



























# The Clinical Patient Management System ERN ReCONNET

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## The Clinical Patient Management System - ERN ReCONNET-

RIIP Paris 5-6 octobre 2023



for rare or low prevalence complex diseases

#### Network

Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET)

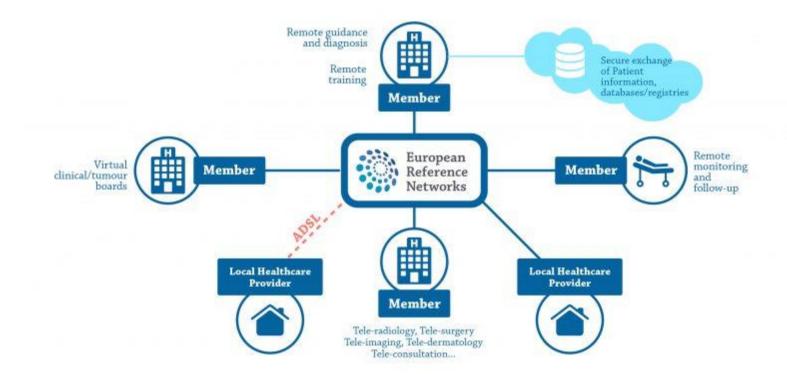






## What is the Clinical Patient Management System?



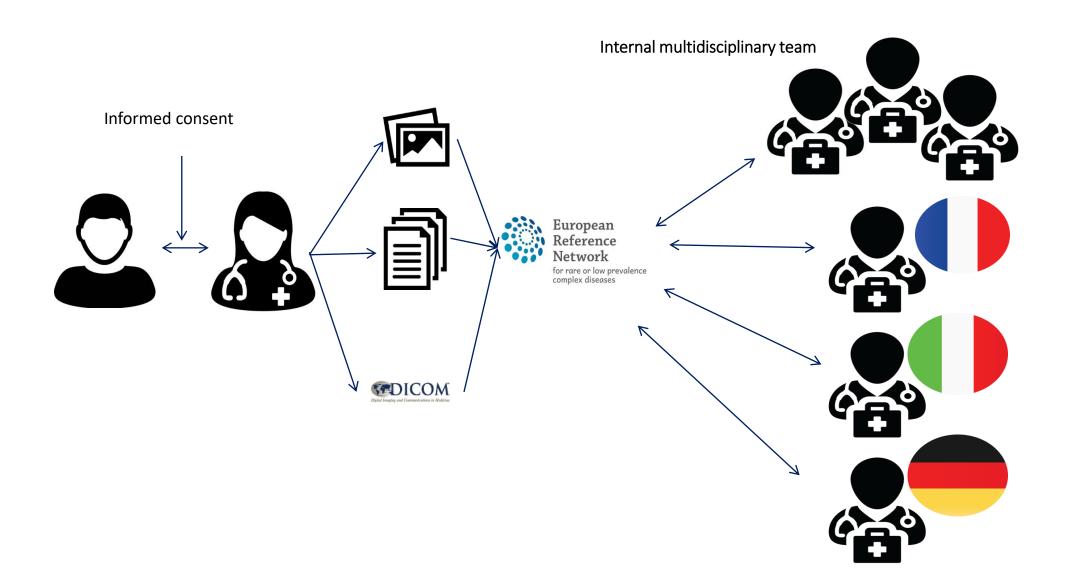


The Clinical Patient Management System (CPMS) is a **secure** web-based application to support European Reference Networks (ERNs) in the **diagnosis and treatment** of rare or low prevalence complex diseases or conditions **across national borders**.

## Added values for the CPMS

- The CPMS provides a crucial tool for rare disease patients enabling healthcare professionals across Europe to discuss clinical cases in a safe environment.
- CPMS is a revolutionising tool to provide capacity for cross-border virtual consultations, and research activities.
- Bringing together highly specialised healthcare providers in complex, rare or low prevalence diseases the CPMS can contribute to the diagnose, treatment and followup of rare diseases patients.

## With the CPMS



#### ★ ReCONNET - Connective Tissue and Musculoskeletal Diseases USER:

## **2** Dashboard























Request Inbox		2		
Panel ID	Date	Centre	Request	
#1704	11 20			
#2250	02 20			
#2325	07. 20			

Panel Invitations			
Panel ID	Date	Nickname	
#2219	11/ 20		

Urgent Panels	27
There are no urgent panels.	

My Panels	27
You are not leading any panels.	

Contributing I	ontributing Panels				
Panel ID	Date		Nickname		
#1704	11	2020			
#1984	24	2021			
#2422	28	2021			
#1981	23	2021			
#2196	28	2021			

#### ROLE:

Member Tasklist		1
Nickname	Task	
#1704	Please review the Patient data that has been provided for this Panel.	
#2219	You have been invited to join a Panel.	

Requests for Additional Data	2.7°
You have no outstanding requests for more data.	

My Meetings	2 <sup>N</sup>	
You are not scheduled to attend any meetings.		

My Proposed Meetings	2
You have not proposed any meetings.	

ERN Panels Managed	2
You are not managing any panels.	

## ERN ReCONNET National Hubs



for rare or low prevalence complex diseases

#### Network

Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET)

FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.





## **ERN ReCONENT National Hub?**



Network
Connective Tissue
and Musculoskeletal
Diseases (ERN ReCONNET

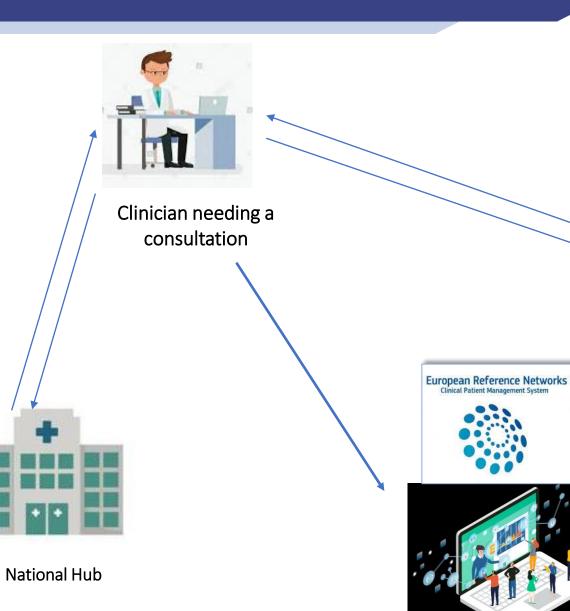
Country	ERN ReCONNET HCP	HCP Representative	Responsible
Belgium	University Hospital Ghent	V. Smith	Yves Piette
France	Hôpitaux Universitaires de Strasbourg	T. Martin	Thierry Martin
Germany	Universitätsklinikum Düsseldorf	M. Schneider	Gamal Chehab
Italy	Azienda Ospedaliero Universitaria Pisana	M. Mosca	Alessio Lunardelli
Netherlands	University Medical Center Utrecht	J. van Laar	Julia Spierings
Portugal	Centro Hospitalar de Lisboa Central, EPE	M. Antunes	Eunice Patarata
Romania	County Emergency Clinical Hospital Cluj	S. Rednic	Cristina Pamfil
Slovenia	University Medical Centre Ljubljana	T. Avcin	Tadej Avcin

## Brief overview of the ERN ReCONNET National Hubs



Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET)

Dissemination at local and national level



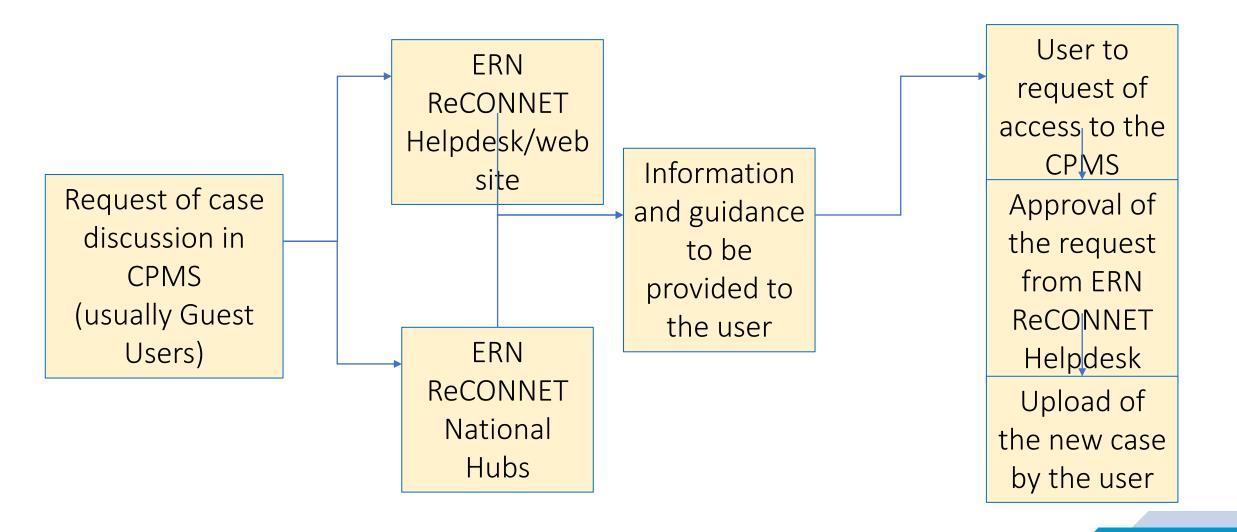


ERN ReCONNET webiste and ERN ReCONNET Helpdesk

## Support the central Helpdesk in the management of the CPMS request



Connective Tissue and Musculoskeletal Diseases (FRN ReCONNET)



### **ERN ReCONNET National Hubs website**



Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET)



### **Role of National Hubs**



#### Contact point

#### The National Hub

- serves as national contact point to support the usage and the dissemination of the CPMS at national/local level
- serves as national reference contact for specialists, general practitioners and other healthcare professionals in each country in order to provide information on the functioning of the platform
- contributes to connecting even the more remoter healthcare providers and patients to highly specialised services of the ERN RECONNET



DISEASES

A PATIENTS

**ACTIVITIES** 

₼ NETWORK

NEWS COVI

OVID-19

□ CONTACT

#### Promotion and dissemination

#### The National Hub

- enables a wider diffusion of the CPMS potentialities and of the CPMS usage, making the CPMS service available for a larger number of patients, even for those living in disadvantaged areas, far from reference centers;
- communicates in the local language and helps in overcoming language barriers;
- ensures that the CPMS is presented in national/local conferences, meetings and web-conferences (at least two times a year);
- creates a leaflet on the CPMS in national language.



Belgium	>
France	>
Germany	>
Italy	>
Netherlands	>
Portugal	>
Romania	>
Slovenia	>