



FACTSHEET: RARE CANCERS IN EUROPE

RARE CANCERS

are cancers with an annual incidence of less than

6 PER 100,000 PEOPLE IN EUROPE¹



5.1
MILLION PEOPLE
in Europe live with a rare cancer

RARE CANCERS ARE NOT SO RARE²

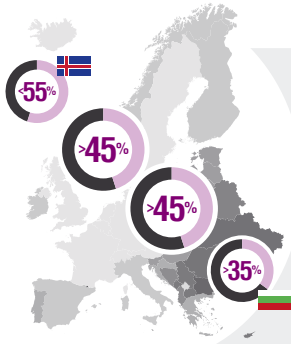
RARE CANCERS

correspond to **650,000 NEW DIAGNOSES ANNUALLY IN EUROPE³**

Therefore, rare cancers represent



24% OF ALL NEW CANCER DIAGNOSES IN EUROPE⁴



The geographical divide is significant, with lower survival values in Eastern European countries (falling all below 45%, down to less than 35% in Bulgaria) than in all others (all above 45%), especially in Northern and Central European countries (up to more than 55% in Iceland)⁵.

63.4%



48.5%

Estimated 5-year relative survival is significantly lower for rare cancers than for their common counterparts (48.5% and 63.4% respectively)⁶.

RARE CANCERS ARE THE RARE DISEASES OF ONCOLOGY: THEY BELONG BOTH TO CANCER AND RARE DISEASES

RARE CANCERS HAVE PARTICULAR SPECIFICITIES AND REQUIRE A UNIQUE POLICY APPROACH TO OVERCOME THEIR CHALLENGES

WHAT ARE THE CHALLENGES POSED BY RARE CANCERS?

1

Late or incorrect diagnosis

2

Lack of access to appropriate therapies and expertise

3

Lack of commercial feasibility in developing new therapies

4

Difficulties in conducting well-powered clinical studies

5

Few available tissue banks

Source: <https://www.rarecancerseurope.org/About-Rare-Cancers/The-Burden-and-the-Challenges-of-Rare-Cancers>

DESPITE THE RARITY OF EACH OF THE 198 RARE CANCERS, THEY REPRESENT ABOUT 24% OF ALL CANCER CASES IN EUROPE, INCLUDING ALL CANCERS IN CHILDREN

¹ <https://pubmed.ncbi.nlm.nih.gov/20824452/>

² [https://www.europarl.europa.eu/RegData/etudes/STUD/2020/642388/IPOL_STU\(2020\)642388_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/STUD/2020/642388/IPOL_STU(2020)642388_EN.pdf)

³ <https://www.rarecancerseurope.org/content/download/294217/5832976/1>

⁴ <https://pubmed.ncbi.nlm.nih.gov/22033323/>

⁵ <https://pubmed.ncbi.nlm.nih.gov/28687376/>

⁶ <https://www.sciencedirect.com/science/article/pii/S147020451730445X?via%3Dihub>



RARE ADULT CANCERS REPRESENT MORE THAN 30% OF CANCER MORTALITY⁷

RARE CANCER AGENDA 2030

In 2016 the European Commission launched the EU Joint Action on Rare Cancers (JARC) with the aim to integrate and maximise efforts of the European Commission, EU Member States, and all stakeholders to advance quality of care and research on rare cancers. In 2019, the JARC came to an end and as its overarching deliverable, produced the Rare Cancer Agenda 2030. Rare Cancers Europe is committed to taking over the JARC legacy, to prioritise rare cancers on the European political agenda.

TEN RECOMMENDATIONS FROM THE EU JOINT ACTION ON RARE CANCERS⁸

- | | |
|---|---|
| <p>1 Rare cancers are the rare diseases of oncology</p> <p>2 Rare cancers should be monitored</p> <p>3 Health systems should exploit networking</p> <p>4 Medical education should exploit and serve healthcare networking</p> <p>5 Research should be fostered by networking and should take into account an expected higher degree of uncertainty</p> | <p>6 Patient-physician shared clinical decision-making should be especially valued</p> <p>7 Appropriate state-of-the-art instruments should be developed in rare cancer</p> <p>8 Regulation on rare cancers should tolerate a higher degree of uncertainty</p> <p>9 Policy strategies on rare cancers and sustainability of interventions should be based on networking</p> <p>10 Rare cancer patients should be engaged</p> |
|---|---|



Rare Cancers Europe (RCE), a 39 partner-strong multistakeholder partnership bringing together scientific societies, patient and research organisations, healthcare and education providers, and the industry. The partnership is committed to tackle rare cancer challenges, to jointly propose multi-disciplinary solutions to improve people's quality of life, and to highlight rare cancers on the European policy agenda.

If you have any questions or want to join us, please write to the Rare Cancers Europe Secretariat at: [@rarecancerseurope@esmo.org](mailto:rarecancerseurope@esmo.org)

Or check out our website: www.rarecancerseurope.org

Follow us on Twitter: [www.twitter.com/_rarecancer](https://twitter.com/_rarecancer)



Joining forces for action

⁷ [https://www.ejcancer.com/article/S0959-8049\(20\)31155-2/fulltext](https://www.ejcancer.com/article/S0959-8049(20)31155-2/fulltext)

⁸ https://jointactionrarecancers.eu/attachments/article/265/Rare_Cancer_Agenda_2030.pdf