Continuous Monitoring of ERNs

ERN Continuous Monitoring and Quality Improvement System (ERN CMQIS)

ERN core indicators

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(Data collection of October 2021 and March 2022)

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

Version	Date	Comments
7.3	21.09.2020	Revision of indicators 3.1, 4.1, 4.2, 5.1, 5.2, 6.1, 7.1 Data collection of October 2020 (reporting period: Jan-Jun 2020)
7.3.1	14.10.2020	Brief summary of changes. Work in progress
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7.4.1	01.03.2021	Work in progress Table of contents, minor rewordings,
7.4.2	08.07.2021	Work in progress Revision of indicator 5.1 by Monitoring Working Group
7.4.3	15.07.2021	Work in progress Further revision of indicator 5.1
7.5	07.09.2021	Editorial review Data collection of October 2021 (reporting period: Jan-Jun 2021)
7.5.1	15.09.2021	Corrected typo on indicator 1.3, discovered during the Monitoring Webinar of Oct 2021 Data collection of October 2021 (reporting period: Jan-Jun 2021) Data collection of March 2022 (reporting period: Jan-Dec 2021)

Contents

Part I - ERNs intervention areas and specific objectives

General organisation and coordination

Objective: To ensure that ERNs are operational and successfully carry out their organisational activities.

Patient Care

Objective: To improve access to clinical advice, diagnosis, treatment and follow-up of patients within the ERNs. Geographical and disease coverage.

Multidisciplinary approach and sharing of knowledge within the ERN

Objective: To optimise patient outcomes by combining skills of healthcare professionals involved and resources used

Education and Training

Objective: To increase capacity of professionals to recognize and manage cases of rare or low prevalence complex diseases and conditions within the scope of the ERN

Contribution to research and innovation

Objective: To reinforce clinical research in the field rare diseases and complex conditions by collecting data and carrying out collaborative research activities

Clinical guidelines

Objective: To ensure that all patients referred to ERNs have access to high quality healthcare services

Communication and dissemination within the scope of the ERN activities

Objective: To guarantee that knowledge and expertise is spread outside the ERN so that more people can benefit from the ERN activities.

In all the intervention areas, the indicators not coming directly from DG SANTE need to be validated by the publication of relevant evidence on the ERN website

Part II - Basic set of 18 ERN Indicators

Objective 1	**To ensure that ERNs are operational**	
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	
Objective 2	**To improve access to clinical advice, diagnosis, treatment and follow-up of patients**	
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	
Objective 3	**To optimise patient outcomes by combining healthcare professionals' skills & resources used**	
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)	
Objective 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**	
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	
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	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.	
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 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	
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	
7.2	Number of individual ERN website hits	
Objective 8	**Complex and long-term indicators which need further development**	
8.1	Level of patient satisfaction	*To be developed*
8.2	Health Care Provider Compliance to Clinical Guidelines	*To be developed*

Part III - Definitions

1	General organisation and coordination	
1.1	Number of Member States with Health Care Providers as full members or affiliated partners in the ERN	**Definition:** The number of Member States within the EEA covered by Directive 24/201 with at least one Health Care Provider participating as full member or affiliated partner in the ERN.
	Source: DG SANTE (ERN Service Directory)	
1.2	Number of full members of the ERN	**Definition:** The number of Health Care Providers participating as *full member* in the ERN.
	Source: DG SANTE (ERN Service Directory)	
1.3	Number of affiliated partners of the ERN	**Definition:** The number of Health Care Providers participating as *affiliated partner* in the ERN.
	Source: DG SANTE (ERN Service Directory)	
1.4	Number of patient organisations represented in the ERN	**Definition:** The number of patient associations represented by one or more persons actively involved in the ERN. Patients may work within an ERN in many different ways to capture their voices and their needs.
	Source: ERN data collection **Evidence**: A list of the patient associations involved in the ERN published on the ERN Website	

2	Patient Care
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
	Definition: The total number of new patients attending the ERNs' Health Care Providers for the first time during the reporting period, whose disease or condition falls within the scope of the ERN[1], whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.
	Source: ERN data collection
2.2	Number of patients entered into CPMS
	Definition: The number of unique patients entered into CPMS during the reporting period.
	Source: DG SANTE (CPMS)

1 The disease should be confirmed at the moment of the data inclusion by using the same codes as those specified in the ERNs disease-area breakdowns. Depending on the particularities of some diseases, patients still under diagnosis process could be included as referred patients.

3	Multidisciplinary approach and sharing of knowledge within the ERN
3.1	Number of panels reviewed by the ERN with an outcome report produced during the reporting period
	Definition: The total number of panels reviewed by at least two experts and for which an outcome report is produced during the reporting period.
	Source: DG SANTE (CPMS)
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)
	Definition: For the panels that have produced an outcome report during the reporting period: number of days from the date of start of the panel in CPMS to the date of issue of the outcome report (not the date of the closure of the panel) where at least two experts have participated.
	Source: DG SANTE (CPMS)

4	Education and Training
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.
	Definition: The total number of unique education/training activities **not accruing higher education credits** aimed at healthcare professionals and/or patients, created by the ERN coordination team, HCP members, Affiliated Partners, ePAGs/Patient Organisations/Representatives of the ERN and delivered during the reporting period. Can be online or physical presentations, courses, educational webinars, and/or videos delivered by the ERN.
	Source: ERN data collection **Evidence:** A list of the activities not accruing higher education credits, including links to the online ones, published on the ERN website.
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.
	Definition: The total number of unique education/training activities **accruing higher education credits**, certified by a formal educational body, aimed at healthcare professionals and/or patients, created by the ERN coordination team, HCP members, Affiliated Partners, ePAGs/Patient Organisations/Representatives of the ERN and delivered during the reporting period. Can be online or physical presentations, courses, educational webinars, and/or videos delivered by the ERN.
	Source: ERN data collection **Evidence:** A list of the activities accruing higher education credits, including links to the online ones, published on the ERN website.

5	Contribution to research and innovation
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 / Case-series studies
	Definitions: 5.1.a) The number of unique clinical trials that involve ERN members from two different Member States and acknowledge the ERN, either ongoing or finalized during the reporting period. 5.1.b) The total number of unique observational prospective studies (including academic and Industry driven studies), observational cohort studies, case control studies or case-series studies that involve ERN members from two different Member States and acknowledge the ERN, either ongoing or finalized during the reporting period.
	Source: ERN data collection **Evidence:** 5.1.a) A list of the unique ongoing Clinical Trials, acknowledging the ERN, registered in a recognized clinical trials registry like the ClinicalTrials.gov and published on the ERN Website. 5.1.b) A list of the unique studies, acknowledging the ERN, and published on the ERN Website, either ongoing or finalized during the reporting period.
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.
	Definition: The total number of unique peer-reviewed publications accepted for publication in scientific journals during the reporting period regarding disease-groups falling within the scope of the ERN. Publications should be PubMed accredited scientific journals and involve as major contributors at least two Health Care Providers from two different Member States within the ERN, and which include an explicit acknowledgement of the ERN such as *"This work is generated within the European Reference Network for…" or "This work is supported by the European Reference Network for…"*
	Source: ERN data collection **Evidence:** A list of unique publications accepted by accredited scientific journals during the reporting period, published on the ERN Website. The list can be provided following any of the recognized Science Citation Indexes like Google Scholar, ORCID, Web of Science, Scopus, etc.

6	Clinical guidelines
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.
	Definition: The number of Clinical Practice Guidelines[2] and other types of Clinical Decision Making Tools[3], such as clinical consensus recommendations for disease areas within the scope of the ERN not developed by the ERN but that were formally endorsed and adopted by the ERN Board and are publically available (e.g. on the ERN website).
	Source: ERN data collection **Evidence:** A list of Clinical Practice Guidelines and other types of Clinical Decision Making Tools not developed but **adopted** by the ERN during the reporting period, published on the ERN Website.
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, in progress or finalized 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, in progress or finalized during the reporting period.
	Definition: The number of Clinical Practice Guidelines (CPG) and Clinical Decision Support Tools (CDST: clinical consensus statements or consensus recommendations), developed by the ERN, involving at least two Health Care Providers from two different Member States within the ERN. They should acknowledge the ERN, for diseases within the scope of the ERN where no guidelines existed previously and be according to an evidence based recognized methodology. The new CPGs or CDST can be in progress or finalised during the reporting period.
	Source: ERN data collection **Evidence:** The list of Clinical Practice Guidelines and other types of Clinical Decision Making Tools published on the ERN Website and using the ERN logo.

7	Communication and dissemination within the scope of the ERN activities
7.1	Number of congresses/conferences/meetings at which the ERN activities and results were presented
	Definition: The total number of congresses/conferences/meetings at which the ERN activities and results were presented via a dedicated slot in the programme/agenda, acknowledging the ERN, during the reporting period.
	Source: ERN data collection **Evidence:** The list of congresses/conferences/meetings published on the ERN Website and with links to the individual events.
7.2	Number of individual ERN website hits
	Definition: The total number of page views including both the homepage of the website and any child page.
	Source: ERN data collection **Evidence:** Statistics page of the ERN website.

2 Clinical practice guidelines are statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options. (*cfr. Clinical Practice Guidelines We Can Trust. Robin Graham, Michelle Mancher, Dianne Miller Wolman, Sheldon Greenfield, and Earl Steinberg, Editors; Committee on Standards for Developing Trustworthy Clinical Practice Guidelines; Institute of Medicine 2011*).

3 A clinical consensus statement is the end product developed by an independent panel of (at least 3) subject matter experts convened specifically to perform a systematic review of the available literature, for the purpose of understanding a clinically relevant issue or surgical procedure. It offers specific recommendations on a topic. Compared to Clinical Practice Guidelines and Clinical Practice Recommendations, Clinical Consensus Statements undergo a less rigorous peer review process.

8	Complex and long-term indicators which need further development	
8.1	Level of patient satisfaction	To be developed
8.2	Health Care Provider Compliance to Clinical Guidelines	To be developed

Part IV - Clarifications and examples

Indicator 1.4 - Number of patient organisations represented in the ERNs

To have a clearer idea of the participation of patients in the ERN, the following types of involvement should be, where possible, counted and reported in the comments box of the monitoring data collection IT tool.

Examples of the types of active participation in an ERN network (and therefore should be counted towards the total number) are:

Number of Patient associations represented:

1) as voting members of the Board of the Network (please count the patient associations represented that are entitled to vote in the decision-making bodies governing the ERN);
2) as Leader (or co-Leader) of specific activities of the ERN project (please count the patient associations represented and involved in working groups, work packages, tasks, etc. as Leader or co-Leader);
3) as members of the panel involved in the production of clinical practice guidelines (please count the number of patient associations represented during the process of creation of new clinical practice guidelines or adaptation - both as adaptation to the countries and adaptation in lay versions - of existing clinical practice guidelines);
4) as co-designer of activities related to the Network project (please count the number of patient associations represented and involved in the main activities of the ERN, such as co-design of surveys, training and education, website contents, dissemination materials, etc.).
5) that are actively involved in translation of ERN documents, evaluation of patient information, and other ERN documents, including proposing changes (to ensure they are suitable for patients or parents)

Participation of patient associations in other type of meetings directly related with the work of a given network (ePAGs meeting, sectorial or thematic patient associations meetings, etc.) should also be counted.

- To clarify that this indicator does not aim to count the number of meetings, nor the type of meeting in which patient representatives are participating.
- Such active involvement would include their participation in advisory groups, committees, and any other bodies within the organization of the network.
- This participation would normally be reflected in the membership and their attendance at the meetings (physical and virtual) of that body.
- In the case of umbrella organizations (for example, EURORDIS) please count each of the umbrella organizations once and count only once the other individual associations represented (whether that be European, national or regional). For example: a patient representative that belongs both to EURORDIS and to a national association of disease X will be counted as 2 patients associations.
- With regards to umbrella organisations, please indicate in the comment box the name of each umbrella organisation represented and the type of coverage they have (e.g national, european or multidisease coverage).
- Patients associations represented by more than one person or in different advisory groups or committees or any other bodies of the ERN will be counted just once.

Indicator 2.1 – Total number of new patients referred to the Health Care Providers participating in the ERN with the diagnosis of a disease / condition that fall within the scope of the ERN

- New patients are those that have attended or been referred to the healthcare provider, within the specified timeframe and having a certified diagnosis of rare disease. These patients should not have been previously included in the patient information system of the healthcare provider.
- Patients who have not obtained yet a diagnosis should not be taken into account.
- In a number of instances, the number of new patients seen each year for some rare diseases will be very low. However, it is the intention of this data collection process to establish a baseline for each healthcare provider, rather than comparing numbers between ERNs.
- There are important differences between the ERNs on the type of contact with the healthcare provider. Some ERNs are mainly having outpatient visits while others are mainly focusing on hospital discharges. Recurrent patients shall be counted once. These clarifications should be noted, as far as is possible, in the comments box of the monitoring data collection IT tool.
- It would be important to consider the aggregated number of patients at the 31 of December of the previous year of the reported period.

Indicator 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

- Education/training activities not accruing higher educational credits that are delivered by an ERN within the specified timeframe and are publically available (eg on websites or ERN educational platforms) should be counted.
- If an educational activity with the same content is delivered 3 times in one year, this should be counted as 1.
- Educational activities should feature the ERN logo.

Indicator 4.2 - Number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organised by the ERN

- The body shall have recognized capacity (at regional, national, EU, or International level) to issue educational credits.
- The credits should be aimed at healthcare professionals, member or non-members of the Networks, organised (including co-organisation or with important contribution) by the coordinating healthcare provider of the ERN or by one or more healthcare providers of the ERN.
- The activity should acknowledge the ERN participation (including the logo of the ERN) within the specified time period.
- Accredited digital educational activities should be included, including accredited Webinars and eLearning courses.
- **Example** (ReCONNET experience):

  An ERN highly involved in the scientific organizing committee in a CME course of one of the diseases covered by the network with a relevant contribution of their HCP as trainers.

  A request of a formal endorsement was submitted to the decision-making body of the ERN that approved the request enabling the organizer to acknowledge the ERN and to add the ERN logo to the materials of the course.

Only after ensuring that all the requested criteria were met, the network included this course as formal education activity of the ERN)

Indicator 5.1 - Number of clinical trials, observational prospective studies, observational cohort or case-control studies and case-series studies within the ERN (involving ERN members in at least two Member States).

- this indicator is asking for the number of trials, observational prospective studies, observational cohort studies, case-control studies or case series studies that

  a) Involve healthcare providers within an ERN and b) includes an acknowledgement of the ERN.

- These qualifying criteria can be presented together or in different documents.
- Please provide a reference for each study on the ERN website: https://clinicaltrials.gov/ct2/home and EMA or EU trials registry systems https://www.crd.york.ac.uk/prospero/
- Transversal studies such as genotype/phenotype correlation studies such can be counted as clinical trials (as clinical data are used on a group of patients within the ERN) as long as they acknowledge the ERN participation (including logo of the ERN) within the specified time period.
- The clarification of possibilities and limits regarding the cooperation with Industry is not a concluded process. The statement of ERN Board of Member States has been recently updated – 25th June 2019. This is impacting on the involvement of healthcare providers as ERN members in Industry driven studies, because ERNs do not have a clear view about how this kind of collaboration can be run – at the moment.
- For this reason, many HCPs have not acknowledged the ERN in the study, and have therefore not counted Industry driven studies in the collection of data.

Examples which should be counted:

1) See clinicaltrials.gov where the study clearly acknowledges an ERN (ERN-NMD) in the study description:

https://clinicaltrials.gov/ct2/show/NCT03857880?id=NCT02971683+OR+NCT03189875+OR+NCT02419365+OR+NCT03857880&rank=1&load=cart

2) See clinicaltrials.gov where the study involves more than two HCPs of ERN (ERN ReCONNET) but there is no clear acknowledgment of ERN; in this case a document with a clear statement of participation of the ERN will be made available as annex:

https://clinicaltrials.gov/ct2/show/study/NCT03189875?id=NCT02971683+OR+NCT03189875+OR+NCT02419365+OR+NCT03857880&rank=2&show_locs=Y&load=cart#locn

After several discussions, the Monitoring Working Group decided at the meeting of 1 July 2021 to adapt Indicator 5.1 on research to include a broader range of ERN research activities, more adequate to the needs of some networks.

In some cases observational cohort studies are conducted, although not purely prospective in design but with a retrospective or mixed cohort design (with both retrospective and prospective phases). They are used with appropriate methodologies to anticipate on the limitations of the study designs.

Case-control studies and case series are used for the identification of new genetic predispositions or (genetic) risk factors, which is an important aspect of research in the field of (unexplained) hereditary or genetic diseases.

Considering the evidence-based medicine pyramid, these study designs score lower however they do contribute to the relevant evidence for certain aspects of the work of some ERNs.

Indicator 5.2 - Number of accepted peer-reviewed publications in scientific journals regarding disease-groups within the ERN and which acknowledge the ERN.

For counting purposes, ERNs should only be counting those publications that include an explicit acknowledgment or reference the ERN's involvement such as **"This work is generated within the European Reference Network for …" or "This work is supported by the ERN for ….".** If the support is not financial, "(not financially)" can be added in brackets after the word "supporting" for additional clarification. This could be the case, for example, for ERNs that are involved in the Solve-RD or other similar European projects where ERN clinicians have been involved in publications but no ERN funding has been used.

The acknowledgment for collaboration can be included in the acknowledgement section and could follow this example:

"This research is supported (not financially) by the European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS)—Project ID No 739547. ERN GENTURIS is partly co-funded by the European Union within the framework of the Third Health Programme "ERN-2016—Framework Partnership Agreement 2017–2021"

The figure captured here should be clearly linked to the ERN and its activities.

Example (ReCONNET)

- 12 peer-reviewed publications about the results of ERN ReCONNET activities on clinical practice guidelines carried out during the first 18 months had been published at the end of 2018.

  These publications are included in the supplement "ERN ReCONNET Supplement on the state of the art on CPGs in rCTDs". It was officially published after a peer-review process of each single article. The Supplement is already available in the RMD Open website

  (https://rmdopen.bmj.com/content/4/Suppl_1).

  Each publication has a different Pubmed ID code.

  After consulting the Communication experts within the ERN policy team within the EC, each publication reports the acknowledgment statement regarding the EU funding and the n. 24 ERNs.

Moreover, the ERN logo is included – in each publication.

Indicator 6.1 - Number of Clinical Practice Guidelines and other types of Clinical Decision Making Tools, adopted for diseases within the scope of the ERN.

- "The ERN has adopted the CPG or Clinical Decision Making Tools" means that the tools are publically available and all the healthcare providers within a network are following the guidance.
- The adaptation of the CPGs already existing appears a very crucial added value of the ERNs, since the adaptation may increase the application of CPGs by healthcare professionals. The adaptation of CPGs can be done by means of the ADAPTE methodology that guarantees the production of defined priorities to be followed across Member States.
- The Clinical Practice Guidelines (CPG) and other Clinical Decision Support Tools (CDST) based on consensus techniques to be counted shall be those adopted on the measured timeframe by the ERN (eg agreed by the ERN Board), not when they are published.
- The adoption of CPGs within an ERN could be defined, for example by means of an official endorsement of the Board of the ERN.

Indicator 6.2 – Number of a. new Clinical Practice Guidelines and b. other types of new Clinical Decision Making Tools (clinical consensus statements or consensus recommendations), written by the ERN in the specified time period.

- ERNs have very different scenarios with reference to the number of diseases covered and also to the number of already existing CPGs.
- It is important to underline that for some diseases, many CPGs are already available, for other rare diseases there are no CPGs available at the moment as there is insufficient evidence to produce new CPGs.
- The differentiation between evidence based Clinical Practice Guidelines (CPG) and other Clinical Decision Support Tools (CDST) based on consensus techniques (mainly expert or consensus recommendations) is important when identifying the elements to count. Currently the main criteria to distinguish CPG from Consensus recommendations shall be the standard definition of CPG.
- The Clinical Practice Guidelines (CPG) and other Clinical Decision Support Tools (CDST) based on consensus techniques to be counted shall be those written on the measured timeframe by the ERN (eg agreed by the ERN Board).
- Measuring only the new CPGs produced by the ERN is probably not sufficient to monitor the improvement of the access of patients to high and quality health care services. CDST production shall be considered crucial
- In many cases the role of ERNs would be to collect the evidence that will represent the baseline for the creation of CPGs. This will be done also through the ERN Registries.
- Another important element that should be considered in measuring the equal access to good quality health care is the adaptation of CPGs in the different Member States.

  example, for those diseases that already have published CPGs, ReCONNET is performing an adaptation of the guidelines in the different contexts by means of the ADAPTE methodology.
- Additional elements could be considered in the future as sub-indicators for 6.2 in order to capture relevant activities of ERNs related to the improvement and harmonization of care across Europe, not limiting to the creation of new CPGs, but also including adaptation, generation of new evidence, new clinical tools for monitoring the diseases, etc.

Indicator 7.1 - Number of congresses/conferences/meetings at which the ERN activities and results were presented

- The aim of this indicator is to capture the dissemination activities of the ERNs.
- The ERN and its activities should be the focus of the presentations.
- If multiple qualifying presentations are given at an event, this should only be counted once.

Indictor 7.2 - Number of individual ERN website hits

- There are different tools available that could help avoiding to count the machine-visits and include only actual page visits

  Example: Please use the google analytics tool for the counting, where “page visits” is a specified variable:

  https://analytics.google.com/analytics/web/