

# Survey on Rare Cancer policies

Dear healthcare professionals,

The following survey investigates policies in the field of rare cancers. Rare cancers are a group of diseases that affect less than six out of every 100,000 individuals per year. These cancers are often difficult to diagnose and treat, which can result in delayed diagnosis and limited treatment options.

The goal of this survey is to collect data on **policies and practices relating to rare cancer prevention, treatment, and care**, specifically from the **perspective of healthcare professionals**. It is encouraged that you respond to all questions to the best of your ability and experience, as your valuable insights and experiences can make significant contributions while also highlighting areas for improvement. The collected information will be used as part of a PhD thesis research.

Your participation is entirely voluntary, and you may opt out at any time. This survey is expected to take approximately **15 minutes to complete**. We appreciate your time and effort.

If you have any questions or concerns about the survey, please do not hesitate to contact

Sincerely,

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There are 33 questions in this survey.

## INFORMED CONSENT

I have had enough time to consider my participation in the study.

I have received sufficient information about my rights and purpose of the study and its implementation, as well as about the possible benefits and disadvantages related to it.

I have not been pressured or persuaded to participate in the study.

I know that my information will be treated confidentially.

I understand that my participation is voluntary.

By clicking **Yes**, I confirm my participation in this study and agree to be a voluntary research subject.

\*

Please choose **only one** of the following:

- ☐ Yes
- ☐ No

Are you responsible for the diagnosis, prevention, research, or clinical management of **patients with rare cancers**?

\*

Please choose **only one** of the following:

- ☐ Yes
- ☐ No

# RESPONDER PROFILE

Please answer the following questions about **yourself**: \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please write your answer(s) here:

|  |                      |
|--|----------------------|
| Age (years)  | <input type="text"/> |
| Country  | <input type="text"/> |
| What is the duration of your personal involvement in the field rare cancers?<br>/in years/ | <input type="text"/> |
| What is the duration of your overall working experience? /in years/                        | <input type="text"/> |

What is your **gender**? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose **only one** of the following:

- ☐ Female
- ☐ Male

**Workplace** type: \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Select all that apply  
Please choose **all** that apply:

|                          |                             |
|--------------------------|-----------------------------|
| <input type="checkbox"/> | Medical establishment       |
| <input type="checkbox"/> | Health authority            |
| <input type="checkbox"/> | University                  |
| <input type="checkbox"/> | Research organisation       |
| <input type="checkbox"/> | Other: <input type="text"/> |

What is your **specialty**? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Select all that apply  
Please choose **all** that apply:

- ☐ Oncology
- ☐ Hematology
- ☐ Surgery
- ☐ Radiotherapy
- ☐ Nuclear medicine
- ☐ (Medical) genetic
- ☐ Histopathologists
- ☐ Not a medical doctor
- ☐ Other:

Which **age group** of patients with rare tumors is the focus of your work? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Choose one of the following answers  
Please choose **only one** of the following:

- ☐ Children
- ☐ Adults
- ☐ Both

In what **area(s) of rare cancers** are you specialized? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Select all that apply  
Please choose **all** that apply:

- ☐ Central nervous system rare cancers (CNS)
- ☐ Digestive rare cancers
- ☐ Endocrine organ rare cancers
- ☐ Female genital rare cancers
- ☐ Haematological rare cancers
- ☐ Head & neck rare cancers
- ☐ Male genital & urogenital rare cancers
- ☐ Neuroendocrine tumours (net) rare cancers
- ☐ Paediatric cancers
- ☐ Sarcomas
- ☐ Skin rare cancers
- ☐ Thoracic rare cancers
- ☐ Other:

In which of the following **ERNs** are you and your organization involved? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Select all that apply  
Please choose **all** that apply:

- ☐ EURACAN
- ☐ ERN PaedCan
- ☐ ERN-EuroBloodNet
- ☐ ERN GENTURIS
- ☐ None
- ☐ Other:

What is the **main focus** of your professional activities in the field of rare cancers? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Choose one of the following answers  
Please choose **only one** of the following:

- ☐ Laboratory, genetic or histopathological diagnosis
- ☐ Clinical diagnosis and management
- ☐ Research and innovation
- ☐ Prevention
- ☐ Social support, rehabilitation and palliative care
- ☐ Other (please specify in the comment box)

Make a comment on your choice here:

OVERALL POLICIES IN THE FIELD OF RARE CANCERS

Is there a **legal definition** of rare cancers in your country? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Choose one of the following answers  
Please choose **only one** of the following:

- ☐ Yes
- ☐ No, but the general definition for rare diseases is applied.
- ☐ No

Make a comment on your choice here:

Is there currently an adopted national cancer plan in place in your country? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose **only one** of the following:

- ☐ Yes
- ☐ No

Are rare cancers defined as a priority group in the national cancer plan? \*

Only answer this question if the following conditions are met:  
Answer was 'Yes' at question ' [Q0Q1]' (I have had enough time to consider my participation in the study. I have received sufficient information about my rights and purpose of the study and its implementation, as well as about the possible benefits and disadvantages related to it. I have not been pressured or persuaded to participate in the study. I know that my information will be treated confidentially. I understand that my participation is voluntary. By clicking Yes, I confirm my participation in this study and agree to be a voluntary research subject. ) *and* Answer was 'Yes' at question ' [G0Q2]' (Are you responsible for the diagnosis, prevention, research, or clinical management of patients with rare cancers? ) *and* Answer was 'Yes' at question ' [G2Q12]' (Is there currently an adopted national cancer plan in place in your country?)

Please choose **only one** of the following:

- ☐ Yes
- ☐ No

How would you assess the **role and relative impact of the National Cancer Plan** based on the following criteria in your country? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y") and (G2Q12.NAOK == "Y"))

Please choose the appropriate response for each item:

|   | 1                     | 2                     | 3                     | 4                     | 5                     |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b><u>GOALS AND OBJECTIVES:</u></b> The plan has a clear, achievable and measurable goals and objectives that are aligned with the overall strategy.                            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>STAKEHOLDER ENGAGEMNT:</u></b> The plan involves a broad range of stakeholders, including patients, healthcare providers, researchers, policymakers, and advocacy groups. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>EVIDENCE-BASED INTERVENTIONS:</u></b> The plan includes interventions that have been shown to be effective in reducing the burden of cancer.                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>IMPLEMENTATION STRATEGY:</u></b> The plan has a clear implementation strategy that outlines how the goals and objectives will be achieved.                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>MONITORING AND EVALUATION:</u></b> The plan includes a framework to track progress towards the goals and objectives.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>EQUITY:</u></b> The plan addresses health disparities and includes strategies to reduce barriers to care, such as geographic or financial barriers.                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>FUNDING:</u></b> The plan is adequately funded to ensure that the goals and objectives are achieved.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>EFFICIENCY:</u></b> The financing of the plan is efficient, ensuring that resources are used effectively to achieve the goals and objectives of the plan.                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please assess each criterion on a scale of 1 to 5, with 1 indicating strongly disagree and 5 indicating strongly agree.

How would you assess the importance of different **funding sources for the National Cancer Plan** in your country? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y") and (G2Q12.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Public - Goverment funding                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Public - Health insurance funding                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Voluntary health insurance funding       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Household out-of- pocket expenditure     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Non-profit institutions serving households | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - EU financing project lines                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Industry                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

This question **is not asking for your subjective opinion but rather about the active cancer plan**. Please rate each source on a scale of 1 to 5, with 1 indicating that the resource is not contributing to the plan and 5 indicating that the resource is a primary source of funding.

Which of the following approaches for rare **cancer policies integration** do you find most suitable? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Choose one of the following answers  
Please choose **only one** of the following:

- ☐ Aligning rare cancer policies with all other cancer-related policies
- ☐ Aligning rare cancer policies with other policies related to rare diseases
- ☐ Establishing rare cancer policies as a distinct area of policies

Make a comment on your choice here:



PREVENTION POLICIES

How would you assess the **effectiveness** of the established cancer prevention policies (including those for rare cancers) in your country based on the following criteria? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|   | 1                     | 2                     | 3                     | 4                     | 5                     |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b>KNOWLEDGE:</b> There is a basic understanding of what rare cancers are, how they differ from common cancers, and their impact on individuals and society.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>PERCEPTION:</b> Rare cancers are perceived as a significant health issue. The unique challenges faced by patients with rare cancers are understood. The need for increased research, funding, and policy support is recognized.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>ATTITUDE:</b> The attitude towards patients with rare cancers is supportive. The society is open to learning more about rare cancers and advocating for increased awareness and support.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>COMMUNICATION:</b> Effective communication strategies are in place to educate society about rare cancers.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>REACH:</b> Awareness campaigns reach a broad range of society, including different age groups, genders, socioeconomic backgrounds, and geographic locations.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>IMPACT:</b> The impact of prevention campaigns is measured through indicators such as changes in incidence and mortality from rare cancers. The campaigns have an impact on the allocation of resources, policy development, and healthcare delivery for patients with rare cancers. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree

How would you assess the **effectiveness of the national cancer registry** in your country based on the following criteria? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b><u>COMPLETENESS:</u></b> The registry includes all cases of cancer diagnosed within a defined population and time period.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>CONTEMPORARY:</u></b> The registry has up-to-date and timely data on cancer cases.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>ACCURACY:</u></b> The data collected in the registry is accurate and reliable.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>VALIDITY:</u></b> The registry is able to produce valid statistics on cancer incidence, mortality, and survival.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>REPRESENTATIVENESS:</u></b> The registry is representative of the population it serves.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>CONFIDENTIALITY:</u></b> The registry ensures the confidentiality and privacy of the individuals whose data are collected  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>PATIENT OUTCOMES:</u></b> The registry demonstrates a positive impact on patient outcomes, such as earlier diagnosis, more effective treatment, and improved survival rates. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>INFLUENCE:</u></b> The registry informs cancer policy decisions.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>RESEARCH:</u></b> The registry facilitates cancer research by providing data and resources for investigators   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>COST-EFFECTIVENESS:</u></b> The registry demonstrates that its benefits outweigh its costs.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>AWARENESS:</u></b> The registry increases public awareness of cancer and its impact on the population.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>COLLABORATION:</u></b> The registry facilitates collaboration among  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|   | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| healthcare providers, researchers, and public health officials. |   |   |   |   |   |

Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree. If there is no national but only a regional registry in place, answer accordingly.

How would you assess the **importance of different funding sources** for screening programs in your country for patients with rare cancers? \*

Only answer this question if the following conditions are met:  
 ((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Public - Goverment funding                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Public - Health insurance funding                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Voluntary health insurance funding       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Household out-of- pocket expenditure     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Non-profit institutions serving households | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - EU financing project lines                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Industry                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

This question is not seeking your subjective opinion but is about the current screening programs. Please rate each source on a scale of 1 to 5, with 1 indicating that the resource is not used and 5 indicating that the resource is a primary source of funding.

How would you assess the implementation of the following **screening programs established by the EU Council recommendation** on strengthening prevention through early detection in your country?

\*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b><u>Breast cancer screening</u></b> with mammography for women aged 50 to 69, and suggested for women from 45 to 74 years old  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Testing for human papilloma virus (HPV) as a tool for <b><u>cervical cancer screening</u></b> for women aged 30 to 65, with an interval of five years or more                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Quantitative faecal immunochemical testing (FIT) as a screening test for <b><u>colorectal cancer</u></b> before referring individuals between 50 and 74 years old to follow-up colonoscopy | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Low-dose computed tomography as a screening test for individuals at high risk for <b><u>lung cancer</u></b> , including heavy smokers and ex-smokers                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>Prostate cancer</u></b> screening for men, on the basis of prostate-specific antigen (PSA) testing in combination with magnetic resonance imaging (MRI) scanning as follow-up        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Screen-and-test strategies for Helicobacter pylori for <b><u>gastric cancer</u></b> .  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

The implementation of a screening program refers to the process of putting into action a planned and organized set of activities aimed at identifying a specific disease or condition in a target population through the use of a specific screening intervention. Please use the scale from 1 to 5, with 1 denoting no implementation and 5 denoting complete implementation.

How would you assess the **relevance** of the following preventive EU cancer plan recommendations, specifically **in the field of rare cancers**? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|   | 1                     | 2                     | 3                     | 4                     | 5                     |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Creation of a <b><u>Knowledge Centre on Cancer</u></b> to facilitate the coordination of scientific and technical cancer-related initiatives at EU level  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Enabling cancer patients to securely <b><u>access and share electronic health records</u></b> for prevention and treatment across borders through the European Health Data Space  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>Elimination of cancers caused by human papillomaviruses</u></b> through EU support for Member States on vaccination with the aim to vaccinate at least 90% of the EU target population of girls and to significantly increase the vaccination of boys | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Improvement of <b><u>health literacy on cancer risk</u></b> by updating the European Code against cancer  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Creation of a ' <b><u>Tobacco-Free Generation</u></b> ', including reviewing the Tobacco Products and the Tobacco Taxation Directives and the legal framework on cross-border purchases of tobacco  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Reducing the <b><u>harmful alcohol consumption</u></b> through support to capacity-building and best practice; reduce young people's exposure to online marketing and advertising of alcohol products; implement evidence-based brief interventions         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>Addressing unhealthy diets, obesity and physical inactivity</u></b> by reducing carcinogenic contaminants in food   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Alignment of the EU's <b><u>air quality standards</u></b> more closely with the   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| WHO guidelines and promote sustainable and smart mobility  |                       |                       |                       |                       |                       |
| Adoption of a new <u>Occupational Safety and Health Strategic Framework</u> to further reduce workers' exposure to chemicals                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Developing a new <u>EU Cancer Screening Scheme</u> to ensure that 90% of the target population is offered breast, cervical and colorectal cancer screening | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please use a scale of 1 to 5. A score of 1 indicates that the recommendation is not relevant for rare cancers, while a score of 5 indicates strong relevance for rare cancers.

## CLINICAL MANAGMENT, RESEARCH AND INOVATION

To what extent are **evidence-based treatment guidelines for rare tumors available** at your center? \*

Only answer this question if the following conditions are met:  
Answer was 'Yes' at question ' [Q0Q1]' (I have had enough time to consider my participation in the study. I have received sufficient information about my rights and purpose of the study and its implementation, as well as about the possible benefits and disadvantages related to it. I have not been pressured or persuaded to participate in the study. I know that my information will be treated confidentially. I understand that my participation is voluntary. By clicking Yes, I confirm my participation in this study and agree to be a voluntary research subject. ) *and* Answer was 'Yes' at question ' [G0Q2]' (Are you responsible for the diagnosis, prevention, research, or clinical management of patients with rare cancers? ) *and* Answer was 'Clinical diagnosis and management ' at question ' [G1Q10]' (What is the main focus of your professional activities in the field of rare cancers?)

Please choose **only one** of the following:

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

Use a scale of 1 to 5, with 1 indicating there are no evidence-based treatment guidelines and 5 indicating the availability of treatment guidelines for all rare cancer patients at the center.

How would you assess the **usability of the available treatment guidelines** for rare cancers in your clinical unit based on the following criteria? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y") and (G1Q10.NAOK == "AO02"))

Please choose the appropriate response for each item:

|   | 1                     | 2                     | 3                     | 4                     | 5                     |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b><u>EFFICACY:</u></b> Guidelines have demonstrated the ability to effectively treat the specific rare cancer for which they were developed.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>SAFETY:</u></b> Guidelines have a favorable safety profile with minimal side effects, and any risks are clearly communicated to patients.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>FEASIBILITY:</u></b> Guidelines are feasible to administer in clinical settings and do not require excessive resources or specialized equipment.                                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>PATIENT-CENTERDNESS:</u></b> Guidelines take into account the unique needs and preferences of patients with rare cancers, considering quality of life and shared decision-making. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>NOVELTY:</u></b> Guidelines offer a new or innovative approach to treating rare cancers, such as targeted therapies or personalized medicine.                                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>COST-EFFECTIVNESS:</u></b> Guidelines are cost-effective, taking into account the potential benefits and harms of the treatment and the costs associated with it.                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>EVIDENCE BASE:</u></b> Guidelines are supported by a strong evidence base, including preclinical and clinical data.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree.



How would you assess the **effectiveness of the clinical collaboration** in the field of rare cancers in your clinical centre based on the following criteria? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y") and (G1Q10.NAOK == "AO02"))

Please choose the appropriate response for each item:

|   | 1                     | 2                     | 3                     | 4                     | 5                     |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b><u>INTERDISCIPLINARY APPROACH:</u></b> Collaboration involves healthcare professionals from different disciplines.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>COMMUNICATION:</u></b> The healthcare team has open lines of communication to ensure that all team members are up-to-date on the patient's condition, treatment plan, and status. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>SHARED DECISION-MAKING:</u></b> Collaboration involves shared decision-making between the patient, their family, and the healthcare team.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>EXPERTISE:</u></b> Collaboration involves healthcare professionals with expertise in treating rare cancers.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>ACCESSIBILITY:</u></b> Collaboration is accessible to patients with rare cancers, regardless of their geographic location or financial circumstances.                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>IMPROVEMENT:</u></b> Collaboration involves a continuous improvement process with regular evaluation of the effectiveness of the treatment plan.                                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree.



How would you assess the **importance** of each of the following factors in the decision-making process for **reimbursement / coverage** of new therapies for rare cancers? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Disease severity/clinical burden   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Value for money and budget impact  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Unmet need/lack of active treatment alternatives   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Strength/robustness/quality of evidence  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Therapeutic value (clinical efficacy/effectiveness and significance of additional benefit) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Use a scale of 1 to 5, with 1 being of minor importance and 5 being of major importance.

How would you assess the effectiveness of the clinical trials for patient enrollment in the field of rare cancers in your country based on the following criteria? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <b>AVAILABILITY:</b> There are numerous clinical trials available for different rare cancers, as well as trials for different stages of the diseases.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>COVERAGE:</b> Patients have access to clinical trials regardless of where they live in the country. Trials are available in different regions, or appropriate travel and accommodation support is provided. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>INCLUSIVITY:</b> Clinical trials are inclusive, with patients from diverse social backgrounds and demographics being able to participate.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>AFFORDABILITY:</b> Clinical trials are affordable for all patients, regardless of their financial circumstances.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b>CONTEMPORARY:</b> Clinical trials are characterized by a shorter duration of time between trial registration and trial initiation.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree.

How would you assess the **relevance** of the following clinical management EU cancer plan recommendations, **specifically in the field of rare cancers**? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Establishing a group of new <b><u>Reference Networks on specific cancer types</u></b>  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Creation of an EU platform to support the <b><u>repurposing of existing medicines</u></b>  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Seting up a <b><u>Partnership on Personalised Medicine</u></b>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Developing a <b><u>roadmap towards personalised prevention</u></b>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Launching a new project using High-Performance Computing to rapidly test <b><u>existing molecules and new drug combinations</u></b>                                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assistance of researchers working on personalised cancer treatments through <b><u>tailored support and new digital platforms</u></b>                                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Supporting collaborative projects on cancer diagnostics and treatment using <b><u>High- Performance Computing and AI</u></b>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Addressing fair access for cancer survivors to <b><u>financial services</u></b> (including insurance), via a code of conduct and a reflection on long-term solutions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Launching a <b><u>Cancer Inequalities Registry</u></b> to map trends in key cancer data identifying inequalities between Member States and regions                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Strengthening and integration of <b><u>telemedicine and remote monitoring in health and care systems</u></b> ; promote the virtual consultation model of the ERNs    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Establishing an ' <b><u>EU Network of Youth Cancer Survivors</u></b>   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please use a scale of 1 to 5. A score of 1 indicates that the recommendation is not relevant for rare cancers, while a score of 5 indicates strong relevance for rare cancers.

How would you assess the importance of different **funding sources for inovate therapy** in your country for patients with rare cancers? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Public - Goverment funding                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Public - Health insurance funding                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Voluntary health insurance funding       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Household out-of- pocket expenditure     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Non-profit institutions serving households | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - EU financing project lines                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Industry                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

This question is not seeking your subjective opinion but is about the current financing mechanisms for innovative therapy. Please rate each source on a scale of 1 to 5, with 1 indicating that the source is not used and 5 indicating that the source is a primary source of funding.

PALLIATIVE AND SOCIAL CARE

Is palliative care **included in your organization's management plan** for patients with rare cancers? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y") and (G1Q10.NAOK == "AO02"))

Choose one of the following answers  
Please choose **only one** of the following:

- ☐ Yes, provided at site
- ☐ Yes, provided by other facilities
- ☐ No

Make a comment on your choice here:

How would you assess the **importance** of each of the following **medico-social support services** for patients with rare cancers? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|   | 1                     | 2                     | 3                     | 4                     | 5                     |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Psychosocial support                                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Financial support                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Occupational support                                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Additional medical support (art therapy, music therapy) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Spiritual and religious support                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Legal support   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Diet and nutrition support                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Use a scale of 1 to 5, with 1 being of minor importance and 5 being of major importance.

How would you assess the **effectiveness of palliative care** in the field of **rare cancers** based on the following criteria in your county? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | Adults rare cancer patients |                       |                       |                       |                       |  | Pediatric rare cancer patients |                       |                       |                       |                       |
|--|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|--|--------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
|  | 1                           | 2                     | 3                     | 4                     | 5                     |  | 1                              | 2                     | 3                     | 4                     | 5                     |
| <b><u>AVAILABILITY:</u></b> Palliative care services are available for patients with rare cancers, including from a number of providers of hospice services and specialized palliative care teams. | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |  | <input type="radio"/>          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>ACCESS:</u></b> Palliative care services are accessible, including the ability of patients to access them regardless of their geographic location or financial circumstances.                | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |  | <input type="radio"/>          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>QUALITY OF CARE:</u></b> Palliative care is provided by interdisciplinary teams based on evidence-based guidelines, and comprehensive supportive care is provided.                           | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |  | <input type="radio"/>          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>TIMING:</u></b> The initiation of palliative services is at the appropriate time in the disease trajectory, including early integration of palliative care in the management plan.           | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |  | <input type="radio"/>          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>PATIENT-CENTEREDNESS:</u></b> Palliative care services provide personalized care plans, shared decision-making, and attention to cultural and social factors.                                | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |  | <input type="radio"/>          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>SYMPTOMS MANAGEMENT:</u></b> Palliative care services provide effective management of pain, nausea, fatigue, and other symptoms commonly associated with advanced cancer.                    | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |  | <input type="radio"/>          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| <b><u>GRIEVING SUPPORT:</u></b> Palliative care services provide grief counseling and support groups.  | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |  | <input type="radio"/>          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree.

How would you assess the importance of different **funding sources for social support and palliative care** for patient with rare cancers in your country? \*

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please choose the appropriate response for each item:

|  | 1                     | 2                     | 3                     | 4                     | 5                     |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Public - Goverment funding                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Public - Health insurance funding                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Voluntary health insurance funding       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Private - Household out-of- pocket expenditure     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Non-profit institutions serving households | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - EU financing project lines                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other - Industry                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

This question is **not asking for your subjective opinion but rather pertains to the current state of social support and palliative care**. Please rate each resource on a scale of 1 to 5, with 1 indicating that the source is not used and 5 indicating that the source is a primary source of funding.

If you have any **comments or suggestions**, please feel free to share them in the box below. We appreciate your time and effort in providing feedback.

Only answer this question if the following conditions are met:  
((Q0Q1.NAOK == "Y") and (G0Q2.NAOK == "Y"))

Please write your answer here:

Thank you for taking the time to complete this survey.

For additional inquiries or comments, please contact Kostadin Kostadinov, MD ([kostadinr.kostadinov@mu-plovdiv.bg](mailto:kostadinr.kostadinov@mu-plovdiv.bg)).

04-11-2024 – 12:25

Submit your survey.

Thank you for completing this survey.