

THE EUROPEAN SOCIETY FOR
PAEDIATRIC ONCOLOGY - SIOP EUROPE



EUROPE'S BEATING CANCER PLAN

For Children with Cancer



EUROPE'S BEATING CANCER PLAN LET'S STRIVE FOR MORE

#EUCancerPlan

CANCER: A THREE-FOLD PROBLEM

1. Cancer can cause huge suffering to individuals and their families
2. Cancer imposes a burden on society and healthcare systems as a whole
3. Substantial and significant inequalities exist across Europe

*Tell us where
Europe should
focus its
efforts*



Concerned
Citizen

Patient

Relative

Healthcare
Worker

Researcher

Pharma
Employee

Policy Maker

*Whether
you are a...*

How to respond?



Contribute to this consultation by **filling in the online questionnaire** - [link attached](#)

DEADLINE

21 May 2020 (midnight Brussels time).

If unable to fill the questionnaire contact *sante-cancer@ec.europa.eu*

MULTILINGUAL

Questionnaire is available in some or all official EU languages. You can submit your responses in any official EU language.

REGISTER

In order to fill the online questionnaire you will have to register at the official website of the European Union. It will take no more than 5 minutes.

Steps to Register

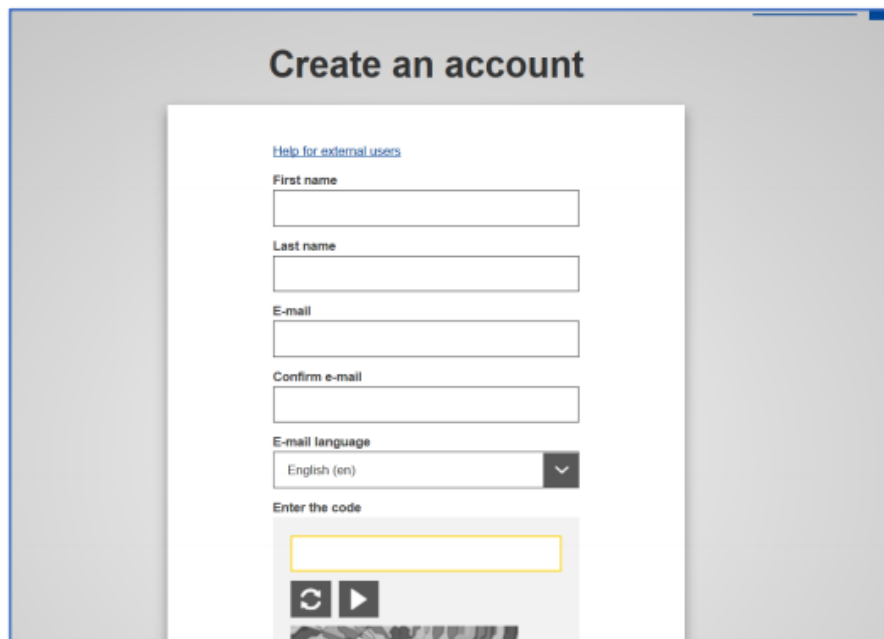
Technical instructions

Confirmation email on newly created account may take up to 24 hours!
Therefore, everyone is strongly encouraged to create account in a timely manner in order to respond on questionnaire.

STEP 1. Create an account on EU Health Policy Platform (required to be able to submit comment)

1a. Go to: <https://webgate.ec.europa.eu/cas/eim/external/register.cgi>

1b. Fill in the form



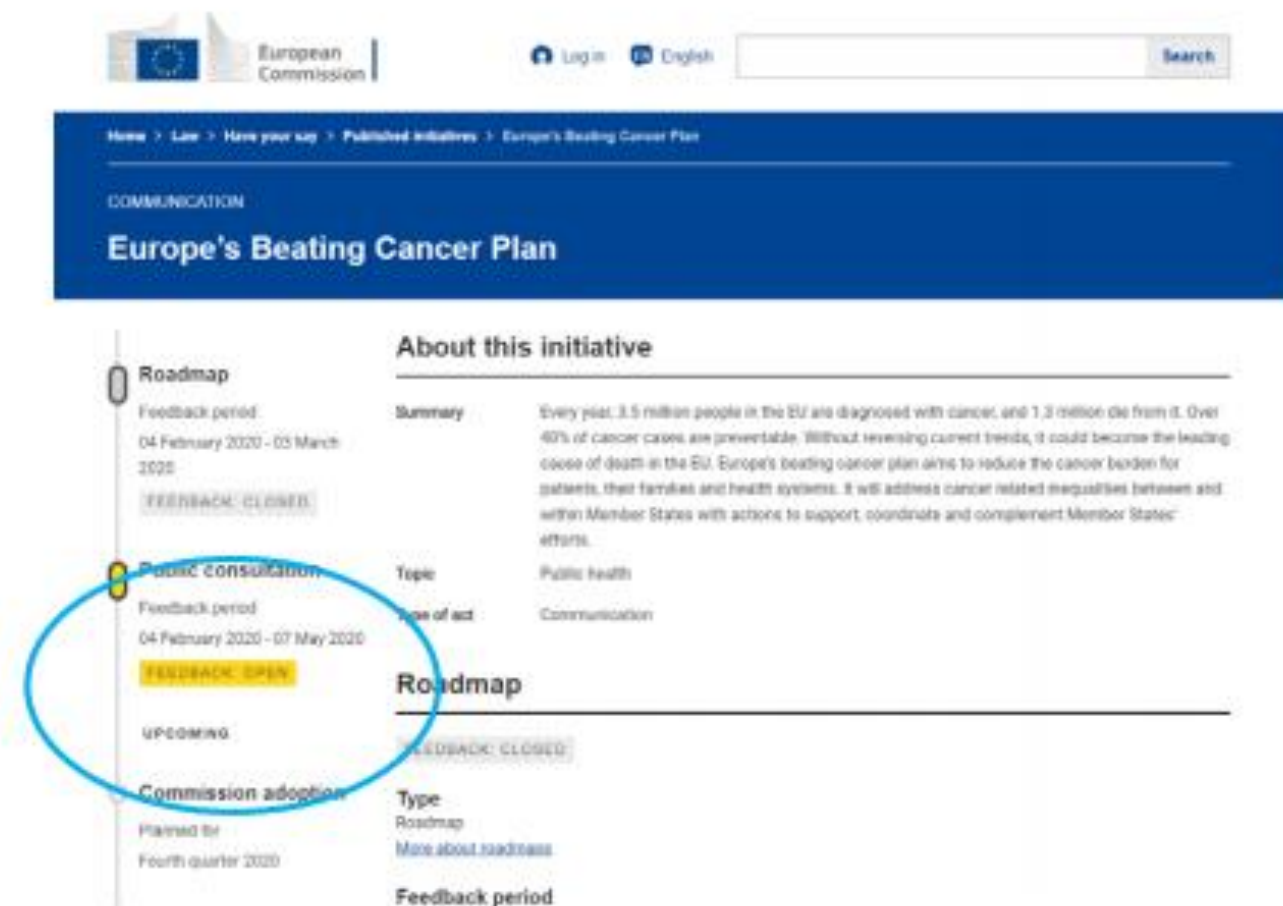
1c. Create a password (activation link will be sent to your email address)

STEP 2: Access the EU Cancer Public consultation

2a. Go to:

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

Scroll to the bottom of the page to “Public consultation”



Steps to Register

Technical instructions



2b. Click 'Go to consultation' (to view the consultation and become acquainted further)

Public consultation ALL FEEDBACK (384)

Feedback period **FEEDBACK: OPEN**
04 February 2020 - 03 March 2020
FEEDBACK: CLOSED

Public consultation
Feedback period
04 February 2020 - 07 May 2020
FEEDBACK: OPEN

Go to consultation >

Commission adoption

Type
Communication
[More about adopted acts](#)

Planned for
Fourth quarter 2020

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[Log in](#) [Register](#)

Share this page:

2c. After clicking 'Go to consultations', you will be directed to this website page:

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

PAGE CONTENTS

- About this consultation
- Target audience**
- Why we are consulting
- Responding to the questionnaire
- Contact

Why we are consulting

Every year, 3.5 million people in the EU are diagnosed with cancer, and 1.3 million people die from cancer each year. In fact, 40% of us are likely to face this disease at some stage of our life. The EU has been actively working to reduce the incidence of cancer for decades. The first 'Europe against Cancer Plan', dating back to the late 1960s, resulted in important EU legislation on tobacco and occupational health. Since then, EU Member States have committed to reducing mortality from chronic diseases, including cancer. Against this background Commission President von der Leyen has committed to a European plan to fight cancer, to support Member States and stakeholders in improving cancer control and care to reduce the suffering caused by this disease. The Commission intends to design the plan to cover the entire cycle of the disease starting from prevention and early diagnosis to treatment and quality of life of patients and survivors. shall be placed at the centre of this plan. With this public consultation, the European Commission invites all interested individuals or organisations to share their views and experiences to feed into a European cancer plan putting European citizens at the centre. More information on EU actions on cancer: https://ec.europa.eu/health/non_communicable_diseases/cancer_en

Responding to the questionnaire

You can contribute to this consultation by filling in the online questionnaire. If you are unable to use the online questionnaire, please contact us using the email address below.

Questionnaires are available in some or all official EU languages. You can submit your responses in any official EU language.

For reasons of transparency, organisations and businesses taking part in public consultations are asked to register in the EU's [Transparency Register](#).

Respond to the questionnaire >

Personal data and privacy statement

The European Union is committed to protecting your personal data and to respecting your privacy. When carrying out public consultations we adhere to the policy on 'protection of individuals with regard to the processing of personal data by the Community institutions', based on [Regulation \(EU\) 2018/1725](#) on processing of personal data by the EU institutions.

3d. Click 'Respond to the questionnaire' in order to access it (you will be asked to log into your account on EU Health Policy Platform)

The Questionnaire

ABOUT YOU

PERSONAL DETAILS

- Language of contribution*
- Giving contribution as*
- Full name*, e-mail address*, gender, age
- Highest degree obtained

- Postal address of your organisation
- Country of origin*
- Publication privacy settings*
(anonymous/public)
- I agree with the personal data protection*
- Are you a Health Care Professional (HCP)

Work experience:

- Cancer care
- Pharmaceutical industry
- Social care sector
- Healthcare sector
- Education sector
- Health/social insurance sector
- Public administration



General questions

Recognising that each stakeholder has specific concerns, the below proposed messages come from our mutually endorsed position statement.

Alignment on these in our respective replies can send a strong unified message.

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?

a) What do you think citizens can do to help beat cancer? *(600 chars max incl. spaces)*

- Raise public awareness of childhood cancer as a leading burden in Europe
- Engage with policymakers at the national and the European levels to convey the urgency of addressing these issues – Members of European Parliament (MEPs), Health Ministry, etc
- Respond to EU consultations

Emphasise the full implications of childhood cancer for young patients, their parents, adult survivors, society and economy at large.

General questions



Alignment on key messages in our respective replies will send a strong unified signal.

b) What do you think health professionals can do to help beat cancer? *(600 chars max incl. spaces)*

- Advance research progress in an area of 'market failure'
- Exploit the AI potential for paediatric cancers
- Eradicate inequalities through cross-border healthcare expertise sharing and interventions, eg ERN PaedCan
- Implement evidence-based follow-up care models to serve childhood cancer survivors
- Provide continuous education and training for health professionals
- Foster multidisciplinary international collaboration

Emphasise that EU funding and enabling policies are imperative if the above actions are to be realised.

General questions



Alignment on key messages in our respective replies will send a strong unified signal.

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

- Dedicate a **section on paediatric cancer in Europe's Beating Cancer Plan** and ensure focused implementation
- Dedicate a **section on paediatric cancer in National Cancer Plans** and ensure focused implementation
- Ensure sustainability and enabling rules of cross-border care to **support the ERN model**
- Revise the **regulatory framework for paediatric medicine development**
- Foster **equal access to essential medicines**
- Make provisions on **appropriate follow-up care and non-discrimination of survivors** based on novel models such as the Survivorship Passport
- Ensuring **financial and job security for parents** caring for severely ill children

General questions



Alignment on key messages in our respective replies will send a strong unified signal.

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: *(pre-defined list - choose top 3)*

- Treatment and quality of life of patients and carers (improve access to innovation)
- Life after cancer (better medical follow up)
- Research and collection of information

Or chose the option 'Other' to call for a Chapter on paediatric cancer across all areas

STEP I: PREVENTION

Preventing cancer by addressing risk factors



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) max incl spaces)*

- Investigate genetic predisposition to paediatric cancers.
- Need for research on oncogenic drivers, supported by big data and AI
- Explore further research opportunities on other types of exposure

All of the above requires EU funding in this highly specific rare disease area.

STEP I: PREVENTION

Preventing cancer by addressing risk factors



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)

Multiple choices *(choose top 3)*:

- Measures on prices (including both taxation and/or incentives)
- Advertising
- Information campaigns
- Legislation
- Other

If you chose "Other", please describe it *(600 character(s))* maximum):

- No known alterable risk factors to prevent most childhood cancers.
- Need to focus on genetic predisposition as the known factor (up to 10% of paediatric cancers)
 - Secondary prevention in survivors is a key orientation

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)

- Increase awareness among HCPs on symptoms of childhood cancers
- Genetic screening and counseling for paediatric cancer.
- Personalised screening programmes for survivors based on the SurPass model

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.

7. What could influence your decision to take part in a cancer screening programme?

Multiple choices:

- 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

(Personal, all pick is possible, not more than 3 choices)

STEP III: TREATMENT

Best available care, treatment and quality of life for all cancer patients



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?

N.B. An open-ended question.

- Review the EU paediatric regulation
- Counter shortages of essential anticancer medicines
- Ensure appropriate pricing and reimbursement of medicines
- Early clinical trial access for children with poor prognosis

- Ensure sustainability of European Reference Networks
- Ensure and align implementation of Cross-border Health Care Directive across Europe (further ensure the reimbursement process across all Member States - MS)

STEP III: TREATMENT

Best available care, treatment and quality of life for all cancer patients



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)*

- Timely access to an overview of available early clinical trials across Europe.
- One stop portal with all clinical trials happening and planned to happen.
- European Reference Networks visibility on national level

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

Yes, No, *I don't know*.

STEP III: TREATMENT

Best available care, treatment and quality of life for all cancer patients



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 the high burden, paediatric cancers have so far been largely left behind in the overarching oncology agenda.
- A chapter on paediatric cancer in Europe's Beating Cancer Plan coupled with focused funding and implementation can make a transformative change

By dedicating specific provisions for the paediatric population, Europe's Cancer Plan can redress the imbalance and put children and adolescents – our future – at the forefront of the anti-cancer effort

STEP III: TREATMENT

Best available care, treatment and quality of life for all cancer patients



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” throughout patient journey
- Secure sustained livelihood for parents of severely ill children, such as social support and employment security.

STEP IV: SOCIAL INTEGRATION



Quality of life with and after cancer

14. In your country/region, do cancer survivors receive follow-up and support after treatment? *Yes, No, I don't know. (Please reply according to your respective situation.)*

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**

STEP IV: SOCIAL INTEGRATION



Quality of life with and after cancer

In the event we cannot tick more than 3 options (we'll find out when filling in the questionnaire online), we can tick “others” and provide the list:

- The **rarity of individual paediatric cancers** translates into specific **long-term side effects** that most survivors experience throughout adulthood.
- The use of **older therapies due to lack of innovation** in the sector compounds the late-effect burden.
- The number of childhood cancer survivors in Europe is estimated at **500,000 and increasing**.
- **Specific approaches and EU support** are needed to facilitate:
 - equal access to **long-term follow-up care**
 - **transition** from paediatric to adult settings.
 - countering **life-long discrimination** in line with the right to be forgotten principle

STEP IV: SOCIAL INTEGRATION



Quality of life with and after cancer

16. Do cancer patients and survivors receive psychosocial support during or after their treatment?

Yes, No, I don't know.

(Please reply according to your respective situation.)

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?

Good practice:

- [Survivorship Passport](#)
- [PanCare Follow Up Project](#)

To support:

- Person Centred Care
- Transition between paediatric and adult care
- Systematic surveillance of long-term side effects
- European survivorship passport
- Implement 'right to be forgotten' in all Europe

General questions

A second round of broader topic queries



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?

- A dedicated section for children, adolescents and young adults in the EU Beating Cancer Plan is integrated in EU and in every Member State (MS) cancer plans with focus on the following key elements:
 - Equality in access to treatment;
 - Developed new drugs specifically for children with cancer;
 - Financing of research on Artificial Intelligence potential;
 - Set-up of a multidisciplinary long-term follow-up for survivors to improve quality of life;
 - Establishment of European database for paediatric cancer;
 - Psychosocial and economic protection for families;

General questions

A second round of broader topic queries



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?

Sharing data is important because all paediatric cancers are rare – data are precious and should not be wasted. Tick which parties you would agree to share your data with.

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

(Please reply according to your respective situation.)

General questions

A second round of broader topic queries



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

- SIOP Europe
- CCI Europe
- PanCare

Working collaboratively we encompass the entire paediatric cancer community in Europe with a long track record of cross-order collaboration, a common strategic plan, and existing implementation platforms. Progress is limited by lack of funding. The EU is ideally positioned to support the sector given the rarity of individual childhood cancers and their large shared burden across Member States.

SUBMIT

Be the change you wish to see!

Q&A

PLEASE SEND YOUR QUESTIONS
ON "office@siope.eu"





e-mail: office@siope.eu



e-mail: europe@cci.care



e-mail: info@pancare.eu

THANK YOU

For participating and
making a change

