**Endo-ERN MONITORING: Annual Data Collection**
**January – December 2022 – [Thematic disease area – e.g. MTG1 Adrenal]**

**Table 1.               Please provide the information for 2022 (Jan-Dec)**

**Definitions**

1. *Education activities*

*The total number of unique education/training activities not accruing higher education credits*

*aimed at healthcare professionals and/or patients, created by the Endo-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 Endo-ERN. Activities should be published on the Endo-ERN website.*

1. *Formal education activities*

*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. Activities should be published on the Endo-ERN website.*

1. *Clinical practice guidelines/Clinical Decision Making Tools*
2. *Adaptions*

*The number of Clinical Practice Guidelines2 and other types of Clinical Decision Making Tools3, such as clinical consensus recommendations for disease areas within the scope of the ERN not developed by the ERN, that were formally endorsed and adopted by the ERN Board, and are publically available (e.g. on the ERN website).*

1. *Written by Endo-ERN*

*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. Should be published on the Endo-ERN website.*

1. *Conferences/meetings*

*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. Activities should be published on the Endo-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.*

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|  |  |  |  |
| --- | --- | --- | --- |
| **Various** | **Definition** | **Number**  | **Details *(Title, date, location, subject, link)*** |
| **Education activities** not accruing higher education credits aimed at healthcare professionals delivered by the coordination team or HCP members of the ERN *(non-accredited)* |  |  |  |
| **Formal educational activities** (i.e. those accruing higher educational credits) aimed at healthcare professionals delivered by the coordination team or HCP members of the ERN (*accredited*) |  |  |  |
| **Clinical Practice Guidelines** and other types of **Clinical Decision Making Tools** *adopted* for diseases within the scope of the ERN. | Such as clinical consensus recommendations, not developed by Endo-ERN but that were formally endorsed and adopted by the Endo-ERN board and are publically available (e.g. on Endo-ERN website) |  |  |
| **Clinical Practice Guidelines** *written* by the ERN \* | Developed by Endo-ERN, involving at least 2 HCPs from 2 different Member States within Endo-ERN. They should acknowledge Endo-ERN, for diseases within the scope of Endo-ERN where no guidelines existed previously and be according to an evidence based recognized methodology. |  |  |
| **Other Clinical Decision Making Tools** (clinical consensus statements or consensus recommendations) *written* by the ERN \* | Developed by Endo-ERN, involving at least 2 HCPs from 2 different Member States within Endo-ERN. They should acknowledge Endo-ERN, for diseases within the scope of Endo-ERN where no guidelines existed previously and be according to and evidence based recognized methodology. |  |  |
| **Congresses/meetings** at which the ERN activities and results were presented  | Via a dedicated slot in the program, acknowledging Endo-ERN. and including the Endo-ERN logo |  |  |

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**Table 2.               New patients referred to your center in 2022 (Jan-Dec) for the endorsed MTGs**

*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, whatever their age, including visits to outpatient’s clinics, hospital discharges and emergencies, coming from national and international referrals.* *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.*

**Do you report your new patients on e-REC?**

[x]  Yes, take our numbers from here

☐ Yes, but this is not accurate/complete. Please take the response below instead.

[ ]  No

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **MTG1 Adrenal** | **MTG2****Disorders of calcium and phosphate homeostasis** | **MTG3** **Genetic disorders of glucose and insulin homeostasis** | **MTG4** **Genetic endocrine tumour syndrome** | **MTG5** **Growth** | **MTG6 Pituitary** | **MTG7** **SDM** |  **MTG8  Thyroid** | **TOTAL** |
|  |  |  |  |  |  |  |  |  |

In case you contribute to multiple MTGs and your HCP is not able to provide you the MTG specific numbers, you may also provide the total number.

**Table 3. Please provide your involvement in CPMS panels for 2022 (Jan-Dec) :**

*Applicable only for those MTGs for which your HCP has been endorsed.*

***Definition****: The number of unique patient panels entered into CPMS during the reporting period.*

This data will be added by the ERN team for the data period 2022.

**Endo-ERN MONITORING: Annual Data Collection
January – December 2022 – MTG1 Adrenal**

**Table 4.               Please provide your involvement in research for 2022 (Jan-Dec)**

***Definition****: The total number of unique clinical trials, 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.*

Please report only what is NOT already listed in Endo-ERN clinical trails or observational studies databases at our website.

[Clinical Trials | Endo-ERN](https://endo-ern.eu/activities/clinical-trials/)

[Endo-ERN Studies | Endo-ERN](https://endo-ern.eu/activities/endo-ern-studies/)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **INVOLVEMENT of your HCP** | **Number**  | **Trial/study name** |  **Trial/study** **ID** |  **Collaborators** | **Link** |
| Ongoing or finalized **Clinical trials** \*\*  |  |   |  |  |   |
| Ongoing or finalized **Observational prospective studies** \*\*  |  |  |  |  |  |
| Ongoing or finalized **Observational cohort** or **cases-control** **studies** |  |  |  |  |  |
| Ongoing or finalized of **case-series** **studies** |  |  |  |  |  |

**Table 5.               Accepted peer-reviewed publications for 2022 (Jan-Dec)**

***Definition****: The total number of unique peer-review publications that have been accepted 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…”*

|  |  |  |  |
| --- | --- | --- | --- |
| **INVOLVEMENT of your HCP** | **Number** | **Doi** | **Link to publication** |
| **Accepted peer-reviewed publications** \*\*\* in scientific journals regarding disease groups within the scope of the ERN and which acknowledge the ERN |  |  |  |