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Background and Objective

Set up under the European Union (EU) directive on patient’s rights in cross-border healthcare (2011/24/EU), the European Reference Networks (ERNs) on rare diseases are aimed to connect healthcare providers across different European Countries to tackle complex and rare medical conditions that require highly specialized treatment. The ERN ReCONNET, constituted in March 2017 and endorsed by the European League Against Rheumatism (EULAR), was approved for rare and complex connective tissue diseases (CTDs) and it aims at developing a framework for the delivery of high quality, innovative, sustainable and equitable standard of care and practice for better access to care of European patients with CTDs. Objective of our work is to report the results of activities of ERN ReCONNET achieved during the first year of the project.

Methods

ERN ReCONNET is composed of 26 Healthcare Providers (HCP) from 8 European Countries: Belgium, France, Germany, Italy, The Netherlands, Portugal, Romania, and Slovenia (figure 1). Patients involvement in the Network is one of the key aspects of the project and at present, the ERN ReCONNET European Patients Advocacy Groups are highly involved in all the activities of the ERN, including the participation as full members of the Steering Committee.

The diseases covered by ERN-ReCONNET are divided in three main thematic areas:

Table with 3 columns: Rare Connective Tissue diseases, Complex Connective Tissue diseases, Hereditary Connective Tissue diseases. Lists various conditions like Systemic Sclerosis, Sjögren Syndrome, Ehlers Danlos Syndromes, etc.

The scientific activities of ERN-ReCONNET officially started in 2017 with the kick-off meeting that was held in Pisa (Italy) from 26th to 28th March.

Results

The scientific activities of the first year of ERN ReCONNET were mainly focused on existing clinical practice guidelines (CPGs). Dedicated working groups have been constituted for each disease (figure 2).

The first phases were aimed at identifying the scientific publications, selecting them by evaluation of titles and abstracts, and by reviewing the full texts. More than 6.000 publications have been screened. The second step was to review critically the articles according to the principles of the AGREEII flow-chart (figure 3).

This work allowed to identify CPGs for the majority of the diseases covered by ERN ReCONNET, as well as unmet needs, in particular for the rarest diseases (IgG4 related diseases, relapsing polychondritis, mixed CTD).

Good progress has also been made in the field of the information technologies, in which ERN ReCONNET was mainly focused on the use of the Clinical Patients Management System web-platform, designed for the interactive discussion of difficult clinical cases proposed from specialists from different EU countries.

Conclusions

The ERN ReCONNET will significantly improve the clinical approach to rare and complex CTDs, promoting an improvement of the quality of the specialized care provided to patients, of the activity of the physicians, the empowerment of the patients sharing expertise and promoting the interaction among EU HCPs. All these activities are addressed to create a highly specialized network, in which the knowledge travels rather than the patient.

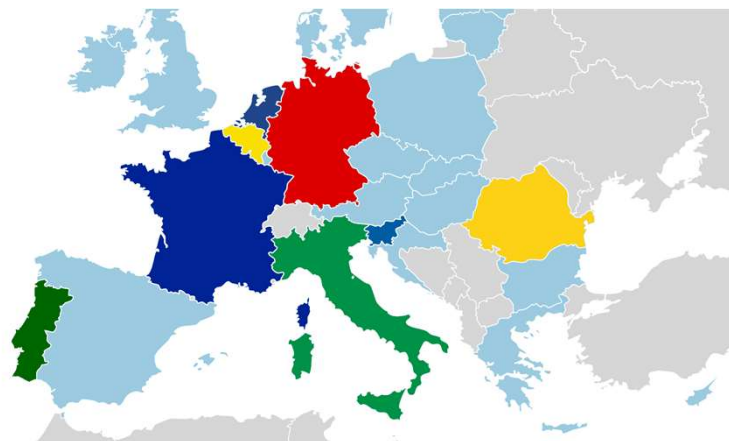


Figure 1: Countries represented in ERN ReCONNET

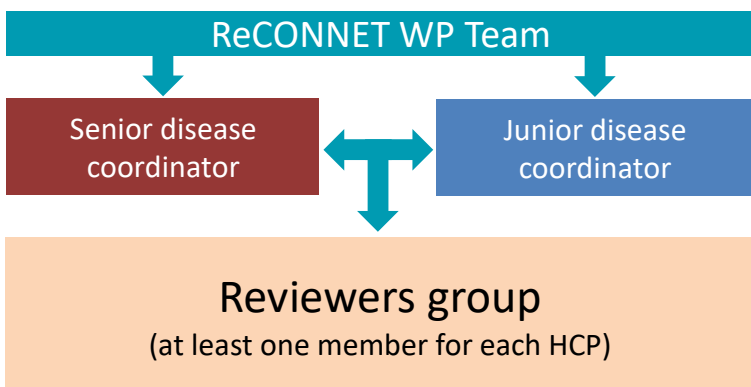


Figure 2: working group for each disease covered by ERN-ReCONNET

- Step 1 Identification of existing guidelines
STEP 2 Evaluation of existing guidelines with AGREE II tool
STEP 3 Report on guidelines assessment during ERN ReCONNET meeting at ACR 2017
STEP 4 Unmet needs identification
STEP 5 Final report

Figure 3: Summary of WP3 activities for guidelines assessment

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