



EU Beating Cancer Plan: Part II - Public Consultation

Deadline: Thursday 7 May midnight CEST

INDIVIDUAL & FURTHER ORGANISATIONAL INPUTS NEEDED FROM AS MANY AS POSSIBLE

The European Commission shall design actions that 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).

This is a second unbelievably golden moment to further cement the immediacy of paediatric haematooncology field and be compulsory in EU agenda. Right after the roadmap consultation was terminated, the paediatric oncology became palpable to the European Commission.

Now is the time to share your experience on the field of paediatric oncology.

Your individual responses and spreading the information to your network is key as legislators will take into account the number of replies

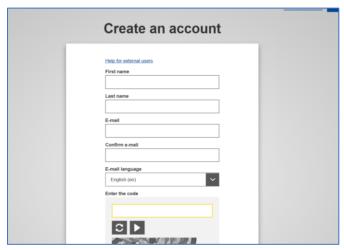
calling for a particular aspect to be emphasised.

GUIDANCE ON HOW TO PROVIDE YOUR INPUTS

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 form





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

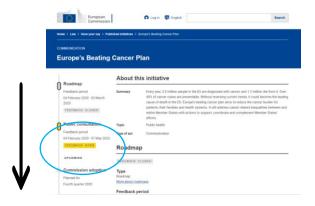
Confirmation email on newly created account may take up to 24 hours to receive!

STEP 2: Access the EU Cancer Public consultation

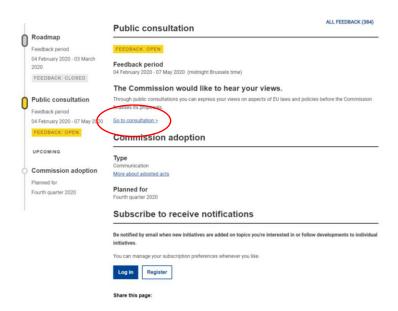
2a Go to

 $\underline{https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Planul (Control of the Control of$

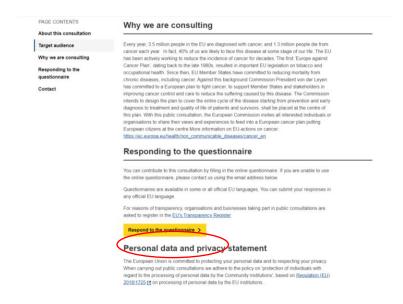
Scroll to the bottom of the page where written "Public consultation"



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



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



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

STEP 3: Provide your inputs

The consultation is addressed to individual citizens, patients, and carers replying in their personal capacity as well as health professionals and organisations involved in cancer prevention, diagnosis, treatment, follow-up care and research.

Drawing on your input, the Commission will go on to complement this initial public consultation with further targeted interactions with specific stakeholder groups.

Below attached questionnaire outlines sections for which the European Commission needs input for the Europe's Beating Cancer Plan. See example of empty questionnaire with hyperlinked references to the key messages of relevance to the childhood cancer community.

Draft SIOPE response in required questionnaire format will be disseminated shortly.

3a. Fill in 'About you' (personal information, fields marked with * are mandatory)

| About you |
|--|
| *Language of my contribution |
| English |
| |
| *I am giving my contribution as |
| ▼ |
| *First name |
| Marko |
| |
| *Surname |
| Ocokoljić / |
| *Email (this won't be published) |
| marko ocokoljic@siope eu |
| That to comorphism operation and the company of the |
| Gender |
| ○ Male |
| Female |
| Age |
| 14 or less |
| o between 15 and 24 |
| o between 25 and 39 |
| o between 40 and 54 |
| between 55 and 64 |
| 65 or more |
| Highest degree obtained |
| Basic education |
| Secondary education |
| Vocational training |
| University degree |
| Postal address of your organisation |
| A |
| |
| *Country of origin |
| Please add your country of origin, or that of your organisation. |
| • |
| *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 |
| Pharmaceutical industry |
| ■ Social care sector |
| ⊟ Healthcare sector |
| Education sector |
| ☐ Health/social insurance sector |
| Public administration |
| |
| Are you a healthcare professional? |
| Yes |
| e No |

3b. Fill in 'General questions'

- Open-ended questions have a limit of 600 character(s) maximum.
- See for example childhood cancer community joint messages embedded in the response to the EU Cancer Plan roadmap consultations here

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 • What do you think health professionals can do to help beat cancer? 600 character(s) maximum • What do you think public authorities/national governments can do to help beat cancer? 600 character(s) maximum 3. Do you support the idea that the EU should do more to address cancer? • Yes • No • I don't know

4c. Fill in your answers from the 'STEP I' to the 'STEP IV'

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,
- · 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.

| Commission and the World Health Organization's International Agency for Research on Cancer. | |
|--|-------|
| | |
| I. Do you have enough information about how to prevent cancer? | |
| Yes | |
| ● No | |
| □ I don't know | |
| 5. Which of the actions below do you think would have the biggest impact on your lifestyle habits (e.g. diet, phy activity, tobacco or alcohol consumption)? (choose top 3) Measures on prices (including both taxation and/or incentives) Advertising Information campaigns Legislation Other | ysica |
| | |

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 |
| o No |
| ⊚ I don't know |
| 7. What could influence your decision to take part in a cancer screening programme? Information about the usefulness of screening and early diagnosis |
| Convenience (proximity,) |
| Cost Expertise and skills of healthcare workers |
| The safety and quality of the equipment |
| Other |
| |
| 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 |
| 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 |
| 1 doil Childw |
| 12. In your experience, do cancer patients receive treatment from a multidisciplinary team of health professionals (oncologists, researchers, psychologists)? |
| No |
| I don't know |
| 13. Do you consider that adequate means are available to help families and friends caring for cancer patients? |
| □ 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. |
| n addition, cancer patients and cancer survivors often face hurdles in the workplace and in matters such as access o 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 |
| 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 |
| |
| |

5d. Fill in second part of 'General questions' and click 'Submit'

GENERAL QUESTIONS:

| 600 character(s) maximum | |
|--|--|
| | |
| 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 improvemen | ts (tick all that apply) |
| ■ With doctors? | |
| ■ With researchers? | |
| With pharmaceutical industry? | |
| 20. Have you received information on or been informed about the benefits and risks? Yes No Not applicable | out the possibility to take part in clinical trials, including their |
| 21. How can you (or your organisation) contribute to the El | J plan on cancer? |
| 600 character(s) maximum | • |
| | |
| | se not been covered in this consultation? |
| 22. Is there anything else that you would like to add that ha | as not been covered in this consultation: |
| 22. Is there anything else that you would like to add that he 600 character(s) maximum | as not been covered in this consultation: |

REFERENCE DOCUMENTS

- SIOPE messages embedded in the EU Cancer Plan roadmap text: <u>here</u>
- Position papers and Manifesto on policy agenda 2019-2024: here
- JARC outcomes: <u>here</u> (scroll down to WP9 Childhood cancers)

For any questions, please contact: olga.kozhaeva@siope.eu or marko.ocokoljic@siope.eu