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

Fields marked with * are mandatory.

Introduction

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 the 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. 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

- 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.

- Afghanistan
- Åland Islands
- Albania
- Algeria
- American Samoa
- Andorra
- Djibouti
- Dominica
- Dominican Republic
- Ecuador
- Egypt
- El Salvador
- Libya
- Liechtenstein
- Lithuania
- Luxembourg
- Macau
- Madagascar
- Saint Martin
- Saint Pierre and Miquelon
- Saint Vincent and the Grenadines
- Samoa
- San Marino
- São Tomé and Príncipe
Burundi  Hong Kong  Northern Mariana Islands  Tonga
Cambodia  Hong Kong  North Korea  Trinidad and Tobago
Cameroon  Hungary  North Macedonia  Tuvalu
Canada  Iceland  Norway  Turks and Caicos Islands
Cape Verde  Indonesia  Oman  Tuvalu
Cayman Islands  Iran  Pakistan
Central African Republic  Iraq  Palau
Chad  Ireland  Palestine
Chile  Isle of Man  Panama
China  Israel  Paraguay
Christmas Island  Italy  Peru
Clipperton  Jamaica  Philippines
Cocos (Keeling) Islands  Japan  Pitcairn Islands
Colombia  Jersey  Poland
Comoros  Jordan  Pitcairn Islands
Cook Islands  Kazakhstan  Portugal
Costa Rica  Kenya  Puerto Rico
Côte d’Ivoire  Kiribati  Qatar
Croatia  Kosovo  Réunion
Cuba  Kuwait  Romania
Curaçao  Kyrgyzstan  Russia
Cyprus  Laos  Rwanda
Czechia  Latvia  Saint Barthélemy
Democratic Republic of the Congo  Lebanon  Saint Helena Ascension and Tristan da Cunha
Denmark  Lesotho  Saint Kitts and Nevis

* 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

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
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**

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
What information would you need?

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

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

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?

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?

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
What additional support do you consider could be made available?

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?

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

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
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?

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:

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?

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?

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.

Contact