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# Mature ERNs Recommendations targeted at Member States

CNA and CEF

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**Our vision is for a mature ERN system that leaves no person living with a rare disease in uncertainty regarding their diagnosis, care and treatment**

# OUR VISION OF A MATURE ERN SYSTEM

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**Areas of work of the ERNs: Care, Research, Knowledge sharing, Training**

2

**Common services that ERNs need to achieve their goals**

4

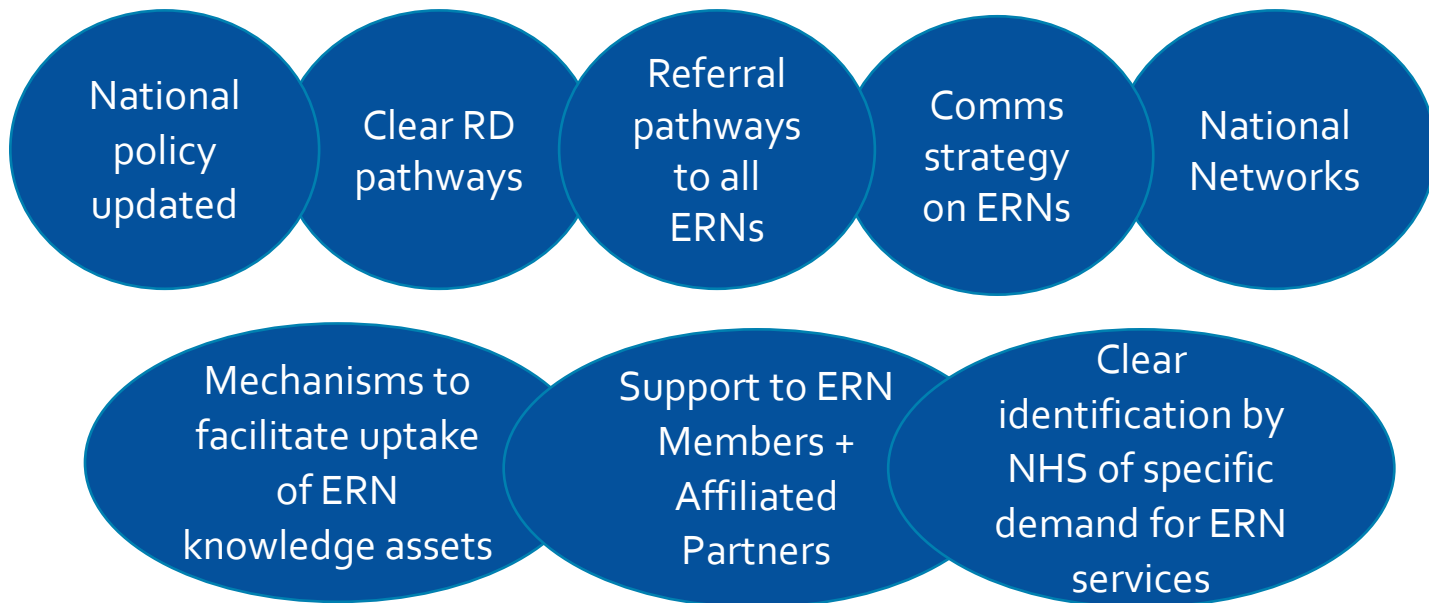
**ERNs Funding, Governance, Scope and Structure**

5

**What needs to be in place at national level**

# What needs to be in place at the national level

1. All MS have a process to identify and designate national centres of expertise.
2. All MS have an annual work plan to strengthen their RD centres of expertise competency and capacity to fulfil the vision of the EUCERD Recos on Quality of CoE.
3. There is a common guidance regarding endorsement criteria and process to join the ERNs and all MS conform to it.
4. All MS have implemented their roadmap to integrate the ERNs into their national health systems ....



# Mature ERN system - Recommendations for Member States representatives

PART 2

HEALTHCARE SYSTEMS ARRANGEMENTS TO MEET RARE DISEASE POPULATION CARE NEEDS

PART 3

STRUCTURE AND SCOPE OF THE EUROPEAN REFERENCE NETWORKS

PART 4

OUR VISION OF A MATURE ERN: CARE, KNOWLEDGE SHARING, TRAINING, RESEARCH



1. Support and strengthen Centres of Expertise capacities. **Target deadline 2025**
2. National workshops on integration should be organised to stimulate local discussions and activities. **Target deadline 2021**
3. Common guiding principles for endorsement and define national designation process of CoE (*endorsement to join the ERNs falls short of the benefits of national designation of CoE*) **Target deadline 2022**
4. Enable networking of CoE at national level. **Target deadline 2025**
5. Develop national care pathways and referral pathways to the ERNs. **Target deadline 2022**



1. Through BoMS - organise international collaboration with other clinical network structures. **Target deadline 2022**



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Consolidate the ERN model of cross-border healthcare.

- Roadmap to develop the suite of digital tools and services to consolidate the 'Networked Care' model and expand the clinical services **Target deadline 2025**
- Funding and reimbursement mechanisms **Target deadline 2030**

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Enable access to highly specialised healthcare, breaking down the barriers and connecting the care chain from ERNs to the local health systems. **Target deadline 2025**

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Accelerate the implementation of best practice at local level.

- BoMs, ERN members and ERN hospital managers should agree on how to facilitate uptake and implementation of patient pathways, CPGs and CDSTs at local level - **Target deadline 2022**
- Validate the methodologies for the development of ERNs CPGs and other CDSTs and clinical pathways to 'pre-approve' ERN tools. **Target deadline 2025**

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Enable innovative training in supra-specialised care as part of the international collaboration strategy. **Target deadline 2025**

R

Secure sustainable funds for the Clinical Research Networks. **Target deadline 2025**

What can **YOU** do to support the  
integration of ERNs ?

**Prioritise**

**Partner**

**Plan**





# Prioritise

integrate ERNs in your advocacy agendas for the next 5 years  
(*ERNs in all areas of action*)

# Partner

with the ePAG advocates (& other ERN champions) + have regular exchanges + build shared leadership

# Plan

create a realistic plan based on your needs and the reality of your health systems



## ERNs promise to share...

Knowledge sharing at scale will only succeed in an inclusive ecosystem, where ERNs coordinate with the national healthcare systems and are fully integrated with local services. **We expect to see real collaboration between the right experts**, supported by effective tools and **we want the ERNs to be the first-stop, go-to place for trusted information on all rare diseases.**

## ERNs promise to care...

Member States should ensure that ERNs' services are accessible to any patient at any moment. Patients from any country should get referred to the best European experts to get proper diagnosis and treatment. The signature of care under an ERN, should be care based on the leading knowledge and experience of a multidisciplinary team, empowering patients in their care. **ERNs may contribute to improve our quality of life by providing good standards of care and guidelines, but health authorities, hospital managers and clinicians must ensure that these are implemented at local level** and that people living with a rare disease can access the right care.

## ERNs promise to cure...

Our hope is that **ERNs will allow rare disease patients to secure a diagnosis within 6-12 months from coming to medical attention.** At the same time we expect the ERNs to accelerate the development and uptake of treatment options for rare diseases, as they integrate European-wide clinical research and care settings, supported by registries.



# RECOMMENDATIONS TO MINISTRIES OF HEALTH EXPLAINED IN DETAIL

Back-up slides

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## Support and strengthen Centres of Expertise capacities

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Member States should *strengthen their CoEs competencies and capacities and invest the resources required to fulfil the vision set out in the EUCERD Recommendations* on Quality of Centres of Expertise and increase or adjust the skill mix of their health workforce to address the needs of its rare disease patient population.

**Target deadline: 2025**

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## National workshops on integration should be organised to stimulate local discussions and activities

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The *European Commission should support Member States* to implement the actions outlined in the ERN BoMs Statement on Integration of ERNs into national health systems, specifically by *funding national multi-stakeholder workshops*, with the national patient community, clinical leads and national authorities, to facilitate discussions and actions on integration into each of the EU27 national health systems.

**Target deadline: 2021**

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## Endorsement to join the ERNs falls short of the benefits of national designation of CoE

Define *common guiding core principles for the endorsement* of their national centres of expertise to participate as HCPs members in the ERNs.

### Target deadline 2022

Define a *process to identify and designate national centres of expertise* where there is none; which integrates the opinion and needs of the patient community, through its representatives being a key stakeholder in the prioritisation and decision making process.

Continue to develop the existing national designation process, with a *quality improvement approach*, ultimately to progress towards a model based on benchmarked health outcomes of clinical services, similar to the one adopted in Sweden.

### Target deadline: 2025



## Enable networking at national level

Member States should create, in partnership with the rare disease patient community and other key stakeholders, ***national rare disease reference networks***, thereby extending the ERNs locally through a 'hub-and-spoke' model; update their RD National Plans or Strategies and engage with clinicians and patients to set them up and drive their implementation. Countries with a decentralised health system and regional networks of CoE, should put in place a strong coordination mechanism to ensure that all people living with a rare disease in these countries get the same quality care, regardless of where they live.

**Target deadline: 2025**



## Develop national care pathways and referral pathways to the ERNs

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Each Member State should have clear and effective transition pathways that support the smooth transition of affected individuals to adult services and to the ERNs, providing continuity of care. They should develop referral pathways and national care pathways and identify shared care arrangements between ERNs members and local care services

**Target deadline 2022**

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## Organise international collaboration with other clinical network structures

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The ERN Board of Member States should develop *strategic guidelines on international collaboration* and define the role and remit of an “ERN international partner”. It should define a common strategy on ERNs international collaboration and partnership, defining the rights and obligations of international partners under an ERN, as well as investing resources in joint projects, infrastructure and initiatives.

**Target deadline: 2022**

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## Consolidate the ERN model of cross-border healthcare

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The EC, BoMS, ERN hospital managers and the ERNs IT WG should agree on a digital roadmap to develop progressively the *suite of digital tools and services to consolidate the 'Networked Care' model* and expand the virtual consultation to a range of clinical services through different channels.

### Target deadline: 2025

The EC should support Member States to develop a fair, transparent pricing model and establish a *funding mechanism for adequate and proportionate reimbursement of virtual care and other ERN services* under a Networked care model, thereby safeguarding the ERNs sustainability.

### Target deadline: 2030

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## Enable access to highly specialised healthcare, breaking down the barriers and connecting the care chain from ERNs to the local health systems

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All Member States should endorse a hospital as a **National Coordination Hub** as the central referral management centre to enable access to ERNs specialist advice.

**Target deadline 2025**

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## Accelerate the implementation of best practice at local level

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The BoMs, ERN members and ERN hospital managers should agree on how to *facilitate uptake and implementation* of patient pathways and clinical decision support tools at local level.

### Target deadline 2022

Member States, after engaging with the ERNs and professional societies, should validate the ERN methodologies for the development of clinical practice guidelines and other CDSTs and clinical pathways to *'pre-approve' ERN tools* developed under these methodologies as ready for implementation within the ERNs member hospitals.

### Target deadline: 2025

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## Enable innovative training in supra-specialised care as part of the international collaboration strategy

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The ERN Board of Member States should develop the ERNs strategy for International Collaboration with other centres of expertise and networks and *include training and educational activities between international partners to learn from other networking initiatives.*

**Target deadline: 2025**

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## Support the ERNs-Clinical Research Networks through sustainable funding

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The Coordination and Support Action funded by the H2020 programme to support the creation of Clinical Research Networks should lay the ground to set up the core services of a common research support structure covering 4 domains: clinical research, data management, engagement and dissemination and administrative support. *Additional funding will be required to gradually deploy the core services so that they will be fully operational by 2025.* Any funding mechanism shall ensure the independence of the ERNs to establish their own strategic research agenda.

**Target deadline: 2025**

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# Thank you!

