

RARE CANCER ADVOCATES NETWORK

A unified approach to the inclusion of childhood cancers and rare adult cancers in National Cancer Control Plans in Europe

1 in 5 cancers is RARE

Incidence of rare cancers is less than 6 per 100,000 people a year. About 5.1 million people live with a rare cancer in Europe.

OBJECTIVE

The Rare Cancer Advocates Network (RCAN) asks that each National Cancer Control Plan (NCCP) in Europe includes dedicated and distinct sections on childhood cancers and on rare adult cancers respectively to address patients' and survivors' various challenges throughout their journey, and foster research for these disease groups. RCAN members have identified a set of **joint patient-centred recommendations** to be included in NCCP for each section on childhood cancers and on rare adult cancers.

Implement dedicated healthcare pathways and mandatory referrals to specialised multidisciplinary Centres of Expertise, or National Networks, and/or European Reference Networks (ERNs)

Improve early detection: educate on warning signs, facilitate access to molecular diagnosis, integrate innovative diagnostic technologies

Implement harmonised preventive measures needed for hereditary cancers/genetic tumour risk syndromes

Ensure access to available best treatments, including innovative therapies and clinical trials at national level or in another European country where needed

Support clinical registries developed by expert centres and European Reference Networks (ERNs)

Develop and support dedicated patient-centred, needs-driven research programmes targeting respectively childhood cancers and rare adult cancers

Provide needs-driven supportive care, psycho-oncology services, and adapted survivorship care planning

Support specialised training programmes intended for health professionals and supportive care providers

Ensure patients, survivors and their families receive the social aid they need. The Right to be Forgotten must be standardised and uniformly implemented

Promote validated information and training programmes intended for patients, survivors and caregivers

Foster European and international collaboration and synergies with other plans.

Childhood cancer and rare adult cancer patient organisations must be involved in the development of NCCP as equal partners