

Continuous monitoring

Rationale

- ▶ “The ERNs need to demonstrate that the networks are delivering services and functioning, but simultaneously - and of particular importance, in terms of longevity - are **adding value** compared to what exists”

Continuous Monitoring of ERNs

ERN Continuous Monitoring and Quality Improvement System (ERN CMQS)

Set of ERN core indicators (18)

Version v.1



ERN Continuous Monitoring Working Group of the ERN Coordinators Group &
the Board of Member States

Brussels 12 December 2018

How did it come about?

- ▶ 10 FPAs were analysed for the initial set of criteria
- ▶ Monitoring Working group established 41 criteria, then reduced it to **18 common performance indicators** to be collected across ERNs
- ▶ First phase - performance monitoring online system goes live to collect 18 common indicators
- ▶ Second phase - ERNs to devise performance indicators specific to their disease area. Including network specificities and addressing outcomes (clinical & non-clinical)

Timeline for quarterly reporting in 2019

- ▶ **February to 31 of March:** data collection of the available information of years *2017 and 2018*
- ▶ **1st April to 30 April:** data collection of months of *January, February and March 2019* .
- ▶ **1st July to 31 July:** data collection of months of *April, May and June 2019*
- ▶ **1st October to 31 October:** data collection of months of *July, August and September*
- ▶ **1st January to 31 January 2020:** data collection of months *October , November and December 2019* and consolidation and *validation of year 2019* data.

Performance indicators

Nº	Indicator	Definition
Obj 1	To ensure that ERNs are operational	
1.1	Within an ERN, the number & percentage of Member States with full Health Care Providers as members	<i>Within a particular ERN, the total number of Member States with at least one full Health Care Provider member within that ERN, also shown as a percentage of the total number of Member States with the EEA covered by Directive 24/201 (currently 29).</i>
1.2	Number of Health Care Providers represented in the ERN	<i>The total number of full Health Care Providers within the ERN.</i>
1.3	Number of affiliated partners (AP) represented in the ERN	<i>The total number of affiliated partners (APs) within the ERN.</i>
1.4	Number of patient organisations represented in the ERN meetings	<i>The total number of recognised patient organisations ¹represented within ERN meetings as agreed by the ERN Board.</i>

Performance indicators - patient care/CPMS

Obj 2	To improve access to clinical advice, diagnosis, treatment and follow-up of patients within the ERNs	
2.1	Total number of new patients referred to Health Care Providers with diseases / conditions that fall within the scope of the ERN	<i>The total number of new patients referred to the ERNs' Health Care Providers within the specified timeframe whose disease/condition falls within the codes listed².</i>
2.2	Number of patients entered into CPMS (total volume)	<i>The total number of unique patients entered into CPMS within the specified timeframe for that ERN.</i>
Objective 3	To optimise patient outcomes by combining healthcare professionals' skills & resources used	
3.1	Number of patients entered into CPMS and reviewed by the ERN (a panel case review)	<i>The total number of patients who have been entered into CPMS within the specified timeframe and whose case is subsequently reviewed by a panel that consists of at least three experts or for bilateral consultation between two experts.</i>
3.2	Delay to provide multidisciplinary clinical advice - non-urgent cases: days (median) between referral to ERN and multidisciplinary clinical advice	<i>The days (expressed by the median) for the time period specified between the date of enrolment of a new patient to CPMS³ and the date of issue of multidisciplinary clinical advice⁴ (i.e. panel closure) from the created panel for that same patient, where at least three experts have participated or for bilateral consultation between two experts.</i>

Performance indicators - education & training

Objective 4	To increase capacity of professionals to recognize and manage cases of rare and complex conditions and diseases within the scope of the ERN	
4.1	Number of educational webinars aimed at healthcare professionals delivered by the ERN	<i>The total number of educational webinars⁵ aimed at healthcare professionals created and delivered on an appropriate platform by the ERN within the specified time period.</i>
4.2	Number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organised by the ERN	<i>The total number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organised by the ERN within the specified time period.</i>

Performance indicators - Clinical trials & guidelines

Objective 5	To reinforce clinical research in the field of rare and complex conditions and diseases by collecting data and carrying out research activities	
5.1	Number of Clinical Trials or Observational prospective studies (with > 1 Member State and Health Care Provider within the ERN)	<i>The total number of Clinical Trials or Observational Prospective Studies within the specified time period that involve at least two Health Care Providers of two different Member States within the ERN.</i>
5.2	Number of accepted peer-reviewed publications in scientific journals regarding disease-groups within the ERN and which name the ERN	<i>The total number of accepted peer-review publications in scientific journals regarding disease-groups within the ERN and within the specified time period. Publications should be PubMed accredited scientific journals and involve as major contributors at least two Health Care Providers of two different Member States within the ERN, and which specifically name the ERN.</i>
Objective 6	To ensure that patients referred to ERNs have equal access to high and quality healthcare services	
6.1	Number of Clinical Practice Guidelines adopted for diseases within the scope of the ERN	<i>The total number of Clinical Practice Guidelines (CPG)⁷ adopted for diseases within the scope of the ERN, according to evidence based recognised methodology.</i>
6.2	Number of new Clinical Practice Guidelines written by the ERN	<i>The total number of new Clinical Practice Guidelines (CPG)⁸ developed by the ERN for diseases within the scope of the ERN where no guidelines existed previously, according to evidence based recognised methodology.</i>

Performance indicators - dissemination

Objective 7	To guarantee that knowledge is spread outside the ERN so that more people can benefit from the ERN activities	
7.1	Number of congresses/ conferences/ meetings at which the ERN activities and results were presented	<i>Within the specified time period, the total number of congresses/ conferences/ meetings at which the ERN activities and results were presented via a dedicated slot in the programme/agenda.</i>
7.2	Number of individual ERN website hits	<i>The total number of page views including both the homepage of the website and the "child" pages.</i>
Objective 8	Complex and long-term indicators which need further development	
8.1	Level of patient satisfaction	<i>To be developed</i>
8.3	Health Care Provider Compliance to Clinical Guidelines	<i>To be developed</i>