care across EU, during and after treatments. Harmonised social policies across EU MS should be promoted

## 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

Please indicate in which areas challenges are particularly significant:

- Lack of social rehabilitation, including employment
- Lack of education and training on self-management of your daily life (empowerment of cancer survivors)
- Lack of psychological support to address distress and depression
- Lack of training and support of your informal carers
- Lack of capacity of physicians and nurses to recognise your distress and depression
- Problems linked with medical follow-up, including management of the late effects of treatment
- Problems linked with other diseases (co-morbidity)
- Others

### 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*

-Survivorship Care Plan:

[www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html)

- Survivorship passport for childhood cancer survivors: [www.survivorshippassport.org](http://www.survivorshippassport.org)
- The 'right to be forgotten' for improving access to loans and insurance for childhood cancer survivors
- Implementing EU Directive on the "Work-Life Balance for Parents and Carers" in every EU MS
- <https://eurocarers.org/publications/joint-white-paper-on-cancer-carers-with-ecpc/>
- ECCO Position Statement: 'Integrated Cancer Care: Bringing Primary Care and Secondary Care Together'

## 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*

A dedicated section for paediatric cancers and RCs in adults with relevant synergies with national rare disease plans is integrated in EU and every MS' cancer plans. People at risk/ patients will have a fair, timely, affordable access to: Screening; Diagnosis; (innovative) Treatments. Latest updated diagnostic/clinical guidelines are widely implemented. Effective referrals shall be in place, national network for RCs established and ERNs solidly integrated into national HC systems. Expected achievements: Improved health outcomes, longer survival rate, improved quality of life for survivors

### 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*

EURORDIS covers all rare diseases including rare cancers; is their voice at EU level; collects members and other patients' views, needs and expectations on rare cancers' care; liaise with EU institutions/organisations to discuss all relevant issues pertaining to the patient journey and propose policy solutions with other stakeholders. EURORDIS can contribute with its long-lasting experience in RD national plans. It will continue supporting the work of patient advocates (ePAGs) in ERNs for RCs and advocate for the inclusion of RCs in adults and paediatric cancers in EU and national cancer plans

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

*600 character(s) maximum*

Incentives for enhancing research on RCs; Make the best use of innovative technologies incl. AI in research, diagnosis and treatment; Training on RCs (all) to be included in medical education & incentives for medical careers in RCs; Trainings for patients, families, carers, e.g. EUPATI; Improve transition from childhood to adult care in every EU MS; Work out solutions for off-label use of medicines of proven efficacy and for the shortage of essential drugs; Access to cross-border clinical trials; Better implementation of the EU cross-border healthcare directive

## Contact

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