
ECHO Responses: Public consultation on the Commission's Europe's Beating Cancer Plan

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Background

The following document represents the European Children's Hospitals Organisation's response to the online consultation on the Commission's Europe's Beating Cancer Plan. The consultation offers the chance to provide feedback on a landmark initiative of the European Commission and ECHO is working to ensure that the perspective of child and young people with cancer is represented. As the Plan is currently written, it is distinctly oriented towards adult cancer. Our objective in participating in this consultation process is to raise awareness about childhood cancer and ensure that the needs of patients and families touched by childhood cancer are addressed in the Plan.

The consultation process is open to all members of society and it is important that a variety of perspectives are represented. Therefore, we encourage everyone involved in childhood cancer to complete the consultation. This includes patients, family members, clinicians, administrators, policy maker, and researchers. The more input supporting the needs of children and young people the better.

How to use this document

The text in this document represents the perspective of the European Children's Hospitals Organisation. We encourage anyone filling out the consultation to use this text as a basis for your answers, modifying it to fit your personal or institutional experience. On multiple choice questions, the **ECHO responses are bolded and in red font**. Rationale for responses to multiple choice questions are also provided, although these will not appear in the submission to the Commission.

Answers to questions about the consultation

How long will it take me to fill out the consultation?

This is an extensive consultation and the time it takes to complete will vary. We anticipate that you should plan on spending at least 20 minutes.

Do I have to complete it all at once?

No. The survey is online and offers the option of saving the portion you have completed and returning to it at a later time.

What is the process for completing the consultation?

To submit your feedback, you need to create an 'EU Login' account or use an existing one if you have it. You can also use one of your social media accounts. You can learn more about the process and register for an account by going here: <https://ec.europa.eu/info/law/better-regulation/have-your-say>.

Do I need to complete the consultation in English?

No. The consultation is available in multiple official European languages and you can select the language of your choice when beginning the process.

Do I need to be a citizen of the European Union to fill it out?

No. The Commission may place more weight on opinions of citizens of the European Union, but the survey is open to everyone.

Does it really matter if I fill it out?

We believe it is important to have as many voices as possible raising the issue of childhood cancer with the Commission. We understand that it will take some time to complete the consultation, but we believe your voice matters and that it is worth it to participate. Children and families affected by childhood cancer thank you for your time.

Where can I find the consultation?

The online consultation is available here: <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan>.

Public consultation on the Commission's Europe's Beating Cancer Plan (Online Questionnaire) with ECHO responses

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!

General Questions

1. On a scale from 0 to 10, how present is cancer in your life?

8

2. What do you think is needed to beat cancer?

What do you think citizens can do to help beat cancer?

(600 characters maximum)

ECHO response

Beating childhood cancer means there are no deaths and no late effects from treatment. The vast majority of childhood cancers do not have a known cause and are not linked to things like smoking that cause cancer in adults. So unlike adult cancer, citizens do not have a direct role in preventing or beating childhood cancer. Citizens can help beat childhood cancer by working with health professionals, public authorities, and industry to help develop new therapies and models of care that meet the needs of children and families with childhood cancer.

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

(600 characters maximum)

ECHO response

Health professionals can help beat childhood cancer by providing high quality care to all children and young people regardless of where they live. This includes follow up care that addresses the physical, emotional, and social needs of patients. They can also help by being involved in the design and implementation of care delivery models to best meet the needs of patients and families. Finally, they can help by participating in setting health policy and research agendas at the national and European level to ensure these policies reflect the needs of providers, patients, and families.

What do you think public authorities/national governments can do to help beat cancer? (600 characters maximum)

ECHO response

- Incentivise the pharmaceutical industry to conduct dedicated paediatric cancer research and develop new therapies for childhood cancer.
- Develop strategies to ensure health systems across Europe can afford to provide new therapies once they come to market.
- Support basic research into the mechanisms and biology of paediatric cancers.
- Invest in health services research to identify the best ways to organize and deliver care.
- Support models of care that take a holistic view of health that accounts for the unique physical, psychological, and social needs of children and young people.

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

**Explanatory note: These three items were selected as they will have the most impact on childhood cancer. The vast majority of childhood cancers do not have a known cause and are not linked to things like smoking that cause cancer in adults. So although prevention and early detection strategies have the potential to dramatically affect adult cancers, these strategies will have minimal impact on children and young people.*

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 characters maximum)

ECHO response

Treatment for childhood cancer should focus on the development of and access to new therapies for cancers that are specific to children and young people. When compared to adult cancer, paediatric oncology remains neglected with very few new therapies authorized in recent years. New drug development must be driven by scientific data and the mechanism of action of drugs, not by the adult market potential. Furthermore, any new drug development strategies should involve the full range of stakeholders including patients and patient advocates, regulators/payers, academics, and clinicians.

** Explanatory note: Although some of the options are important to childhood cancer, answering "other" provides the opportunity to write free text and focus the response on the specific needs of childhood cancer. Furthermore, it was not clear that selecting "treatment and quality of life of patients and carers" includes the development of new treatments.*

Life after cancer

- Better social reintegration including employment
- Better medical follow up
- Fight stigma and discrimination
- Increase survivors' empowerment
- **Other, please describe**

(600 characters maximum)

ECHO response

Addressing transition to adult care is essential for survivors of childhood cancer. Resources are needed to support the identification and implementation of best practices. Transition to adult care should take an integrated care approach and include multidisciplinary health and social care teams to support survivors of childhood cancer.

Teens and young adults have different emotional, physical, and medical needs from infants, toddlers and children and their needs can be

overlooked. Plans to address quality of life after cancer should also address the specific needs of these populations.

** Explanatory note: Although some of the options are important to childhood cancer, answering "other" provides the opportunity to write free text and focus the response on the specific needs of childhood cancer within the existing options.*

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

The vast majority of childhood cancers do not have a known cause and are not preventable. More research is needed to identify the genetic factors that predispose some children and young people to cancer. Additionally, more research is also needed on environmental factors that may predispose or cause some childhood cancers.

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**

ECHO response

There are currently no lifestyle interventions that have been shown to reduce the risk of childhood cancer. So although prevention has the potential to dramatically affect adult cancers, these strategies will have minimal impact on children and young people.

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**

** Explanatory note: Because ECHO represents children's hospitals where cancer screenings are not relevant to our patient population, we have not provided input on this question.*

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 characters maximum)

ECHO response

Because childhood cancers are relatively rare, general population screening is not feasible or economically warranted. There are also no widely recommended screening tests to look for cancer in children. However, there is evidence that targeted screening in children with an increased risk of cancer can be beneficial, helping improve survival and decrease the late effects of therapy. ECHO supports screening programmes directed toward

children, and the family members of children, who are at an increased risk of cancer such as those with hereditary cancer predisposition syndrome.

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 characters maximum)

ECHO response

Access and affordability strategies needs to involve regional administrators and hospital managers who oversee healthcare financing and delivery.

Suggested strategies include:

- Supporting negotiations between member states and the pharmaceutical industry to regulate pricing,
- Linking price of treatment to favourable health outcomes,
- Concentrating care in regional centres of excellence to improve efficiency,
- Supporting workforce development to ensure hospitals have the required staff to provide specialized paediatric cancer care,
- Allocating funds to support the European Reference Network model.

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

ECHO response

Across Europe there are inequalities in access to advanced cancer care, with survival rates between countries varying by up to 20%. To ensure all children have access to cancer treatment services, the European Reference Networks need sustained funding. Additional support is also needed for cross-border virtual advice and care provision that include reimbursement

mechanisms. Increased access to cross-border clinical trials is also needed. Finally, parent and patient involvement is needed to ensure information on available treatment services are clear, user friendly, and widely available.

10. Do you consider sufficient written information regarding cancer diagnosis and possible treatments is available to patients?

- Yes
- **No**
- I don't know

**Explanatory note: Although there is a significant effort to provide patients and parents with information on treatment options, there is evidence that in some situations information is lacking. For example, vast amounts of information are provided early on in the treatment process, but farther into care parents express that they are often dissatisfied with the information they receive. There is also evidence that patients, especially younger patients, are interested in receiving more information and being actively involved in treatment decisions. Parents also express that they are interested in more information on late effects. Given the evidence that in a variety of situations the provision of information can be improved, we have answered no on this question.*

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

ECHO response

Childhood cancer affects the entire family, often removing patients and families from regular support networks. Comprehensive services addressing the financial and psychological burden are needed. Specifics include:

- Schooling is important for kids but there are no established best practices during treatment.
- Siblings can be overlooked but their mental health can suffer during cancer treatment. More focus is needed on supporting their overall wellbeing.
- Adolescents and young adults have unique needs during and after treatment around employment, dating, and education that need more attention.

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

**Explanatory note: Although in many hospitals children with cancer receive care from multidisciplinary teams, we know this is not the case in all hospitals. Where a pharmacist or play specialist may be a standard member of a team in one country, these professionals may not be a regular part of a cancer care team in another country. Because ECHO represents children's hospitals across Europe, we have answered no to this question.*

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

- Affordable housing close to treatment facilities.
- Written information address issues that arise throughout the treatment process, not just at diagnosis.
- Family support groups.
- Coaching from health professionals to empower family members.
- Classroom interventions explaining to teachers and classmates what childhood cancer means.
- Support to cope with the impact on professional lives.

These services should be paid for by health and social care systems and provided by professionals including social workers, psychologists, child life specialists, and social educators.

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

ECHO response

Many childhood cancer survivors feel lost and on their own after treatment ends. They can suffer from bullying, isolation, or learning disabilities and require support from a range of professionals like psychologists, social workers, social educators, and case managers.

Transition to adult care is also problematic. Recommendations on transition exist, but standardized implementation is not widespread and reimbursement is inconsistent. The result is that most youth receive less than optimal support. Programmes addressing the unique health a social needs of maturing young adults are needed.

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

Multiple examples of best practices exist to support survivors of childhood cancer. The issue is not that we do not know what to do, but that there are often insufficient resources to implement the programmes that we know would help children, young people, and their families.

Examples include:

- The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers.
- St. Jude's Research Hospital LIFE & After Completion of Therapy Clinic (ACT Clinic).
- Long-term follow up clinic at Memorial Sloan Kettering.

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

10 years after implementation children with cancer should be treated with personalised, highly effective novel therapies with few long-term effects. These should be available to all children and offered in settings that support the mental and physical health of patients and families.

It will be standard for patients and families to be involved in the design and implementation of services and in the definition of research agendas.

Cancer survivors will have a seamless transition to adult care and will be cared for by professionals who understand the long-term implications of childhood cancer.

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?**

** Explanatory note: From the point of view of children's hospitals, we recognise the need to work with clinicians, researchers, and industry to provide the best possible care for children with cancer. Therefore, we support sharing anonymized patient data with all of the entities mentioned above.*

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**

** Explanatory note: From the point of view of children's hospitals, this statement is not applicable. Individuals should answer this questions based on their own personal experience.*

21. How can you (or your organisation) contribute to the EU plan on cancer?

600 character(s) maximum

ECHO represents leading children's hospitals on the front lines of caring for children with cancer. We offer a unique perspective on the needs of children, their families, and the professionals working to beat childhood cancer. Our contribution to the Plan is twofold. First, we can help contribute to the design of the plan by drawing on the knowledge and experience of our members including managers, clinicians, and patients. Second, our members will be responsible for implementation of the Plan, positioning them to ensure that proposals are translated into real change in the lives of patients.

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

600 character(s) maximum

Paediatric cancer is its own entity, biologically distinct from adult cancer. Addressing childhood cancer will require a cross-sectional strategy that goes from the bench to the bedside and beyond. Europe's Beating Cancer Plan offers a once in a generation opportunity to address childhood cancer. We encourage the Commission to use this opportunity to provide children and young people with cancer the best possible start in life and ensure their needs are fully addressed in the EU Cancer Plan.