

# Survey

## Introduction

Dear healthcare professionals,

The following survey investigate policies in field of rare cancer. Rare cancers are a group of diseases that affect a small proportion of the population, typically less than 6 per 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 purpose of this survey is to gather information about the policies and practices related to rare cancer prevention, treatment, and care, specifically from the perspective of healthcare professionals. Each category of questions is intended to gather specific information that is essential to understanding the current state of policies and practices related to rare cancers. It is encouraged to answer all questions to the best of your knowledge and experience, as your valuable insights and experiences can provide important contributions, as well as highlight areas for improvement.

It is assured that all data collected will be used only for the purposes of the survey results and analysis. The data will be treated confidentially and in accordance with the General Data Protection Regulation (GDPR). Your participation is voluntary, and you may withdraw from the survey at any time. It is estimated that this survey will take approximately [XXX minutes] to complete. Your time and effort are appreciated. If you have any questions or concerns about the survey, please do not hesitate to contact.

Sincerely,

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Thank you for your time and contributions to this important research. Your input is greatly appreciated.

## Target responders

1. EURACAN for all rare adult solid cancers <https://euracan.eu/who-we-are/members-and-partners/> (135)
2. The European Reference Network on Paediatric Cancer (ERN PaedCan) <https://paedcan.ern-net.eu/home/member-institutions/#1668687768259-03a2076d-8f1b> (113)
3. ERN-EuroBloodNet <https://eurobloodnet.eu/members/representative/>
4. ERN GENTURIS - European Reference Network (ERN) for all patients with one of the rare genetic tumour risk syndromes (genturis). <https://www.genturis.eu/l=eng/Our-experts/Our-healthcare-providers.html> (82)

## Study information and consent form

1. By clicking the “I agree” button below, you confirm that you have read and understood the information above and you agree to participate in this survey

- ☐ I agree  
☐ I don not agree

## Administrative questions

1. Before we start, please fill out questions about yourself and the organization you’re working at:
  - Name of the organization you are working at .../text/...
  - Sex
  - Age /years/
  - What is your position / work title .../text/...
  - Country of residence .../text/...
2. What is your specialty? (MCQ)
  - ☐ Oncology
  - ☐ Hematology
  - ☐ Surgery
  - ☐ Radiotherapy
  - ☐ Nuclear medicine
  - ☐ (Medical) genetic
  - ☐ Not a medical doctor
  - ☐ Other
3. In what area(s) of rare cancers you and your center are specialized? /MCQ/

- ☐ 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
4. Are you responsible for diagnosis or clinical management of patients with rare cancers?
- ☐ Yes
  - ☐ No
5. For each of the two age groups below, you are responsible in regard to diagnosis or clinical management of patients with rare cancers? (MCQ)
- ☐ 0-18 years
  - ☐ Over 18 years
  - ☐ Both
6. What is the duration of your personal involvement in the field rare cancers? /in years/...
7. What is the duration of your overall working experience /in years/...
8. In which of the following ERNs are you and your organisation involved? (MCQ)
- ☐ EURACAN
  - ☐ ERN PaedCan
  - ☐ ERN-EuroBloodNet
  - ☐ ERN GENTURIS
  - ☐ None
  - ☐ Other
9. What is the main focus of your professional activities in the field of rare cancers?
- ☐ Clinical management of patients with rare cancers
  - ☐ Research and innovation in the field of rare cancers (including accademic research, clinical trials, registries, etc.)
  - ☐ Prevention of rare cancers
  - ☐ Social support, rehabilitation and palliative care in the field of rare cancers
  - ☐ Other (please specify) .../text/...

## Overall policy in the field of rare cancers

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

- ☐ Yes
- ☐ The definition for rare diseases is used
- ☐ No - there is no official legal definition adopted in the field

2. Is there an adopted national cancer plan in your country?

- ☐ Yes
- ☐ No

3. If yes, are rare cancers addressed in the national cancer plan as a priority group? (*only if 2 is yes*)

- ☐ Yes
- ☐ No

4. How would you rank the effectiveness 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:

- **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.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

5. How would you rank 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:

- **Government agencies**

[1] - [2] - [3] - [4] - [5]

- **Insurance companies**

[1] - [2] - [3] - [4] - [5]

- **Private foundations**

[1] - [2] - [3] - [4] - [5]

- **Industry (Pharmaceutical and biotechnology companies) partners**

[1] - [2] - [3] - [4] - [5]

- **Philanthropic donations**

[1] - [2] - [3] - [4] - [5]

- **Corporate social responsibility initiatives**

[1] - [2] - [3] - [4] - [5]

- **EU funding Programmes (e.g.EU4Health)**

[1] - [2] - [3] - [4] - [5]

6. 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.

## Prevention policies in the field of rare cancers

1. 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:

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

5. **Representativeness:** The registry is representative of the population it serves.

[1] - [2] - [3] - [4] - [5]

6. **Confidentiality:** The registry ensures the confidentiality and privacy of the individuals whose data are collected.

[1] - [2] - [3] - [4] - [5]

7. **Improved patient outcomes:** The registry demonstrates a positive impact on patient outcomes, such as earlier diagnosis, more effective treatment, and improved survival rates.

[1] - [2] - [3] - [4] - [5]

8. **Influence on cancer policy:** The registry informs cancer policy decisions at the local, regional, and national levels.

[1] - [2] - [3] - [4] - [5]

9. **Research opportunities:** The registry facilitates cancer research by providing data and resources for investigators.

[1] - [2] - [3] - [4] - [5]

10. **Cost-effectiveness:** The registry demonstrates that its benefits outweigh its costs.

[1] - [2] - [3] - [4] - [5]

11. **Public awareness:** The registry increases public awareness of cancer and its impact on the population.

[1] - [2] - [3] - [4] - [5]

12. **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.

[1] - [2] - [3] - [4] - [5]

3. How would you rank 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:

- Health insurance coverage

[1] - [2] - [3] - [4] - [5]

- Governmental funding

[1] - [2] - [3] - [4] - [5]

- Out-of-pocket payment

[1] - [2] - [3] - [4] - [5]



- Test provided by the pharmaceutical companies

[1] - [2] - [3] - [4] - [5]

4. 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?

- Breast cancer screening with mammography for women aged 50 to 69, and suggested for women from 45 to 74 years old:

[1] - [2] - [3] - [4] - [5]

- 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]

- 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:

[1] - [2] - [3] - [4] - [5]

- Low-dose computed tomography as a screening test for individuals at high risk for lung cancer, including heavy smokers and ex-smokers:

[1] - [2] - [3] - [4] - [5]

- 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:

[1] - [2] - [3] - [4] - [5]

- Screen-and-test strategies for *Helicobacter pylori* for gastric cancer

[1] - [2] - [3] - [4] - [5]

5. Please rate your level of agreement or disagreement regarding 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]

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

[1] - [2] - [3] - [4] - [5]

- 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.

[1] - [2] - [3] - [4] - [5]

- Improvement of health literacy on cancer risk by updating the European Code against cancer.

[1] - [2] - [3] - [4] - [5]

- 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;

[1] - [2] - [3] - [4] - [5]

- 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.

[1] - [2] - [3] - [4] - [5]

- Addressing unhealthy diets, obesity and physical inactivity by reducing carcinogenic contaminants in food; addressing childhood obesity and reviewing the EU school fruit, vegetables and milk scheme; supporting Member States and stakeholders on reformulation of and on effective policies to reduce marketing of unhealthy food products; propose harmonised, mandatory front-of-pack nutrition labelling; launch the ‘HealthyLifestyle4All’ political commitment.

[1] - [2] - [3] - [4] - [5]

- Alignment of the EU’s air quality standards more closely with the WHO guidelines and promote sustainable and smart mobility.

[1] - [2] - [3] - [4] - [5]

- Adoption of a new Occupational Safety and Health Strategic Framework to further reduce workers’ exposure to chemicals.

[1] - [2] - [3] - [4] - [5]

- Developing a new EU Cancer Screening Scheme to ensure that 90% of the target population is offered breast, cervical and colorectal cancer screening.

[1] - [2] - [3] - [4] - [5]

## Research and innovation in the field of rare cancers

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

- ☐ Yes  
☐ No

2. 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:

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

3. 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:

- **Interdisciplinary approach:** Collaboration involves healthcare professionals from different disciplines, such as medical oncologists, surgical oncologists, radiation oncologists, pathologists, geneticists, and supportive care specialists. [1] - [2] - [3] - [4] - [5]
- **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.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- **Continuous improvement:** Collaboration involves a continuous improvement process, with regular evaluation of the effectiveness of the treatment plan and modifications made as necessary. This includes regular monitoring of the patient's condition and quality of life, as well as ongoing education and training for the healthcare team.

[1] - [2] - [3] - [4] - [5]

4. 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:

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

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

5. 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:

- Disease severity/clinical burden

[1] - [2] - [3] - [4] - [5]

- Unmet need/lack of active treatment alternatives

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- Strength/robustness/quality of evidence

[1] - [2] - [3] - [4] - [5]

- Value for money and budget impact

[1] - [2] - [3] - [4] - [5]

6. 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.

- Establishment of an EU Network linking recognised National Comprehensive Cancer Centres in every Member State to improve access to high-quality diagnosis and care.

[1] - [2] - [3] - [4] - [5]

- Launching a ‘Cancer Diagnostic and Treatment for All’ initiative to improve access to innovative cancer diagnosis and treatment.

[1] - [2] - [3] - [4] - [5]

- Launching the UNCAN.eu (European initiative to understand cancer proposed by the Mission Board and the European Beating Cancer Plan) to help identify individuals at high risk from common cancers.

[1] - [2] - [3] - [4] - [5]

- Launching an ‘Inter-specialty training programme’ focusing on oncology, surgery and radiology to optimise diagnosis and treatment of cancer patients.

[1] - [2] - [3] - [4] - [5]

- Establishing a group of new Reference Networks on specific cancer types.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- Adoption of the proposal for a Regulation on Health Technology Assessment.

[1] - [2] - [3] - [4] - [5]

- Presentation of the SAMIRA Action Plan (EU’s first comprehensive plan for action to support a safe, high quality and reliable use of radiological and nuclear technology in healthcare) to ensure quality and safety of radiation technology and the supply of radioisotopes of medical importance for diagnostic and treatment.

[1] - [2] - [3] - [4] - [5]

- Setting up a Partnership on Personalised Medicine.

[1] - [2] - [3] - [4] - [5]

- Developing a roadmap towards personalised prevention.

[1] - [2] - [3] - [4] - [5]

- Launching the ‘Genomic for Public Health’ project to support Member States in making the most of the rapid evolution of genomics.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- Launching the ‘Better Life for Cancer Patients Initiative’, including a ‘Cancer Survivor Smart Card’ and the creation of a virtual ‘European Cancer Patient Digital Centre’ to support the exchange of patients’ data and monitoring of survivors’ health conditions.

[1] - [2] - [3] - [4] - [5]

- Ensuring a full implementation of the Directive on work-life balance for parents and carers.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- 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.

[1] - [2] - [3] - [4] - [5]

- Improving the overall resilience, accessibility and effectiveness of European health systems to safeguard provision of cancer care in future health crises.

[1] - [2] - [3] - [4] - [5]

- Mainstream equality action in other areas addressed by Europe's Beating Cancer Plan such as screening and high-quality cancer care.

[1] - [2] - [3] - [4] - [5]

- Launching the 'Helping Children with Cancer Initiative' to ensure that children have access to rapid and optimal detection, diagnosis, treatment and care.

[1] - [2] - [3] - [4] - [5]

- Establishing an 'EU Network of Youth Cancer Survivors.

[1] - [2] - [3] - [4] - [5]

- Launching the Childhood cancers and cancers in adolescents and young adults' initiative to increase understanding of paediatric cancer.

[1] - [2] - [3] - [4] - [5]



## Social support, rehabilitation and palliative care in the field of rare cancers

1. 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)

- Psychosocial support

[1] - [2] - [3] - [4] - [5]

- Financial support

[1] - [2] - [3] - [4] - [5]

- Occupational support

[1] - [2] - [3] - [4] - [5]

- Additional medical support - art therapy, music therapy, etc.

[1] - [2] - [3] - [4] - [5]

- Spiritual and religious support

[1] - [2] - [3] - [4] - [5]

- Legal support

[1] - [2] - [3] - [4] - [5]

2. 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

3. 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.

- **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.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- **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.

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

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

[1] - [2] - [3] - [4] - [5]

- **Bereavement support:** Palliative care services provide grief counseling and support groups.

[1] - [2] - [3] - [4] - [5]

4. 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:

– Health insurance coverage

[1] - [2] - [3] - [4] - [5]

– Governmental funding

[1] - [2] - [3] - [4] - [5]

– Out-of-pocket payment

[1] - [2] - [3] - [4] - [5]

- Non-profit organizations

$$[1] - [2] - [3] - [4] - [5]$$

Please use the box below if you would like to share your comments or suggestions.