ERN on adult cancers (solid tumours) (ERN EURACAN)

The Surveillance of Rare Cancers in Europe (RARECARE) defines rare cancers as malignant disorders with an incidence of fewer than six per 100,000 per year. They account for around 20-25 percent of all new cancer diagnoses and 30 percent of cancer deaths.

Experts agree that patients with rare cancers should, from initial diagnosis, be referred to certified reference centres. This enables them to benefit from the most up-to-date, multidisciplinary expertise - from effective therapies to evidence-based treatment guidelines - and ensures appropriate care for all patients, regardless of the initial point of access.

EURACAN covers more than 300 rare adult solid cancer types, grouping them into ten domains corresponding to the RARECARE classification and ICD10. The network collaborates closely with patient representatives from European Patient Advocacy Groups (ePAGs) to provide information and perspectives on patients' needs and expectations.

Since its inception, EURACAN has reached 26 EU and EAA countries, aiming to standardise patient management and improve survival rates by generating and sharing best practice tools, and regularly updating diagnostic and therapeutic clinical practice guidelines in collaboration with several scientific societies. The network has developed communication tools in all languages for patients and physicians, while the STARTER project (STarting an Adult Rare Tumour European Registry) is creating a crucial tool for the future - the EURACAN federated registry model.

EURACAN builds on existing networks and successful clinical trials through the European Organisation for Research and Treatment of Cancer (EORTC), the European Neuroendocrine Tumour Society (ENETS), the Connective Tissues Cancer Network (Conticanet) and several previous EU research programmes, including the EURACAN-initiated SPECTA/Arcagen and TRacKING projects.

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