

## 2021 Thematic Networks: Rare Cancers in All Policies

Note: Rare Cancers Europe proposes a Joint Statement in synergy with The Pharmaceutical Strategy and Integrative Oncology in patient centred cancer care health policy areas

Rare Cancers Europe (RCE) is a multi-stakeholder partnership, representing 39 member organisations including patient groups, educational providers, research organisations, scientific societies and healthcare professionals, and industry. We are committed to placing the issue of rare cancers firmly on the European policy agenda and believe that there is a need for additional EU-level action to address outstanding challenges for the rare cancer community.

Rare cancers are defined as those with an annual incidence of less than six per 100 000 people in the European Union (EU). 24% of all new cancer diagnoses across Europe each year are rare forms of the disease. With 650,000 new rare cancer diagnoses annually, and around 5.1 million people in the EU living with a rare cancer, taken together rare cancers are not all that rare. The EU has a long legacy of improving the conditions of cancer patients and the policy environment is ripe for a Joint Statement from a common group of multistakeholder organisations representing the rare cancer community to ensure that their needs are reflected in the current discussions.

### 1. Scope of the future Joint Statement

Despite the current focus on oncology, the Europe's Beating Cancer Plan, and on the implementation of the Pharmaceutical Strategy, rare cancers are still a neglected area deserving attention across all policies, on-going and planned initiatives. Though the importance of rare cancers has been noted in the Commission's Pharmaceutical Strategy for Europe and Europe's Beating Cancer Plan, this must be reflected in concrete, targeted initiatives across the entire policy spectrum. In the Cancer Plan adult solid rare cancers have been neglected.

Rare cancers face challenges linked to late or incorrect diagnoses, lack of access to appropriate therapies and expertise, lack of understanding of underlying science, lack of commercial feasibility in developing new therapies, difficulties in conducting well-resourced clinical studies, few available registries and tissue banks. Additionally, there is a need for incentivising research in rare cancers which is crucial for the development of new treatments. Thus, dedicated initiatives are needed to ensure that their specificities are taken into consideration to deliver higher standards of care for rare cancers patients.

A rare cancer Thematic Network and Joint Statement will ensure that the needs of the rare cancer community and most importantly rare cancer patients, will be reflected and subsequently integrated across the various policy initiatives at EU level. Additionally, the future Joint Statement will also be a step forward for the implementation of the Rare Cancer Agenda 2030 deliverables. These were the outcomes of the EU Joint Action on Rare Cancers, a collaborative effort with the involvement of the European Commission, 18 Member States, and 34 partners. For additional information on the Joint Action on Rare Cancers, please visit the following link [here](#).

### 2. The relevance of the proposal for the selected area and the synergy with ongoing or planned EU actions on health in the European Union

As mentioned above, the creation of a Thematic Network on rare cancers ties into the existing and ongoing work including the Pharmaceutical Strategy for Europe, the Europe's Beating Cancer Plan, the Conquering Cancer: Mission Possible as well as various other initiatives which are crucial for the community. Please find below a list of ongoing EU actions which are directly relevant for this Joint Statement:

- Conquering Cancer: Mission Possible
- Pharmaceutical Strategy for Europe
- Europe's Beating Cancer Plan
- EU Research and Innovation Programme (2021-27) and Horizon Europe
- EU4Health and the European Semester Programmes
- Patients' Rights in Cross-Border Healthcare
- A European Strategy for Data
- European Health Data Space

- Clinical Trials Regulation
- Proposal for a Regulation on Health Technology Assessment
- Orphan Medicinal Products and the Paediatric Regulations
- General Data Protection Regulation

### **3. Objectives and how they will be reached**

#### **3.1. Objectives**

The rare cancer community would welcome the implementation of a Thematic Network on rare cancers on the following overarching points, among others:

- Improving research with the aim of expanding knowledge of the disease area, fostering medical education dedicated to rare cancers, and improving treatment outcomes for patients.
- Creating and connecting the European Reference Networks with the national networks dedicated to rare cancers with the final objective to reach higher and harmonised healthcare standards for European patients.
- Ensuring access, collection, storage, sharing and optimal use of health data for healthcare while protecting privacy and fostering the harmonisation of the General Data Protection Regulation (GDPR).
- Improving accessibility and affordability through the harmonisation of the HTA process and ensuring the implementation of joint clinical assessments at EU level for cancer and rare cancers.
- Co-creating policy solutions based on the involvement and expertise of stakeholders from across the rare cancer community.

The Thematic Network on rare cancers will also contribute to the EU's objectives of improving availability, to better define unmet medical/patients' needs, and to ensure "*that patients across Europe can access high-quality treatment and new therapies when they need them*" (Pharmaceutical Strategy for Europe).

#### **3.2. How the objectives will be reached**

Rare Cancers Europe is a partnership that ensures an equal and fair representation of its partners and all decisions are taken based on a consensus approach. Our main mode of operation is "working together in partnership", and we will achieve this through a collaborative approach, following relevant steps, such as:

- Regular cooperation between all stakeholders in the area of rare cancers, who will be a part of the Thematic Network to align on the way forward and the goal to achieve.
- Regular discussions and collaboration among all members of the Thematic Network, to ensure that all stakeholders' views are considered.
- Regular involvement of all members, with the aim of collecting, sharing, and maximizing their unique expertise.
- Scheduling regular Thematic Network calls with the members.
- Dissemination of relevant materials among the rare cancer community, members of the Thematic Network.
- Presentation of the Joint Statement to the rare cancer community via an event.

### **4. Possible networks and partners involved**

All Rare Cancers Europe's partners will be involved in providing their sectoral expertise, along with others who may be interested in being a part of the thematic network. Please find enclosed in attachment the entire list of Rare Cancers Europe's partners. Regarding paediatric cancers, please see separate proposal for a Joint Statement by RCE member SIOPEurope in partnership with CCI-Europe and PanCare.

### **5. Leading organisation**

Rare Cancers Europe (RCE) was established in 2008 to highlight the challenges posed by rare cancers and place the topic on the European policy agenda. It is a partnership comprised of 39 stakeholders, coordinated by the European Society for Medical Oncology (ESMO), and brings together scientific societies, patient and research organisations, healthcare and educational providers, and industry. Since our foundation in 2008, we have been actively involved in driving achievements for rare cancer care by calling on regulators and policymakers to address treatment challenges and improve treatment quality.

### **6. Contact point**

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