



# TOGETHER ReCONNET

a European Registry Infrastructure  
for data harmonization in Rare  
and Complex Connective Tissue  
and Musculoskeletal Diseases



European  
Reference  
Network

for rare or low prevalence  
complex diseases

Network  
Connective Tissue  
and Musculoskeletal  
Diseases (ERN ReCONNET)

INSTITUTE  
OF MANAGEMENT



Sant'Anna  
School of Advanced Studies - Pisa



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# TogethERN ReCONNET:

**TogethERN ReCONNET**, the European Registry Infrastructure for data harmonization in **rare and complex connective tissue and musculoskeletal diseases** (rCTDs), aims at integrating all existing

and newly developed **registries** on rCTDs across Europe and providing a sufficient number of cases that will help in better understanding the natural course of the diseases, characterizing diseases in the early phases, mapping disease history, identifying different

disease **phenotypes** and distinguishing predictive variables for disease outcomes. Information gathered through the **long-term follow-up** of

a large number of patients will facilitate a better assessment of the clinical problems of patients with rCTDs and may help in determining an **improved management** of these patients and healthcare planning in general.

The creation of a **European Registry Infrastructure** on rCTDs is crucial to improve clinical practice and disease understanding in the field of rCTDs and the

**ERN ReCONNET** offers the natural framework for the development of this project, providing an

established Network of rCTDs experts, patients and patients representatives, health economists, policy maker and quality assessors.

**for data harmonization in rare and complex**





# a European Registry Infrastructure

**TogethERN ReCONNET** will represent a European Registry Infrastructure integrating both existing and novel registries within the project timeframe. In detail, **TogethERN ReCONNET** aims at:

- Promoting a harmonised data collection approach on rCTDs in Europe;
- Integrating and implementing existing rCTDs data;
- Improving disease knowledge, clinical management and care provided to rCTDs patients;
- Facilitating rCTDs research, post-authorisation studies and cost-effective healthcare planning.



## **TogethERN ReCONNET**

integrates and improves the existing knowledge in the field of rCTDs, addressing the needs of different stakeholders, supporting the improvement of the disease knowledge and management, current and future policies on the treatment and management of rare diseases.

- WP1 - Coordination of the project
- WP2 - Dissemination of the project
- WP3 - Evaluation
- WP4 - Registry governance and sustainability
- WP5 - Creation of the registry
- WP6 - Identification of the economic dimension
- WP7 - Implementation of the registry
- WP8 - Registry quality assurance and training
- WP9 - Preliminary output of the registry



## **TOGETHERN ReCONNET is a Consortium between**



**ERN  
ReCONNET**



**Sant'Anna School of  
Advanced Studies**



**Italian National  
Institute of Health**

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