



# Joint Action on Networks of Expertise

## Deliverable 15.1

### Recommendations to improve EU cancer care networking in general & specifically for new NoEs

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## DOCUMENT INFORMATION

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<b>Work Package</b>	<b>WP15 – TTF4 The ERN Model</b>
<b>Task</b>	<b>1-3</b>
<b>Deliverable type</b>	<b>Report</b>
<b>Due delivery date</b>	<b>30/09/2024</b>
<b>Actual delivery date</b>	<b>30/09/2024</b>
<b>Dissemination level</b>	<b>Public</b>
<b>Annex version</b>	<b>2</b>

*Deliverable 15.1 is part of the Joint Action "JANE", GA 101075328, which has received co-funding from the European Union under the EU4Health programme*

## REVISION HISTORY

Version	Date of Issue	Author(s)	Brief description of changes
0.1	29/08/2024	Muriel Santoro, Jean-Yves Blay	First draft
0.2	30/09/2024	Venice Hancock	Final draft

## LIST OF ABBREVIATIONS

Abbreviation	Definition
CPMS	Clinical Patient Management System
ERN	European Reference Network
HCP	Healthcare Providers
JA	Joint Action
MS	Member State
NoE	Network of Expertise
TTF	Transversal Task Force
WP	Work Package



## **RECIPIENTS OF THIS DOCUMENT**

This document is addressed to the whole JANE consortium. It is an official deliverable for the project and shall be delivered to the European Commission and appointed experts.

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## 1. Executive summary

This report is the final deliverable of Work Package 15 (WP15), dedicated to the European Reference Network (ERN) Model, also known as Transversal Task Force 4 (TTF) of European Joint Action (JA) JANE. It outlines the working methods and main advances achieved between October 1, 2022 and September 30, 2024 by the WP15 working group under the leadership of Professor Jean-Yves Blay, President of Unicancer, the French Federation of Comprehensive Cancer Centers.

It is structured in three main sections: a description of the work methodology used, the state of play, and recommendations for the seven (7) Networks of Expertise (NoEs) of the next JA (JANE-2).

## 2. Introduction

TTF4's main objective was to assess the current functioning of the ERNs to identify problems, challenges, and solutions associated with EU networking, with a view to suggesting improvement strategies for EU networking in general and specifically for the new NoEs. Four of the 24 ERNs are specifically dedicated to cancers, namely GENTURIS, PAEDCAN, EUROBLOODNET, AND EURACAN.

## 3. Methodology used

### Major stages of development

The TTF had three tasks to perform:

- Task 15.1: Assessment of the ongoing problems and challenges currently encountered by the ERNs on rare cancers
- Task 15.2: Assessment of the ongoing functioning of ERNs on rare cancers
- Task 15.3: Holding of a brainstorming meeting

The TTF working group engaged in **discussions with EURACAN, PaedCan, GENTURIS and EUROBLOODNET** to assess the ongoing challenges faced by ERNs. Four online meetings took place. However, each NoE had to first more clearly define its scope and objectives before embarking on an assessment of the pros and cons of the ERN model.

Moving forward, exchanges with the different stakeholders helped provide clearer understanding of the differences and complementarities between the different types of networks (ERNs on rare

cancer and NoEs). However, **PaedCan and EUROBLOODNET explicitly stated that, at least initially, they felt no need to interact with the NoEs being shaped in JA JANE.**

- 1) The leader of the PAEDCAN network deemed that the activities being shaped by the NoEs had already been developed and were operational at the ERN centers. Moreover, important interactions were already ongoing between EURACAN and PaedCan centers, which are frequently at the same hospital sites.
- 2) EUROBLOODNET specified that the rare haematological conditions treated within the ERN were not all malignant, with malignancies representing about 50% of the total diseases treated. Activities related to local management were not relevant for malignant diseases. Platforms dedicated to preclinical molecular biology models were specific to haematological malignancies and were already present on site. However, one area where future interaction could potentially be explored was that of platforms dedicated to the manufacturing of modified immune cells.
- 3) The leaders of GENTURIS considered that the ERN's specific oncogenetic and diagnostic activity did not require the expertise proposed by NoE, although interaction could potentially be explored in the future, particularly in relation to the prevention and development of targeted agents.

**Discussions on the ERN model thus focused on EURACAN**, which is in charge of approx. 22% of all solid cancers, with a growing proportion of them related to molecular characterization, which is regularly used to identify new entities with specific natural histories. Prof. Jean-Yves Blay coordinates both the ERN and this TTF4 within Joint Action JANE. He also leads WP10 on the Hi-tech Medical Resources NoE.

## Stakeholder involvement

The **coordination team** and all **WP leaders** were invited to the online meetings held during the JA. The representatives of the four ERNs on rare cancer contributing to the discussions were:

- EURACAN for rare solid tumours:
  - Jean-Yves Blay
  - Muriel Rogasik
- PaedCan for paediatric cancers:
  - Ruth Ladenstein
  - Zoltán Dobai

- GENTURIS:
  - Nicoline Hoogerbrugge
  - Nicoline Geverink
- EuroBloodNet for haematological cancers:
  - Pierre Fenaux
  - Mariangela Pellegrini
- ePAG:
  - Kathy Oliver

## Info/data sources used

- In-house:

This report is complementary to the report of Task 4.1 of WP4 on Sustainability entitled, “Mapping and analysis of existing networks: comparative framework”.
- External sources:

Three out of four ERNS on rare cancers (all but PaedCan) shared detailed Power Point Presentations.

## 4. State of play

### Main challenges expressed by EURACAN

**EURACAN** shared with the TTF4 team the **main challenges** they faced as an existing EU network on cancer:

- Budget limitations
- Involvement of all Member States (MS) in supporting EURACAN’s work, through specific support for rare cancer networks at the national level and for the endorsement of Health Care Providers (HCPs).
- The Clinical Patient Management System (CPMS) provided by the EC to all ERNs needs to be customized to match the needs of each individual ERN and is currently only open to EU health professionals (but not clinical research assistants, for instance).
- Maintaining the involvement of members and ePAGs.
- Heavy administrative burden
- Lack of legal status to enable collaboration between EURACAN and industry



- Difficulties in organizing cross-border healthcare, when needed
- Issues with guideline development
- Individual HCP resources (human and financial) needed to participate in EURACAN
- Lack of integration of ERNs into national healthcare systems (currently being addressed by JA JARDIN)

**EURACAN can be of great interest for NoEs and NoEs can be of great interest for EURACAN for multiple reasons:**

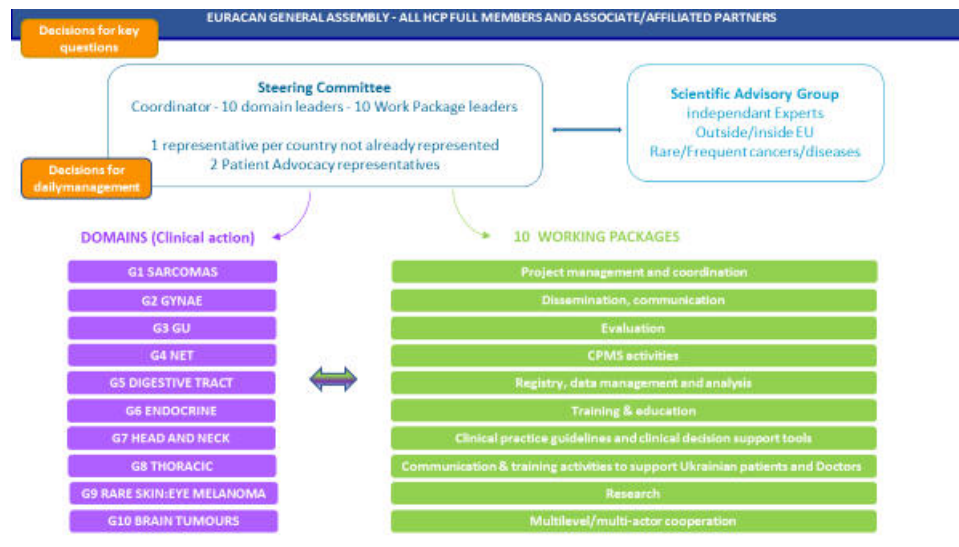
- EURACAN treats 20% of all cancers (rare adult solid cancers causing 30% of deaths)
- Rare cancers have unmet diagnostic and therapeutic needs
- EURACAN disseminates rare cancer expertise in a global EU network to serve underserved cancer patients
- EURACAN is a network in which to deploy innovative organizational strategies, e.g., centralized patient management to improve survival
- EURACAN HCPs are in need of support for emerging diagnostic and therapeutic activities, in a context of sparse resources in numerous medical specialties
- EURACAN HCPs are ideal places to develop innovative clinical research strategies for rare adult solid cancers (devices, medications, cell therapies, etc.)
- ERNs are an ideal setting in which to develop new paradigms in earlier lines due to limited routine options
- Importantly, many of EURACAN's HCPs are also HCPs of other ERNs, and despite limited interest in the NoE activities, interactions are more likely to occur in this context.

## Topics of interest for the NoEs

The **main transversal topics of interest identified by the NoEs based on the EURACAN** experience are as follows:

- governance
- funding
- implementation in MS, role of MS, and integration of ERNs in national healthcare systems
- impact evaluation and sustainability
- education and digital learning
- communication and dissemination (including multilingualism)
- multicentric research in Europe and regulations in MS

▪ **Governance:**



**EURACAN governance**, including partner status and meeting framing and frequency, is clearly defined in the **Consortium Agreement (Terms of Reference)**. By signing this document, which also provides operating rules and status, all partners (HCPs, scientific societies, rare cancer networks, ePAGs) become **accountable** in the network. It can be regularly updated.

The EURACAN **Steering Committee** gathers around fifty professionals, including the leaders of each rare cancer domain, WP leaders and MS representatives (when a MS is not represented in any other group), a patient representative, and the EURACAN Project Manager and Coordinator. On behalf of the Board, EURACAN's Steering Committee makes all the decisions related to the network during **monthly meetings**, whereas all the partners can discuss unforeseen topics or activities at the **Members' annual Meeting**. The minutes of meetings are shared on **the online collaborative platform (ECP)**. The **Scientific Advisory Board** is a group of around ten international experts from outside the EURACAN network.

▪ **Health Care Providers & ePAGs:**

In the EURACAN network, HCP and ePAG representatives have rights and obligations. There is at least one patient representative per cancer domain in the network. They participate in guidelines development, communication activities, education and training. Dedicating a bimonthly meeting only to patient representatives has been highly beneficial in advancing the work of the network.

- **Implementation in Member States, role of Member States and integration of ERNs in national healthcare systems:**  
EURACAN is not formally participating in the new JA JARDIN launched in April 2024. The network sporadically contributes to discussions.
- **Impact evaluation means and sustainability:**  
The rare cancer networks in general, and the ten EURACAN rare cancer domains in particular, have expertise in developing clinical practice guidelines for rare conditions in a context of limited scientific information. Data collection in real-life setting registries has been implemented in several domains and MS. These tools are essential for assessing the impact of the networks (NoE and ERN) in real life settings, such as in nationwide and regional populations. This approach was found to be particularly operational when MS were nationally supporting the reference network for rare cancer. A similar approach should be undertaken for the NoEs working with ERNs, ideally with dedicated EU support for these interactions
- **Education and digital learning:**  
With the support of EURACAN's associated partners, ESO, ESMO, ESTRO, ESSO and patient advocacy groups, educational material has been prepared and is ready to be shared with the NoEs. Although temporarily disrupted by COVID, teaching courses on rare cancers have been organized regularly in person and more recently virtually. These tools will be useful to disseminate the activities and knowledge of NoEs.
- **Communication and dissemination (including multilingualism):**  
EURACAN has held national meetings to communicate locally about the network in each participating MS. Educational material, brochures for patients and general practitioners, translated in all EU languages have been prepared. This effort enabled centers and ePAG representatives to be better informed.
- **Multicentric research in Europe and regulations in Member States**  
Rare cancers are becoming paradigmatic models for the development of novel therapies in cancer. They require multinational studies, and common methods. ERNs and NoEs are ideal structures to develop this research. This will also promote further work on cross-border health care, which is paramount to ensuring equal access of all EU citizens to this research.

## 5. Recommendations

**The main recommendations for NoEs from the EURACAN experience are the following:**

- 1) Invite all ERNs to participate in the different NoEs, even if they do not initially express any specific interest
- 2) Set up funding mechanisms to facilitate connections between the future NoEs and the various cancer-related ERNs
- 3) Use existing guidelines and develop those that are missing, provide information materials, and teaching courses. Give rare cancer patients better access to the JANE-2 NoEs, nationally and internationally
- 4) Facilitate cross border health care for diagnosis, MDT participation, and treatment
- 5) Set up a simple governance for NoEs
- 6) Work with the European Health Data Space (EDHS) to create registries
- 7) Measure and regularly publish the activities of NoEs, and interactions between NoEs and ERNs