



# Joint Action on Integration of ERNs into healthcare systems

## Reaching out to national authorities

6 October 2022

CNA monthly call

[EURORDIS.ORG](https://eurordis.org)

# A Joint Action on ERN integration into national healthcare systems

## 2022 Work Programme of EU4Health

- **HS-g-22-16.02 Direct grants to Member States' authorities: support ERNs integration to the national healthcare systems of Member States**
- This action supports the integration of the ERNs into the national healthcare systems that will ensure long term sustainability of the ERN system, enable the Member States to strengthen the resilience of their national health system and improve accessibility of the ERN system to rare diseases patients and their health professionals at national, regional, and local level with the aim to enable access to timely diagnosis and appropriate treatment.
- Budget: 11.2 Mill. EUR



# What is a Joint Action ?

- A Joint Action is **primarily for Member State Authorities** (“Competent Authorities”)
- Addresses “**high policy level**” demands and challenges to provide **solutions with high public interest** within the European Union
- The primary objective of the Joint Action on ERN Integration is **for the MS authorities to develop their national strategies, solutions and infrastructures** (“integration”)
- Fulfilment of outcome indicators is one key element for a positive evaluation of the JA

# What will the JA ERN integration do?

- **National care pathways that interface with ERNs**
- **National reference networks**
- **Undiagnosed diseases programmes**
- **Data governance models** to ensure interoperability of national/local data structures and ERN data structures (CPMS, ERN registries...)
- **Quality assurance models** to recognise -amongst other- the production of ERNs such as CPG (clinical practice guidelines)
- **National support solutions for HCPs** part of ERNs at national level

## In detail ...

(a) development of **proposals for national governance models** and practices for rare and complex disease centres and care pathways that are fully interoperable with ERNs and **recommendations to ensure interoperability between national and local data structures and ERN data structures** (including ERN registries and CPMS), taking fully into account the ongoing work on the European Health Data Space and the joint action 'Towards the European Health Data Space' (TEHDAS)

(b) development of a proposal for **national quality assurance models** for rare and complex diseases and **recommendations for the organisation of national care pathways for rare and complex diseases** that interface with ERNs, including processes to recognise at the national level evidence-based resources such as ERN Clinical Practice Guidelines.



(c) development of a **proposal for the referral systems to the ERNs**, including guidelines for **incorporation of CPMS advice into patients' care** and recommendations on **CPMS reimbursement models**;

(d) preparation of a blueprint for a **national dissemination and communication strategy on the ERNs** and patient empowerment targeted at multi-stakeholder communities at national level;

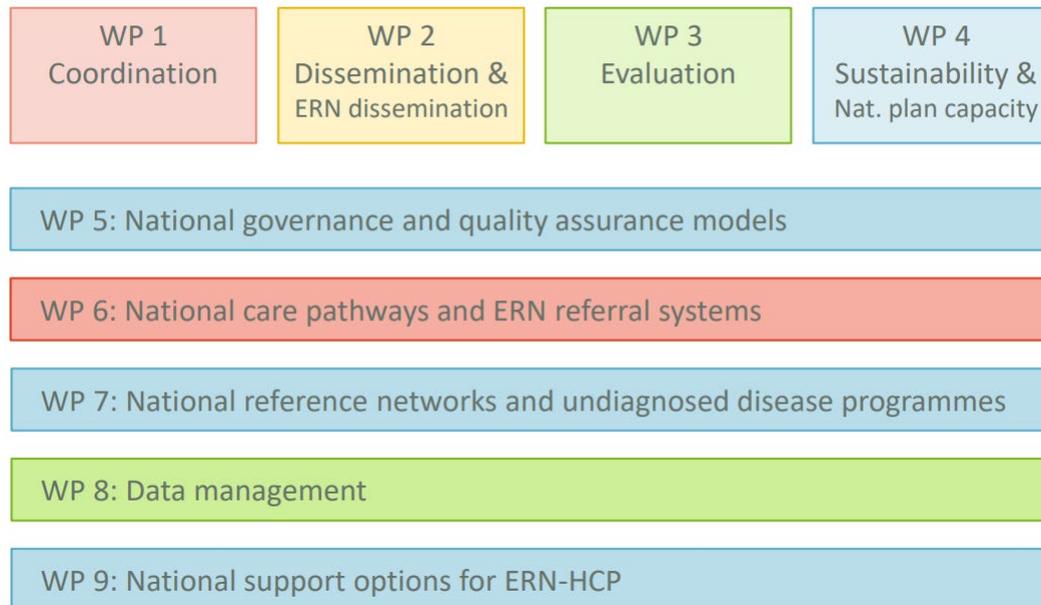
(e) preparation of an **overview of good practices of mechanisms to provide support to the healthcare providers that participate in the ERNs at the national level** and develop a set of specific recommendations on how the Member States should support their healthcare providers participating in the ERN system;

(f) support for **capacity building in the Member States**, for national rare disease plans and **setting up of the national networks** on rare disease and their integration with the ERNs.

# Possible structure (under discussion!)

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## (Potential) WPs of the Joint Action (TIV):



## TIMELINE

Deadline for the nomination of CA	01.09.2022
Hands-on workshop with the Nominated CA	13-14-15.09.2022
Invitation to submit a proposal	15.09.2022
Deadline for the submission proposal	17.01.2023
Evaluation Committee Meeting	28.03.2023
Letters to (un)successful applicants	15.05.2023
Estimated signature GA	15.08.2023

# What else we know so far

- **ALL 27 EU Member States** have accepted to participate in the ERN integration JA ! Big success!
- Member States have designated a **Competent Authority** that will be the lead in their country within the Joint Action.
- Some Member States have also nominated **Affiliated Entities**
- **It is still possible for MS to nominate Affiliated Entities.**

**Your organisation could be an Affiliated Entity!**

for ex. **Rare Disease Sweden**

# What to do ?

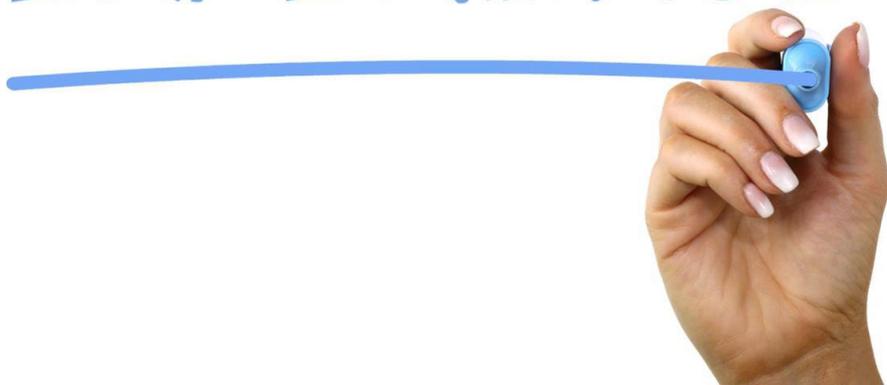
To become an Affiliated Entity in your country:

- **Contact your national Competent Authority !**
- Whom to contact? It varies across countries! Ministries of Health, national health boards, university hospitals ...
  - If **unsure, please contact us and we will provide contact the information**
- **NOW !** This needs to be done now because decisions are being taken these days: national Competent Authorities are now working on the draft proposal for the Joint Action (and they have until 17 January)
- **What does it mean to be an Affiliated Entity in terms of financial commitments ?** Please reach out to the Competent Authority (CA) if you want to find out : CA are the ones that have the answer!

# Remarks from the Coordinator

- » **Top expertise** regarding **health policies** and **national healthcare planning** is key for any lead function
- » **Close feedback loops to National Health Authorities** (and further stakeholders highly relevant in national healthcare planning) are key for any lead function, but to some degree also for all participants in a work package
- » **Close and longstanding link** between the Nominated Authorities and the **relevant Health Authorities** is key

EXPERIENCE



QUESTIONS

