

# 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

Claire

\* Surname

Champeix

\* Email (this won't be published)

cc@eurocarers.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*

Eurocarers : European Association working with and for Informal Carers

Postal address of your organisation

Rue Père de Deken, 1040 Bruxelles

\* 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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- Antigua and Barbuda
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- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
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- Bosnia and Herzegovina
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- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
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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
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- Taiwan
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- Tanzania
- Thailand
- The Gambia
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- China
- Christmas Island
- Clipperton
- Cocos (Keeling) Islands
- Colombia
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- Cook Islands
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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*

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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*

Many citizens already contribute to the fight against cancer as informal carers – i.e. people who provide unpaid care to someone with a chronic illness, disability or other long-lasting care need, outside of a professional framework. Carers are the primary source of support for cancer patients, providing support with household tasks, medical care and emotional support. Informal carers provide 80% of care in Europe and our care systems would not be sustainable without them. Yet, informal care often result in high levels of emotional, physical, social and financial burden for carers.

### ● What do you think health professionals can do to help beat cancer?

*600 character(s) maximum*

Considering the central role played by informal carers in the life of cancer patients, health professionals should value their contribution and recognise them as equal partners in care. They should provide them with the information and training they need to provide good-quality care. Furthermore, informal carers of patients with cancer, often described as the 'invisible secondary patient', should be subject to health prevention. Their mental and physical health is indeed at risk, due to the psychological burden as well as the practical issues they face throughout the disease trajectory

### ● What do you think public authorities/national governments can do to help beat cancer?

*600 character(s) maximum*

The role of informal cancer carers should be recognised by public authorities/national governments, as part of an improved framework for carers generally, based on:

- Respect for people's right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring;
- Carers' empowerment, enabling them to manage their caring responsibilities with confidence and in good health and to remain included in society;
- Prevention of situations where carers are disadvantaged, or discriminated against, by virtue of being a carer, notably on the labour market.

## 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

- **Treatment and quality of life of patients and carers**

- Improve access to existing treatments
- Improve access to new innovative treatments
- Better Psychological support inside and outside of health care services
- Improve palliative care
- Improve pain treatment
- Other

Please describe

*600 character(s) maximum*

Informal carers play a key role for the well-being of the patient. They should be able to communicate easily with health professionals, receive information (on the disease, the treatments, the side effects....) tailored to the phase of the disease they are facing, during and after cancer. They should also be trained and supported adequately in the case of treatment provided at home.

Furthermore, measures should be put in place enabling cancer carers to retain employment (flexible work arrangements, carer' leaves, awareness raising measures....) and compensating for potential financial loss.

## **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

Overall, people who provide care informally to a relative who is vulnerable because of age or chronic disability or disease such as cancer lack information tailored to the many roles they take along the care trajectory. This concerns also information about how to prevent the onset of cancer as well as relapses.

## 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

## 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

Please explain

600 character(s) maximum

Informal carers can play a key role in ensuring that elderly and people with a disability or a chronic disease take part in cancer screening programmes, provided they are supported in this task. Therefore, they should be involved in the design of measures aimed at supporting them in this prevention role.

Furthermore, carers are particularly at risk of neglecting their own health. Indeed, being under considerable stress and time pressure, they often prioritise the needs of the person they care for over their own.

Therefore carers' access to screening programmes should be facilitated.

## **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*

Among other actions, Europe could support the exchange and dissemination of information about available treatments and prices at local level by EU networks of patients' and informal carers' civil society organisations.

### **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*

In many European countries, informal carers of people with cancer are struggling to navigate the health care systems and help the person with cancer find reliable information about services and treatments.

### **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*

The financial toxicity of cancer, which is having an impact on the entire household, is often raised by informal carers. In addition to psychological support and counselling available to all cancer patients and carers across Europe, measures aimed at buffering the economic impact of the disease on households should be put in place.

### 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*

Integrated healthcare systems, including one central contact point for carers; Early involvement in an equal partnership between the care recipient, HCP and the carer, should the carer wish to be involved; Access to educational resources and training ; Psychosocial support and counselling; Access to peer support; Flexible respite care; Carer-friendly working environment including flexible working conditions and paid care leave; Other financial support measures.  
Online resources should be accessible to informal carers, complementing face-to-face support.

## 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*

Informal cancer carers should be better informed and supported in relation to the situation of cancer survivors. They should be made aware of what to expect in the medium and long-run in relation to the impact of treatment, the risk of relapse, the risk of depression for the patient, etc. Support measures including information, psychological support and peer support, including access to peer support to access and remain in the labour market, should be made available to informal carers not only during the treatment phase but after, as long as they feel it is needed.

**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 successful cancer plan would have achieved in 10 years in all EU countries:

- An improved identification of cancer carers;
- The formal recognition of informal carers as equal partners in the healthcare systems;
- The provision of adequate support to all cancer carers helping them to provide care should they wish to;
- Measures aimed at preventing the detrimental impact of caring responsibilities on carers' health and well-being;
- Measures helping cancer carers to combine work and caring responsibilities;
- An increased awareness in our societies of carers' contribution.

**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*

Progress in the support offered to cancer carers will only be achieved through innovative measures co-designed with carers themselves, building on dedicated research and exchange of good practices. Eurocarers brings together 71 carers' and research organisations in the areas of care and caring from 26 countries, and is engaged in a variety of EU projects aimed at designing efficient support measures for carers building on exchange of practice and applied research. Our organisation is willing to contribute to the EU plan on cancer, building on its expertise regarding support to carers.

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

*600 character(s) maximum*

In many cases the specific needs of cancer carers, where the psychological burden may be particularly high, are an acute reminder of the general need to support carers. Therefore, improved support for cancer carers should be part of comprehensive strategies at local, national and EU level, aimed at developing carer-friendly societies, building on legal instruments, needs assessment, targeted support measures and awareness raising. The ongoing digitalisation of our health care systems should provide for adequate and accessible support to carers online.

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