

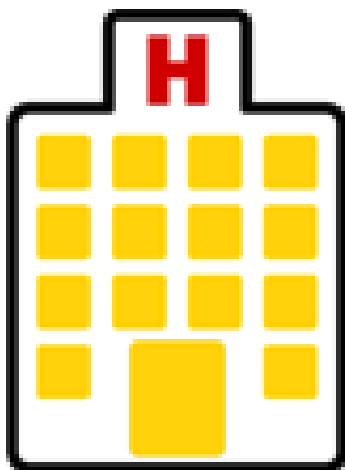
## ERN-RND Monitoring Data of 2021

## Basic set of 18 ERN Indicators

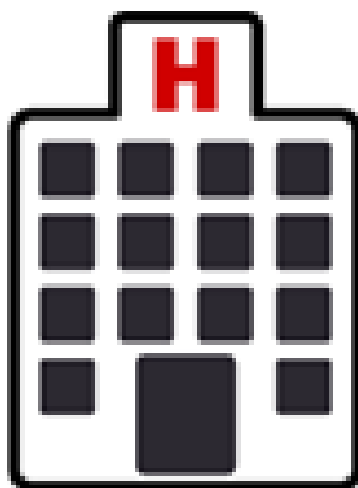
<b>Objective 1</b>	<b>To ensure that ERNs are operational</b>
1.1	Number of Member States with Health Care Providers as full members or affiliated partners in the ERN
1.2	Number of full members of the ERN
1.3	Number of affiliated partners of the ERN
1.4	Number of patient organisations represented in the ERN
<b>Objective 2</b>	<b>To improve access to clinical advice, diagnosis, treatment and follow-up of patients</b>
2.1	Number of new patients referred to the Health Care Providers participating in the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN
2.2	Number of patients entered into CPMS by the ERN during the reporting period
<b>Objective 3</b>	<b>To optimise patient outcomes by combining healthcare professionals' skills &amp; resources used</b>
3.1	Number of panels reviewed by the ERN with an outcome report produced during the reporting period.
3.2	Time taken to provide multidisciplinary clinical advice between referral to the ERN and multidisciplinary clinical advice. 3.2.a - Non-urgent cases: days (median) 3.2.b - Urgent cases: days (median)
<b>Objective 4</b>	<b>To increase the capacity of professionals to recognize and manage cases of rare and complex conditions and diseases within the scope of the ERN</b>
4.1	Number of education/training activities not accruing higher education credits aimed at healthcare professionals delivered by the coordination teams or HCP members of the ERN
4.2	Number of formal educational activities that are accruing higher educational credits aimed at healthcare professionals delivered by the coordination teams or HCP members of the ERN
<b>Objective 5</b>	<b>To reinforce clinical research in the field of rare and complex conditions and diseases by collecting data and carrying out research activities</b>
5.1	This indicator covers different activities involving ERN members in at least two Member States: 5.1.a - Number of Clinical Trials 5.1.b - Number of Observational prospective studies / Observational cohort or case-control studies / Number of case-series studies
5.2	Number of accepted peer-reviewed publications in accredited scientific Journals regarding disease-groups falling within the scope of the ERN and acknowledging the ERN.
<b>Objective 6</b>	<b>To ensure that patients referred to ERNs have equal access to high and quality healthcare services</b>
6.1	Number of Clinical Practice Guidelines and other types of Clinical Decision Making Tools, adopted for diseases within the scope of the ERN during the reporting period
6.2.	This indicator is split into two sub indicators, for diseases within the scope of the ERN: 6.2.a - Number of new Clinical Practice Guidelines written by the ERN and released during the reporting period 6.2.b - Number of other types of new Clinical Decision Making Tools (clinical consensus statements or consensus recommendations), written by the ERN and released during the reporting period
<b>Objective 7</b>	<b>To guarantee that knowledge is spread outside the ERN so that more people can benefit from the ERN activities</b>
7.1	Number of congresses/conferences/meetings at which the ERN activities and results were presented
7.2	Number of individual ERN website hits

indicators of ERN-RND for 2021	Numbers
<b>Indicator 1: To ensure that ERNs are operational</b> → number of HCPs	41
<b>Indicator 2: To improve access to clinical advice, diagnosis, treatment and follow-up of patients</b> → number of new patients <ul style="list-style-type: none"> <li>seen for the 1st time by the HCPs</li> <li>in the Clinical Patient Management System</li> </ul>	7063 12
<b>Indicator 3: To optimise patient outcomes by combining healthcare professionals' skills &amp; resources used</b> → number of days in panels <ul style="list-style-type: none"> <li>number of days until panel closure in the Clinical Patient Management System</li> </ul>	289
<b>Indicator 4 : To increase the capacity of professionals to recognize and manage cases of rare and complex conditions and diseases within the scope of the ERN</b> → number of educational activities <ul style="list-style-type: none"> <li>without Higher Educational Credits</li> <li>of which were webinars</li> <li>with Higher Educational Credits</li> </ul>	69 23 56
<b>Indicator 5: To reinforce clinical research in the field of rare and complex conditions and diseases by collecting data and carrying out research activities:</b> → number of trials <ul style="list-style-type: none"> <li>Clinical Trials</li> <li>Observational Trials</li> <li>Publications with PubMedID</li> </ul>	1 25 115
<b>Indicator 6 : To ensure that patients referred to ERNs have equal access to high and quality healthcare:</b> → number of Clinical Guidelines <ul style="list-style-type: none"> <li>Clinical Guidelines adopted, written</li> <li>Decision Making Tools written</li> </ul>	- 2
<b>Indicator 7 : To guarantee that knowledge is spread outside the ERN so that more people can benefit from the ERN activities:</b> → number of engagements with community and public <ul style="list-style-type: none"> <li>presentations at Conferences</li> <li>visitors at <a href="http://www.ern-rnd.eu">www.ern-rnd.eu</a></li> </ul>	82 3269

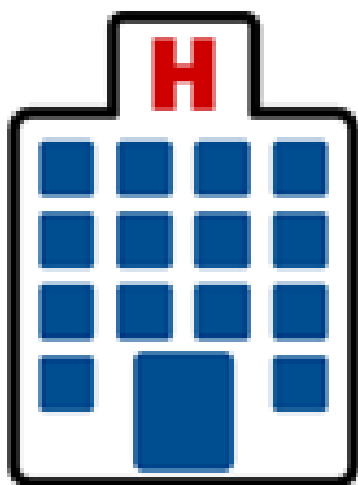
## Indicator 1: To ensure that ERNs are operational



41 Health Care Providers  
in ERN-RND in 2021



31 full members



10 affiliated members

## Indicator 2: To improve access to clinical advice, diagnosis, treatment and follow-up of patients

7063 new patients  
in total in 2021



12 patients entered into  
Clinical Patient  
Management System in 2021

## Indicator 3: To optimise patient outcomes by combining healthcare professionals' skills & resources used



4 panels reviewed by the ERN-RND with an outcome report produced in 2021

## Indicator 4: To increase the capacity of professionals to recognize and manage cases of rare and complex conditions and diseases within the scope of the ERN

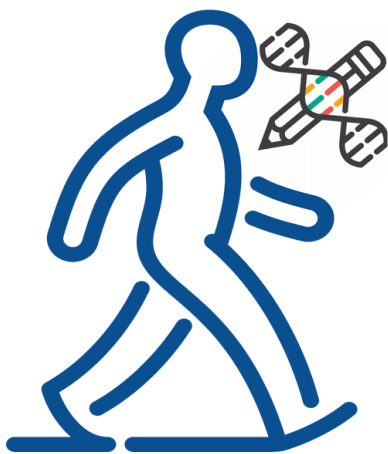
69 educational activities without accruing Higher Educ. Credits in 2021, including 23 webinars



56 educational activities accruing Higher Educ. Credits in 2021



## Indicator 5: To reinforce clinical research in the field of rare and complex conditions and diseases by collecting data and carrying out research activities



1 Clinical Trial at Radboud University Medical Center, Nijmegen, NL

25 Observational Trials at ERN-RND members

115 publications listed in PubMedID and acknowledging ERN-RND in 2021





## Indicator 6: To ensure that patients referred to ERNs have equal access to high and quality healthcare



2 clinical decision making  
tools written in 2021

More:

<https://www.ern-rnd.eu/disease-knowledge-hub/>



## Indicator 7: To guarantee that knowledge is spread outside the ERN so that more people can benefit from the ERN activities

82 presentations given by  
members at conferences  
in 2021 and acknowledging ERN-RND



3269 Website Hits on:  
[www.ern-rnd.eu](http://www.ern-rnd.eu) in 2021



**Thank you for your interest  
in ERN-RND!**

**to contact us, please send an  
E-Mail to: [info@ern-rnd.eu](mailto:info@ern-rnd.eu)**