

### Evaluation section III No 10- List of monitoring indicators

We requested the highlighted 4 indicators from you. The Coordination Office submitted the other indicators. Unfortunately, we can not provide you the numbers of these indicators. You are free to indicate as many indicators as applicable.

	<b>Indicator</b>
<b>1</b>	<b>To ensure that all 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>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 <ul style="list-style-type: none"> <li>• New patients/ full member</li> <li>• New patients/ affiliated partners</li> <li>• New patients total</li> </ul>
2.2	Number of patients entered into CPMS by the ERN during the reporting period <ul style="list-style-type: none"> <li>• By guests</li> <li>• By full members</li> <li>• By affiliated partners</li> <li>• <b>Total</b></li> </ul>
<b>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. <p>Urgent panels</p> <ul style="list-style-type: none"> <li>• Guest</li> <li>• Full members</li> <li>• Affiliated Partners</li> <li>• <b>Total</b></li> </ul> <p>Non-urgent panels</p> <ul style="list-style-type: none"> <li>• Guest</li> <li>• Full members</li> <li>• Affiliated Partners</li> <li>• <b>Total</b></li> </ul> <ul style="list-style-type: none"> <li>• <b>Total</b></li> </ul>
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) <ul style="list-style-type: none"> <li>• Guest</li> <li>• Full members</li> <li>• Affiliated Partners</li> <li>• <b>Average</b></li> </ul>
3.2.b	Urgent cases: days (median) <ul style="list-style-type: none"> <li>• Guest</li> <li>• Full members</li> <li>• Affiliated Partners</li> <li>• <b>Average</b></li> </ul>

	<b>Indicator</b>
<b>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 <ul style="list-style-type: none"> <li>• Activities</li> <li>• HCPs</li> </ul>
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 <ul style="list-style-type: none"> <li>• Activities</li> <li>• HCPs</li> </ul>
<b>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	<b>Number of Clinical Trials</b> <ul style="list-style-type: none"> <li>• Trials</li> <li>• HCPs</li> </ul>
5.1.b	<b>Number of Observational prospective studies/ Observational cohort or case-control studies/Number of case-series studies</b> <ul style="list-style-type: none"> <li>• Trials</li> <li>• HCPs</li> </ul>
5.2	<b>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> <ul style="list-style-type: none"> <li>• Publications</li> <li>• HCPs</li> </ul>
<b>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>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	<b>Number of congresses/conferences/meetings at which the ERN activities and results were presented</b>
7.2	Number of individual ERN website hits

<b>8</b>	<b><i>Complex and long-term indicators which need further</i></b>
8.1	<i>Level of patient satisfaction – To be developed</i>
8.2	<i>Health Care Provider Compliance to Clinical Guidelines – To be developed</i>