



Do the ERN networks and their members meet quality requirements related to the achievement of their objectives?

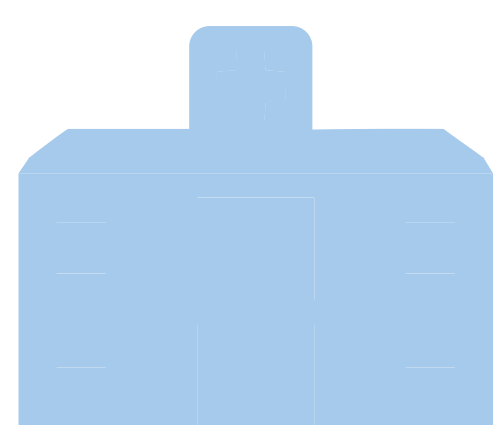
The goal of the evaluation process is to improve care for patients with rare diseases by ensuring networks and healthcare providers demonstrate compliance with the EU legislative requirements:

- Helping to improve the delivery of high-quality healthcare
- Improving the patient and family experience
- Facilitating medical training and research
- Identifying and disseminating best practices in the field

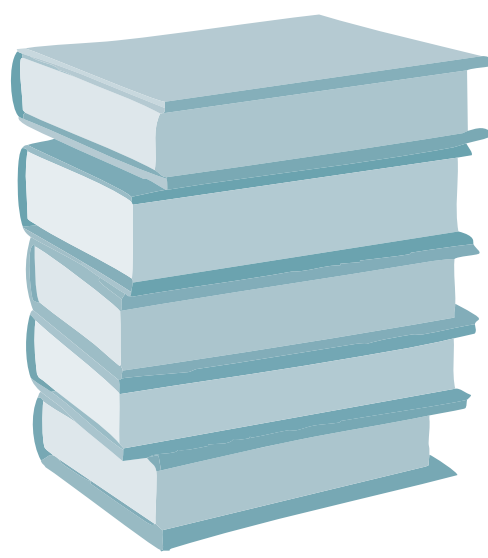
Work Plan

	Continuous monitoring	HCP Performance indicators system	ERN evaluation
Who is evaluated?	HCPs (clinical center)	HCPs (clinical center)	- ERNs as network - HCPs as institution - HCPs as clinical center
By whom?	ERN-RND	ERN-RND	Independent evaluation body
Reported to who?	European Commission	Its members	European Commission
Frequency	Annually	Annually	Every 5 years
Goals	Follow evolution over time and build a quality improvement system	- Track HCP contributions to ERN-RND activities - Inform the members	Determinate the worth of the work and actions developed by the ERNs and their HCPs during the first 5 years of activity
Consequences		Request to write and implement an improvement plan if contributions below threshold	Membership terminated if evaluation not satisfactory
Format	Mostly identical for all ERNs + some customized questions	Customized for every ERN	Identical for all ERNs

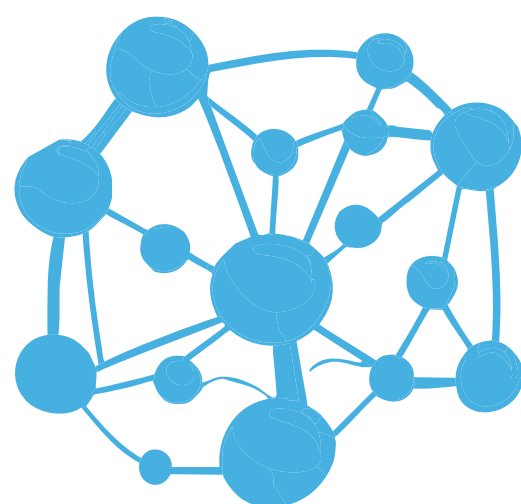
Results for 2024



Access to clinical advice, diagnosis and treatment:
7439 new patients referred to HCPs



Equal access to high quality healthcare services:
10 clinical practice guidelines and clinical decision support tools developed, updated or appraised



Better patient outcome:
46 CPMS outcome reports

Reinforcement of clinical research:
20 clinical trials, 14 observational studies, 51 publications acknowledging ERN-RND, 8116 patients in the registry



Knowledge dissemination:
18 webinars presented by experts, 1 winter school (10 speakers, 150 participants from 34 countries), 3 short-exchange programmes

5-year eavaluation
ERN-RND as network: satisfactory
27/31 HCPs: satisfactory
4 HCPs: satisfactory after improvement plan
Next time: stronger focus on HCPs' rare diseases expertise



European
Reference
Network
for rare or low prevalence
complex diseases

Network
Neurological Diseases
(ERN-RND)



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