



Section A: Informed consent

A1.

I have had enough time to consider my participation in the study. I have received sufficient information about my rights, 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 and will not be disclosed to third parties.

I understand that my participation is voluntary. I am aware that I can withdraw my consent to participate in the study at any time, without giving any reason and the suspension will not have any impact on the way I am being treated.

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

Yes
No

A2. Are you responsible for diagnosis or clinical management of patients with rare cancers?

Yes
No

Section B: Respondent profile

This section contains administrative and socio-demographic questions related to you and your profession.

B1. Before we start, please fill out questions about yourself and the organization you're working at:

Gender

Age (years)

What is your position / work title

Name of the organization you are working at

Country

What is the duration of your personal involvement in the field rare cancers? /in years/

What is the duration of your overall working experience? /in years/

**B2. What is your specialty?**

- Oncology
- Hematology
- Surgery
- Radiotherapy
- Nuclear medicine
- (Medical) genetic
- Pediatric oncology
- Not a medical doctor
- Other

Other

B3. For each of the two age groups below, you are responsible in regard to diagnosis or clinical management of patients with rare cancers?

- 0-18 years
- Over 18 years
- Both

B4. In what area(s) of rare cancers you and your center are specialized?

- 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

Other

B5. In which of the following ERNs are you and your organisation involved?EURACAN ERN PaedCan ERN-EuroBloodNet ERN GENTURIS None Other 

Other

B6. What is the main focus of your professional activities in the field of rare cancers?Diagnosis and clinical management of patients with rare cancers Research and innovation in the field of rare cancers (including academic research, clinical trials, registries, etc.) Prevention of rare cancers Social support, rehabilitation and palliative care in the field of rare cancers Other (please specify in the comment box)



Section C: Overall policy in the field of rare cancers

C1. Is an official legal definition of rare cancers adopted in your country?

Yes

No, The general definition for rare diseases is applied

No - there is no official legal definition adopted in the field

C2. Is there an adopted national cancer plan currently in place in your country?

Yes

No

C3. Are rare cancers defined in the national cancer plan as a priority group?

Yes

No

C4. How would you assess the effectiveness and relevance of the National Cancer Plan in your country? Please rate each criterion on a scale of 1 to 5, with 1 indicates strongly disagree and 5 indicates strongly agree

1 2 3 4 5

Goals and objectives: The plan has a clear and measurable goals and objectives that are aligned with the overall strategy. The goals are achievable within a reasonable timeframe and is based on the best available evidence.

Stakeholder engagement: The plan involves a broad range of stakeholders, including patients, healthcare providers, researchers, policymakers, and advocacy groups

Evidence-based interventions: The plan includes evidence-based interventions that have been shown to be effective in reducing the burden of cancer

Implementation strategy: The plan has a clear implementation strategy that outlines how the goals and objectives will be achieved.

Monitoring and evaluation: The plan includes a monitoring and evaluation framework to track progress towards the goals and objectives.



1 2 3 4 5

Equity: The plan addresses health disparities and ensure that all members of the population have access to high-quality cancer care.

This includes strategies to reduce barriers to care, such as geographic or financial barriers.

Adequacy of resources: The plan is adequately funded to ensure that the goals and objectives are achieved. This includes funding for prevention, screening, treatment, research, and survivorship care.

Efficiency: The financing of the plan is efficient, ensuring that resources are used effectively to achieve the goals and objectives of the plan. This includes strategies to reduce waste and improve the quality of care.

C5. How would you assess the importance of different financing resources for the National Cancer Plan in your country? Please rate each resource 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

This question is not asking for your subjective opinion but rather about the current plan.

1 2 3 4 5

Government agencies/ Health authority

Insurance companies and funds

Industry (Pharmaceutical and biotechnology companies) partners

Philanthropic donations / Crowdfunding

EU funding Programmes (e.g.EU4Health)

C6. How do you think rare cancer policies should be integrated with other healthcare policies: Which of the following approaches do you find most suitable?

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 and separate area of policies



Section D: Prevention policies in the field of rare cancers

D1. How would you rate the effectiveness of the established cancers prevention policies (including rare cancers) in the public in your country based on the following criteria? Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree

1 2 3 4 5

Knowledge: The public have a basic understanding of what rare cancers are, how they differ from common cancers, and their impact on individuals and society

Perception: The general public perceive rare cancers as a significant health issue and understand the unique challenges faced by patients with rare cancers. They recognize the need for increased research, funding, and policy support to address this issue

Attitudes: The general public have positive attitudes towards patients with rare cancers and are supportive of their needs and challenges. They also are open to learning more about rare cancers and advocating for increased awareness and support

Communication: Effective communication strategies are in place to educate the general public about rare cancers. This includes the use of accessible language, clear and concise messaging, and appropriate channels for reaching different audiences

Reach: Awareness campaigns reach a broad range of the general public, including different age groups, genders, socioeconomic backgrounds, and geographic locations. This includes engaging with community groups, schools, workplaces, and other organizations

Impact: The impact of awareness campaigns is measured through indicators such as changes incidence, mortality of rare cancers or public knowledge, attitudes, and behaviors related to rare cancers.

The campaigns have a measurable impact on the allocation of resources, policy development, and healthcare delivery for patients with rare cancers.

D2. How would you rate the effectiveness of the national/regional cancer registry in your country based on the following criteria? Please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree

1 2 3 4 5

Completeness: The registry includes all cases of cancer diagnosed within a defined population and time period

Timeliness: The registry has up-to-date and timely data on cancer cases

Accuracy: The data collected in the registry is accurate and reliable

Validity: The registry is able to produce valid statistics on cancer incidence, mortality, and survival



	1	2	3	4	5
Representativeness: The registry is representative of the population it serves.	<input type="checkbox"/>				
Confidentiality: The registry ensures the confidentiality and privacy of the individuals whose data are collected	<input type="checkbox"/>				
Improved patient outcomes: The registry demonstrates a positive impact on patient outcomes, such as earlier diagnosis, more effective	<input type="checkbox"/>				
Influence on cancer policy: The registry informs cancer policy decisions at the local, regional, and national levels	<input type="checkbox"/>				
Research opportunities: The registry facilitates cancer research by providing data and resources for investigators.	<input type="checkbox"/>				
Cost-effectiveness: The registry demonstrates that its benefits outweigh its costs.	<input type="checkbox"/>				
Public awareness: The registry increases public awareness of cancer and its impact on the population.	<input type="checkbox"/>				
Collaboration: The registry facilitates collaboration among healthcare providers, researchers, and public health officials. This can include sharing data and resources, and promoting the development of multidisciplinary teams to address complex cancer issues	<input type="checkbox"/>				

D3. How would you rate the importance of different financing resources for screening programmes in your country for patient with rare cancers? Please rate each resource 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 used a source of funding

This question is not seeking your subjective opinion but is about the current screening programs.

	1	2	3	4	5
Health insurance coverage	<input type="checkbox"/>				
Governmental funding	<input type="checkbox"/>				
Out-of-pocket payment	<input type="checkbox"/>				
Test provided by the pharmaceutical companies	<input type="checkbox"/>				

D4. On a scale from 1 to 5, where 1 indicates no implementation and 5 indicates full implementation, how would you rate the following screening programs established by the EU Council Recommendation on strengthening prevention through early detection in your country?

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 test. It involves the deployment of the screening test, the training of healthcare providers, the development of policies and guidelines, the establishment of referral systems for follow-up diagnosis and treatment, and the evaluation of the program's effectiveness.

	1	2	3	4	5
Breast cancer screening with mammography for women aged 50 to 69, and suggested for women from 45 to 74 years old	<input type="checkbox"/>				



Testing for human papilloma virus (HPV) as a tool for cervical cancer screening for women aged 30 to 65, with an interval of five years or more

1	2	3	4	5
<input type="checkbox"/>				

Quantitative faecal immunochemical testing (FIT) as a screening test for colorectal cancer before referring individuals between 50 and 74 years old to follow-up colonoscopy

<input type="checkbox"/>				
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Low-dose computed tomography as a screening test for individuals at high risk for lung cancer, including heavy smokers and ex-smokers

<input type="checkbox"/>				
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Prostate cancer 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="checkbox"/>				
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Screen-and-test strategies for Helicobacter pylori for gastric cancer

<input type="checkbox"/>				
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D5. Please rate the effectiveness of the following preventive EU cancer plan recommendations specifically in the field of rare cancers. Please use a scale of 1 to 5. A score of 1 indicates strong disagreement, while a score of 5 indicates strong agreement

Creation of a Knowledge Centre on Cancer to facilitate the coordination of scientific and technical cancer-related initiatives at EU level

1	2	3	4	5
<input type="checkbox"/>				

Enabling cancer patients to securely access and share electronic health records for prevention and treatment across borders through the European Health Data Space

<input type="checkbox"/>				
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Elimination of cancers caused by human papillomaviruses 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="checkbox"/>				
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Improvement of health literacy on cancer risk by updating the European Code against cancer

<input type="checkbox"/>				
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Creation of a 'Tobacco-Free Generation', including reviewing the Tobacco Products and the Tobacco Taxation Directives and the legal framework on cross-border purchases of tobacco

<input type="checkbox"/>				
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Reducing the harmful alcohol consumption 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="checkbox"/>				
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Addressing unhealthy diets, obesity and physical inactivity by reducing carcinogenic contaminants in food

<input type="checkbox"/>				
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Alignment of the EU's air quality standards more closely with the WHO guidelines and promote sustainable and smart mobility

<input type="checkbox"/>				
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Adoption of a new Occupational Safety and Health Strategic Framework to further reduce workers' exposure to chemicals

<input type="checkbox"/>				
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Developing a new EU Cancer Screening Scheme to ensure that 90% of the target population is offered breast, cervical and colorectal cancer screening

<input type="checkbox"/>				
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Section E: Clinical management, research and innovation in the field of rare cancers

E1. Is there a national standard treatment protocols for rare cancers used regularly in your center?

Yes
No

E2. How would you rate the effectiveness of the treatment protocols for rare cancers in your country. Based on the following criteria please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree:

1 2 3 4 5

Efficacy: The treatment protocols have demonstrated an ability to effectively treat the specific rare cancer for which they were developed

Safety: The treatment protocols have a favorable safety profile with minimal side effects, and any risks is clearly communicated to patients

Feasibility: The treatment protocols are practical and feasible to administer in clinical settings, and do not require excessive resources or specialized equipment

Patient-centeredness: The treatment protocols take into account the unique needs and preferences of patients with rare cancers, including considerations for quality of life, emotional and psychological support, and shared decision-making

Novelty: The treatment protocols offer a new or innovative approach to treating the rare cancer, such as targeted therapies or personalized medicine, and should represent a significant improvement over existing treatment options

Cost-effectiveness: The treatment protocols are cost-effective, taking into account the potential benefits and harms of the treatment, and the costs associated with its administration and follow-up care

Evidence base: The treatment protocols are supported by a strong evidence base, including preclinical and clinical data, and are subject to ongoing evaluation and refinement based on emerging research and clinical experience



E3. How would you rate the effectiveness of the clinical collaboration in the field of rare cancers in your country. Based on the following criteria, please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree

1 2 3 4 5

Interdisciplinary approach: Collaboration involves healthcare professionals from different disciplines, such as medical oncologists, surgical oncologists, radiation oncologists, pathologists, geneticists, and supportive care specialists

Communication: The healthcare team have open lines of communication to ensure that all team members are up-to-date on the patient's condition, treatment plan, and any changes in the patient's status

Shared decision-making: Collaboration involves shared decision-making between the patient, their family, and the healthcare team

Expertise: Collaboration involves healthcare professionals with expertise in treating rare cancers. This includes healthcare professionals who are knowledgeable about the latest research and treatment options for rare cancers and who have experience treating patients with rare cancers

Accessibility: Collaboration is accessible to patients with rare cancers, regardless of their geographic location or financial circumstances

Continuous improvement: Collaboration involves a continuous improvement process, with regular evaluation of the effectiveness of the treatment plan and modifications made as necessary

E4. Please rate the importance of each of the following factors on a scale of 1 (strongly disagree) to 5 (strongly agree) in the decision-making process for approving new therapies for rare cancers

1 2 3 4 5

Disease severity/clinical burden

Unmet need/lack of active treatment alternatives

Therapeutic value (clinical efficacy/effectiveness and significance of additional benefit)

Strength/robustness/quality of evidence

Value for money and budget impact



E5. How would you rate the effectiveness of the clinical trials patients enrollment in the field of rare cancers in your country. Based on the following criteria, please use the scale from 1 to 5, where 1 indicates strongly disagree and 5 indicates strongly agree

1 2 3 4 5

Availability: There are a numerous of clinical trials available for rare cancers in the country. This includes trials of different rare cancers, as well as the availability of trials for different stages of the disease

Geographic location: Patients have access to clinical trials regardless of where they live in the country. This includes the availability of trials in different regions and the provision of appropriate travel and accommodation support for patients who need to travel for treatment

Inclusivity: Clinical trials are inclusive, with patients from diverse backgrounds and demographics being able to participate. This includes that clinical trials are open to patients regardless of age, gender, race, ethnicity, or socioeconomic status

Affordability: Clinical trials are affordable for all patients, regardless of their financial circumstances

Timeliness: The clinical trials for rare cancers are characterized by a shorter duration of time between trial registration and trial initiation compared to trials for other types of cancers

E6. Please rate the effectiveness of the following clinical management EU cancer plan recommendations, specifically in the field of rare cancers, using a scale of 1 to 5. A score of 1 indicates strong disagreement, while a score of 5 indicates strong agreement

1 2 3 4 5

Establishing a group of new Reference Networks on specific cancer types

Creation of an EU platform to support the repurposing of existing medicines

Setting up a Partnership on Personalised Medicine

Developing a roadmap towards personalised prevention

Launching a new project using High-Performance Computing to rapidly test existing molecules and new drug combinations

Assistance of researchers working on personalised cancer treatments through tailored support and new digital platforms

Supporting collaborative projects on cancer diagnostics and treatment using High- Performance Computing and AI

Addressing fair access for cancer survivors to financial services (including insurance), via a code of conduct and a reflection on long-term solutions

Launching a Cancer Inequalities Registry to map trends in key cancer data identifying inequalities between Member States and regions



1 2 3 4 5

Strengthening and integration of telemedicine and remote monitoring in health and care systems; promote the virtual consultation model of the ERNs

Establishing an 'EU Network of Youth Cancer Survivors'

Section F: Social support, rehabilitation and palliative care in the field of rare cancers

F1. In your experience rate the importance of each of the following social support services for patients with rare cancers on a scale of 1 (strongly disagree) to 5 (strongly agree)

1 2 3 4 5

Psychosocial support

Financial support

Occupational support

Additional medical support - art therapy, music therapy, etc

Spiritual and religious support

Legal support

F2. Is palliative care included in your organization management plan of patients with rare cancers?

Yes, provided at the center

Yes, provided by other facilities/ centres

No, palliative care is not provided

F3. Please rate the effectiveness of the palliative in the field of rare cancers, using a scale of 1 to 5. A score of 1 indicates strong disagreement, while a score of 5 indicates strong agreement

1 2 3 4 5

Availability:Palliative care services are available for patients with rare cancers, including the number of providers of hospice services, and specialized palliative care teams



1 2 3 4 5

Access: Palliative care services are accessible, including the ability of patients to access services regardless of their geographic location or financial circumstances

Quality of care: Palliative care are provided by interdisciplinary teams, based on evidence-based guidelines, and the provision of comprehensive supportive care

Timing: The initiation of palliative services is at the appropriate time in the disease trajectory, including early integration of palliative care in the management plan

Patient-centeredness: Palliative care services are providing personalized care plans, shared decision-making, and attention to cultural and social factors

Symptom management: Palliative care services provide effective management of pain, nausea, fatigue, and other symptoms commonly associated with advanced cancer

Bereavement support: Palliative care services provide grief counseling and support groups

F4. How would you rank the importance of different financing resources for social support and palliative care for patient with rare cancers in your country? Please rate each resource 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 used a source of funding

This question is not asking for your subjective opinion but rather pertains to the current state of social support and palliative care.

1 2 3 4 5

Health insurance coverage

Governmental funding

Out-of-pocket payment

Non-profit organizations

F5. Thank you for your participation. Your input is valuable. 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.