



Rare Cancers – Commission's perspective

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Rare Cancers – Commission's perspective

- Around 4 million people in the EU affected by rare cancers. Rare cancers represent about 22% of all cancer cases diagnosed in the EU each year.
- Objective: to ensure accessibility of all rare cancer patients, including children, to the best knowledge, diagnosis and treatment available.
- Commission's actions:
 - Europe's Beating Cancer Plan
 - EU4HEALTH Programme
 - European Reference Networks

#HealthUnion
#EUCancerPlan

EUROPE'S BEATING CANCER PLAN



- Adopted on 3 February 2022
- New EU approach to cancer prevention, treatment and care
- To tackle the entire disease pathway, from prevention to quality of life of cancer patients and survivors, focusing on actions where the EU can add the most value.

Europe's Beating Cancer Plan

- Four pillars: (1) prevention; (2) early detection; (3) diagnosis and treatment; and (4) quality of life of cancer patients and survivors
- Cross-cutting themes: research and innovation, digital and personalised medicine, reducing inequalities, paediatric cancer
- 10 flagship initiatives and 32 actions - at every key stage of the disease
- Lesson learnt from Covid-19 impact on cancer patient's and care
- 4 billion EUR budget

EU4HEALTH Programme

- Adopted in March 2021 (Regulation (EU) 2021/552)
- €5.3 billion for actions with an EU added value, complementing EU countries' policies and pursuing one or several of EU4Health's objectives
- EU4Health will pave the way to a European Health Union by investing in health priorities, including Europe's Beating Cancer Plan actions and the European Reference Networks

EU4HEALTH Programme

2021 Annual Work Programme: Budget of 312 mil. EUR, out of which 81.5 mil. EUR allocated to cancer actions

- Health promotion and prevention of non-communicable diseases and related risk factors (budget: €18.4 million in total of which €8.4 allocated to cancer).
- Saving lives through sustainable cancer prevention (budget: €13.5 million).
- Improving early detection of cancer (budget: €15.5 million).
- Ensuring access to high standard in cancer diagnosis and treatment (budget: €26.2 million)
- Improving the quality of life for cancer patients, survivors and carers including reducing inequalities in cancer care and childhood cancers (budget: €17.9 million).

European Reference Networks



https://ec.europa.eu/health/ern_en



Key achievements so far

24 ERNs



25 Countries

Affiliated
Partners

Call for new
members

2017

2019
2020

Established structure

- ✓ Clear Legal Basis and Institutional framework
- ✓ Consolidated governance structure and networking capacity
- ✓ EU funding sources available
- ✓ Joint ownership (Member States authorities, patients, health professionals, hospitals, EU institutions)
- ✓ Strong political support (EU) and perceived as a good example of European cooperation
- ✓ 24 Networks started their clinical work with patients

Actions and outcomes

- ✓ Clinical cooperation, **patient cases** discussed virtually (CPMS)
- ✓ Knowledge Generation and development of **training, education and awareness** actions
- ✓ Development and implementation of **clinical practice guidelines**
- ✓ Important number of **scientific publications**
- ✓ Development of **research projects**
- ✓ Support for ERN patient **registries** as part of EHDS



ERNs on rare cancers

ERN EURACAN (Adult Rare and Solid Cancers)

<https://euracan.eu/>

PaedCan-ERN (Paediatric Cancers)

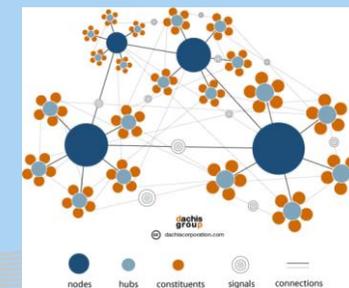
<https://paedcan.ern-net.eu/>

ERN EuroBloodNet (Haematological Cancers)

<http://www.eurobloodnet.eu/>

ERN GENTURIS (Inherited Genetic Disorders)

<https://www.genturis.eu/>





ERNs explicitly mentioned under the **specific objectives** of the Programme for 2021-2027

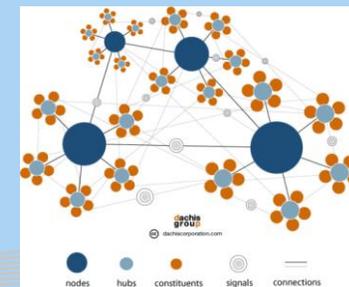
Grants to the ERNs to be awarded without prior publication of calls for proposals (**direct grants**) and may be up to 100 % of the eligible costs (**no co-funding** requirement anymore)

2021 Annual Work Programme:

- Direct Operating Grant to ERN eUROGEN;
- Direct Grant to Orphanet: technical assistance and support for disease codification, knowledge and information sharing;
- Upgrade of the CPMS to a new enhanced modular version and maintenance of the current CPMS until the new one becomes available;
- Virtual ERN and EHDS Academy;
- Framework contract for independent assessment and evaluation bodies for ERNs;
- Service contract for ERN logistic, administrative and secretarial support;
- Analysis of options for administrative simplification for ERN coordination teams.

ERNs: Next Steps

- Manage ERN enlargement and consolidate the ERN system for clinical collaboration
- Support ERN knowledge generation actions
- Support ERN research activities
- Integrate ERNs into national healthcare systems
- Demonstrate the added value of the ERNs: Evaluation and monitoring



ERNs: Next Steps

Demonstrate the added value of the ERNs: Evaluation and monitoring



- Evaluation of Cross-border Healthcare Directive (2011/24/EU), including legal provisions on ERNs and rare diseases cooperation (2021-2022)
- First periodic 5-year evaluation of performance of ERNs and their members (2022-2023)

