

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 [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

* 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

Frank

* Surname

DE MAN

* Email (this won't be published)

frankdeman@newyield.nl

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 Nutrition for Health Alliance

Postal address of your organisation

308 High Street, Croydon CR0 1NG, United Kingdom

* 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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- Bangladesh
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- Belgium
- Belize
- Benin
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- Bhutan
- Bolivia
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- Bosnia and Herzegovina
- Botswana
- Bouvet Island
- Brazil
- British Indian Ocean Territory
- British Virgin Islands
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- Bulgaria
- Burkina Faso
- Equatorial Guinea
- Eritrea
- Estonia
- Eswatini
- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
- Finland
- France
- 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
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- Cameroon
- Canada
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- Cayman Islands
- Central African Republic
- Chad
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- China
- Christmas Island
- Clipperton
- Cocos (Keeling) 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.

* 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

The deaths of 10-20% of patients with cancer can be attributed to malnutrition rather than to the malignancy itself. Citizens can reduce the prevalence and burden of cancer:

- by living healthier (e.g. nutrition, exercise);
- timely access to dietitians to provide dietary advice;
- as patients, to be better evidence-based informed about treatment options, recovery support including adequate nutritional care and support;
- laypeople versions of clinical treatment and nutritional care guidelines inform patient

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

600 character(s) maximum

Health care professionals should be educated on the risks of malnutrition (i.e. undernutrition) and the importance of optimal nutritional care to optimize the clinical outcome during therapy. Developing clinical guidelines on cancer and comorbidities based on the best scientific evidence, with the consensus of experts and patients on board, to harmonize and give the best nutritional care. Facilitating the implementation of these guidelines through short-versions/practical guidelines, including app versions for HCPs and lay versions for patients (see <https://www.espen.org/guidelines-home/esp>)

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

600 character(s) maximum

Screening and assessment of nutritional status are vital to initiate appropriate nutritional interventions and reduce cancer-related complications and comorbidities. Awareness among patients, informal carers, healthcare professionals and policymakers is still too low.

Governments/national health authorities should include optimal nutritional care as a key pillar to their national cancer programmes, including:

- equal access for cancer patients to nutritional risk screening and follow-up nutritional care;
- awareness and education programs for health care professionals and patients.

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

- **Prevention**

- Reduce tobacco consumption
- Improve (healthy) diets
- Reduce alcohol consumption
- Increase physical activity
- Reduce obesity
- Increase vaccination against Human papillomaviruses and Hepatitis B
- Avoid excessive exposure to sunlight (including sunbeds)
- Protection from exposure to certain chemicals that can cause cancer
- Other

Please describe

600 character(s) maximum

EU can and should lead actions to promote health and disease prevention across Europe and secure that HCPs obtain the necessary knowledge during their education. Facilitating exchange models and best practices among EU members, creating a network of medical faculties, education regulators and professional associations is the way to improve the knowledge for our future HCPs' generations.

- **Screening and early diagnosis**

- Improving the participation to breast, cervical, and colorectal cancer screening
- Extension of screening to other cancer type
- Other

Please describe

600 character(s) maximum

An absolute necessity is to include mandatory screening for the risk of malnutrition (i.e. undernutrition) and follow up personalised nutritional care in all phases of cancer treatment and recovery.

- **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

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
- No
- I don't know

What information would you need?

600 character(s) maximum

healthy lifestyle including diets, nutritional risk screening

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

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

- Include screening for nutritional risk and malnutrition (undernutrition) as a mandatory component of the screening of all types of cancer.
- Include the recommendation to provide effective and safe individualized nutrition care follow best practice principles and supported by the nutrition care process model http://www.efad.org/media/1186/ncp-sl_vision_paper_final_mar_2014.pdf

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

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

Key areas for Europe to add value and support national policies are:

- support patients self-disease management among others through patients' versions of treatment guidelines, including nutrition;
- support European health professionals' societies to improve curricula and education programs regarding prevention, treatment and recovery including nutritional care;
- support exchange of good practices, ENHA supports such process, see www.european-nutrition.org;
- utilize existing networks of European patient organizations and NGO's like ENHA and initiatives also for healthy food and catering

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

What additional support do you consider could be made available?

600 character(s) maximum

Stress the importance to include information to patients about their nutritional status and care options. Together with the European Patient Forum (EPF), ESPEN, ECPC, EFAD and ENHA works on developing laypeople/patients' versions of clinical guidelines.

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

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

Two years ago, ENHA started to publish good practices in nutritional care across Europe. The input is currently driven and provided by the ENHA members and 18 member countries across Europe, see www.european-nutrition.org. Health professionals across Europe contribute by regular updates to share the good practices for implementation and education purposes with their peers and students.

ENHA members and partners are ready to work together with other European partners in the Europe's Beating Cancer Plan to gather good practices specifically focusing on nutrition and cancer care and education.

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

Key indicators:

- decrease in incidence and prevalence;
- decrease complications and comorbidities;
- improved management of the longterm consequences of cancer and its treatment resulting in enhanced recovery and improved quality of life.

Optimal nutritional care contributes substantially to achieving these objectives through

- nutritional screening for people at risk and patients;
- equal access of patients to individualized nutritional care;
- decrease the risk for malnutrition (i.e. undernutrition)
- Access to professional dietetic advice for all patients.

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

ENHA and participating countries can substantially contribute to Europe's Beating Cancer Plan by

- focus activities in nutritional care more specifically on prevention, treatment, recovery of cancer;
- education and support for cancer patients through laypeople/patients' version of clinical guidelines;
- foster education of health care professionals on nutritional care and its contribution to improving cancer care;
- contribute to decrease complications and comorbidities;
- share good practices, e.g. via www.european-nutrition.org;
- provide its communication and coordination channels.

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

600 character(s) maximum

- Future definition of key performance indicators of key tracks of the Europe's Beating Cancer Plan;
- Bottom up collaboration with existing European health care societies and other NGO's, to utilise their networks and channels and maximize effective implementation and impact, do not reinvent the wheel but build on existing, proven reliable partners.

Contact

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