

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

Olga

* Surname

KOZHAEVA

* Email (this won't be published)

olga.kozhaeva@siope.eu

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

The European Society for Paediatric Oncology (SIOP Europe, or SIOPE).

Postal address of your organisation

Clos Chapelle-aux-Champs 30, Bte 1.30.30, 1200 Brussels, Belgium

* Country of origin

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

- | | | | |
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| <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 |
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| <input type="radio"/> Andorra | <input type="radio"/> El Salvador | <input type="radio"/> Madagascar | <input type="radio"/> São Tomé and Príncipe |

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- Bosnia and Herzegovina
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- Bouvet Island
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- French Southern and Antarctic Lands
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- Georgia
- Germany
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- Grenada
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- Guam
- Guatemala
- Guernsey
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Heard Island and McDonald Islands
- Honduras
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania
- Mauritius
- Mayotte
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
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- Nauru
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- Netherlands
- New Caledonia
- New Zealand
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- Niger
- Nigeria
- Niue
- Norfolk Island
- Saudi Arabia
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- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Sint Maarten
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- Slovenia
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- Somalia
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- South Korea
- South Sudan
- Spain
- Sri Lanka
- Sudan
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- Tanzania
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- The Gambia
- Timor-Leste
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- Saint Barthélemy
- Saint Helena Ascension and Tristan da Cunha
- Saint Kitts and Nevis
- Saint Lucia
- Tonga
- Trinidad and Tobago
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- Turkey
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- 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

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

Citizens will identify with the need to protect children: our future. All rare, paediatric cancers jointly are a major under-addressed burden across Member States. With over 35,000 new cases and 6,000 deaths each year in Europe, they are the main cause of mortality by disease in children aged above one. Long-term morbidity affects at least 70% of 500,000 survivors. Cross-border EU action is well placed to aid progress in this rare disease area. By engaging with policy makers, citizens can foster a Europe united against childhood cancer through an effort focused on underserved young patients.

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

600 character(s) maximum

Despite limited market innovation, long-term cross-border collaboration between paediatric cancer clinicians and academia in Europe enabled to markedly improve cure rates. There is great potential for continued progress: the community is well organised, has defined a common strategy to further improve survival and quality of life, and established international collaborative implementation platforms. Yet progress is limited by lack of resources. EU investment can boost cross-border initiatives of health professionals to save more lives and reduce the late-effects burden of childhood cancer.

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

600 character(s) maximum

The inclusion of a dedicated Paediatric Cancer section in Europe's Beating Cancer Plan and in the National Cancer Plans is crucial to provide a framework for focused action. Adequate public funding allocation is likewise required. Among the immediate priorities suggested for EU and Member States are ensuring the sustainability of the European Reference Networks to combat inequalities, investing into state-of-the-art cross-border research to deliver innovation in an area of relative market failure, and providing quality follow up care to survivors of childhood cancers consistently across Europe

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

The distinct features of paediatric cancers across the whole patient pathway should be acknowledged and addressed. All individually rare and biologically specific, paediatric cancers are jointly the leading cause of disease-attributable mortality in children older than 1 year in Europe, contribute to life-long morbidity in survivors, and are marked by inequalities and lack of innovation. Europe's Cancer Plan is a unique opportunity to make a difference for children and adolescents by including a dedicated Paediatric Cancers section covering all areas. Suggested content is detailed below.

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

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

In contrast to adult cancers, paediatric malignancies develop early in life over a short time period. There is very limited scientific evidence on the role of external exposures in the incidence of paediatric cancers, although pre- and peri-natal risk factors merit further exploration. The major known cause of primary paediatric cancers is genetic predisposition. Further investigation of this aspect also calls for an appropriately funded research effort. Another important orientation is prevention of secondary cancers among childhood cancer survivors as a high-risk group.

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

Lifestyle may influence cancer risk in adults, but there are no known alterable risk factors for most childhood cancers. Speculative information on external exposures can cause unnecessary parental distress. The major factors known to increase the risk of cancer in children - genetic predisposition and prior disease in survivors - are still not explored enough and should be prioritised to foster meaningful prevention strategies in paediatric haemato-oncology. AI and Big Data hold great potential in these areas and can also enable the exploration of pre-, peri- and postnatal risk factors.

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

Personalised screening programmes for childhood cancer survivors are a major need. This group counts almost half a million people in Europe and is at high risk of severe adverse late effects, including secondary malignancies. The Survivorship Passport model was developed with EU project support and can greatly facilitate the necessary surveillance if widely adopted. For paediatric cancers overall, awareness programmes for the general public and primary care actors, research and counselling on genetic predisposition, and equal access to state-of-the-art diagnostics are further key needs.

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

We would like to stress the importance of organised personalised screening for childhood cancer survivors as a growing high-risk population in Europe. Based on prior EU project investment in this area, the inclusion of the Survivorship Passport model in Europe's Beating Cancer Plan can greatly facilitate long-term surveillance of this group in existing healthcare settings. Childhood cancer survivors are at risk of several second cancers due to their treatment, e.g. brain tumours, skin cancers as well as those already recognised, i.e. breast and colorectal.

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

Inequalities in access to standards of care lead to differential childhood cancer survival across Europe. Children are also disadvantaged by lack of innovation compared to the market-driven adult cancer sector. The latter saw over 150 new medicines in the last decade, while only 9 were introduced for a truly paediatric indication. Europe can act to ensure sustainable non-competitive funding to European Reference Networks, streamline cross-border healthcare, revise the regulation on paediatric cancer medicine development, and allocate a comprehensive funding stream to childhood cancer research.

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

The rarity of paediatric cancers makes centralised information particularly important. Working collaboratively, SIOP Europe, ERN PaedCan, and CCI Europe link national paediatric cancer societies, disease-specific European clinical trial groups, and parent organisations across Europe. Unfortunately, these entities and their members rely on limited or uncertain funding, which may substantially hinder activities. Targeted EU investment can boost the sustainability of the paediatric cancer care sector and its ability to serve the major unmet information and other needs of the affected citizens.

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

Despite their high burden, paediatric cancers tend to be left behind from overarching health and socio-economic programmes. Old anti-cancer medicines are still widely used across the paediatric cancer spectrum (>100 molecular subtypes), inequalities persist, and survivors and families lack support structures. Europe's Cancer Plan can redress this imbalance and provide the affected citizens with the dedicated effort that they deserve. A chapter on paediatric cancer coupled with focused funding for implementation will send a powerful signal that Europe will not forget its children.

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

The right of the hospitalised child to “constant and continuous parental involvement” is embedded in the European Standards of Care for Children with Cancer, an outcome of the EU EPAAC Joint Action. Active engagement of parents throughout the child’s cancer journey is essential but often subject to time and financial constraints. Governments can support families in these highly demanding circumstances through targeted provisions on employment and income security. An EU Resolution on the rights of children with cancer can be instrumental in raising awareness and mobilising necessary action.

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

Please describe

600 character(s) maximum

The number of childhood cancer survivors in Europe is estimated at 500,000 and increasing. The rarity of individual paediatric cancers translates into specific long-term side effects that most of this growing population experience throughout adulthood. The use of older therapies due to lack of innovation in the sector adds to the late-effect burden. Specific approaches and EU support are needed to foster long-term outcomes research, equal access to follow-up care, transition from paediatric to adult settings, and countering life-long discrimination of survivors due to their childhood disease.

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

Developed with EU project support, the Survivorship Passport is a personalised electronic tool to empower childhood cancer survivors and guide health professionals on the required surveillance based on individual clinical history. PanCare has been developing consensus-based surveillance guidelines for a range of paediatric cancer side-effects. The ERN PaedCan can facilitate the implementation of survivorship programmes across Europe. Initiatives like the right to be forgotten (eg in FR) can counter the discrimination faced by childhood cancer survivors in accessing financial services and jobs.

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

Childhood cancer mortality and late-effect burden have reduced by at least 50%. All children and adolescents with cancer have access to the best possible specialised care. Stable and sustainable paediatric cancer research enabled progress at all stages of the patient pathway. The number of innovative anti-cancer medicines for the paediatric population has increased to meet all needs. All childhood cancer survivors have access to quality follow-up care and transition pathways and participate fully in society. All families affected by childhood cancer have psychosocial and economic protection

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

SIOPE is the single, united European organisation of academia and healthcare professionals dedicated to childhood and teenage cancers, working across the whole spectrum of activities in this disease area in partnership with parents, patients, and survivors. We represent the sector with a track record of fruitful cross-border collaboration in Europe for more than 50 years, including through coordinating roles in EU programmes on cancer. We are thus ideally positioned to further mobilise for the dissemination and successful delivery of the paediatric cancer dimension of the EU Cancer Plan.

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

600 character(s) maximum

Systematic population-based registration of paediatric cancers enriched with long-term outcome data and linkage with clinical registries is key. Security safeguards for data sharing are essential. A European paediatric cancer database should be considered. Overall, the Cancer Plan can drive life-enhancing change for children and adolescents and position the EU as the global leader in this area. A specific focus on paediatric cancers is supported by evidence of scarce public funding of this sector globally, the new WHO GICC effort, and the outcomes of the EU Joint Action on Rare Cancers.

Contact

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