# Table Of Content

**European Reference Network on Rare Endocrine Conditions** ............................................................... 2

Summary ....................................................................................................................................................... 3

**Work Package** ..................................................................................................................................... 7
- Education & Teaching ............................................................................................................................... 7
- E-Health & ICT ....................................................................................................................................... 7
- Research & Science ................................................................................................................................. 7
- Quality of Care & Patient View .............................................................................................................. 7
- Diagnostics & Laboratory Analysis ....................................................................................................... 7
- Management ........................................................................................................................................... 7

**Coordinator, Leader contact and partners** ......................................................................................... 9

**Outputs** .............................................................................................................................................. 10
- Report on EU network creation ............................................................................................................ 10
- Report on accreditation and quality control measures ........................................................................ 10
- Year 1 annual ERN report ...................................................................................................................... 10
- Dissemination tools ............................................................................................................................... 10
- Dissemination material ........................................................................................................................... 10
- Educational strategy .............................................................................................................................. 10
- ICT and E-Health strategy report ......................................................................................................... 10
- Science and Research strategy report .................................................................................................. 10
- Quality of care and Patient view strategy report .................................................................................. 10
- Dissemination strategy .......................................................................................................................... 10
<table>
<thead>
<tr>
<th><strong>START DATE:</strong></th>
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</thead>
<tbody>
<tr>
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<td>3rd Health Programme (2014-2020)</td>
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<td><strong>CALL:</strong></td>
<td>EUROPEAN REFERENCE NETWORKS SPECIFIC GRANT AGREEMENTS COVERING YEAR 2017</td>
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<td>Rare diseases</td>
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Project abstract

Endo-ERN is directed at bringing together EU expertise on rare endocrine conditions. This is set-up in a 5-year plan including 3 phases. In Year 1 – the first phase - the consortium will focus on the inventory and mapping of the knowledge base, innovation and resource capacity and quality of care (QoC) of the Member States (MS) involved. Geographical differences will be charted on knowledge and awareness gaps, relevant biobanks, trials European patient advocacy groups (ePAGs) and other initiatives will be identified. In phase 2, comprising Year 2-4, a stepwise execution will follow to implement actions addressing gaps and opportunities that are identified in Year 1. To maintain and consolidate the equalisation of the healthcare and research level, the third phase – Year 5 – will focus on ensuring long term continuation (although this will be of continuous importance throughout phases 1 and 2.

The work plan is subdivided in 5 work packages (WPs) containing the phased activities aimed at 8 main thematic groups (MGTs). For the first time in the history of endocrinology, we are bringing together paediatric and adult endocrinologists, and both are also represented in the overall management structure of Endo-ERN. Tasks aimed at overall management and coordination of the execution of the work-plan activities in Year 1 are co-funded under the FPA, of which many are aimed at the initial inventory and surveying activities. Endo-ERN will setup a specific communication and dissemination strategy aimed at all stakeholders involved in the rare endocrine disease field to ensure awareness and engagement.

The combined activities in Year 1 will foster new collaborations, grow the network and start to align all EU wide activities to an equal high level.

Summary of context, overal objectives,strategic, relevance and contribution of the action

Endo-ERN’s mission is to reduce and ultimately abolish inequalities in care for patients with rare endocrine disorders in Europe, through facilitating knowledge sharing and facilitating related healthcare and research. The mission of Endo-ERN is defined into 5 Work Packages (WP) and is to be delivered throughout all 8 Main Thematic groups (MTGs). Endo-ERN provides equality between paediatric and adult patients. Ultimately, Endo-ERN will result in the best possible care for every patient with a rare endocrine condition.

The multi-annual objectives of Endo-ERN (the FPA) are 1): To mitigate differences in awareness and knowledge regarding diagnosis and treatment, 2) The reinforcement of research and epidemiological surveillance, 3) Facilitating mobility of expertise to optimise communications between stakeholders, 4): To
create a single, easy-access platform containing all existing and future information, 5) To setup agreements among the network for EU-wide access to the most fitting care.

Methods and means

In order to achieve Endo-ERN’s mission and accomplish the concrete objectives for Endo-ERN, a concrete 5-year plan has been devised. According to this plan, the first year was mainly focused on mapping the knowledge base, innovation capacity, and quality of care for each of the MTGs, while the second year is focused on the stepwise execution/implementation of the planning that was generated in the 1st year.

Work performed during the reporting period

In the first year of Endo-ERN, the coordination efforts were geared at connecting and include the large pool of dispersed, yet committed partners and relevant stakeholders, and to map their capacities and their needs. This year of initiation has entailed the largest part of the Phase 1 activities and has positioned Endo-ERN rather favourably to commence with Phase 2, barring a few residual Phase 1 activities. The collective of the Phase 1 actions resulted in two key outcomes:

- Identification of active members and networks, and development of specific different committees within each Main Thematic Group (MTG) and Work Package (WP)
- Development of surveys for each MTG/WP to identify specific available structures and resources and identification of unmet needs.

The main output achieved so far and their potential impact and use by target group (including benefits)

- Development of surveys to identify educational gaps, patient disease gaps, laboratory analysis gaps, e-health & ICT gaps and research gaps. Survey and data collection almost completed.
The adoption of an electronic surveillance programme of the HCPs within the ERN (as part of the EuRRECa project, see further). This programme, called the electronic notification of rare endocrine conditions (E-REC), will perform a monthly pseudo anonymised survey which will enquire whether the Endo-ERN members have encountered any of the conditions listed within the ERN. The results of a survey show that not only there is a need to cover a wider range of conditions but there is also a need to improve the awareness and signposting of existing registries.

Approval of project application ‘European Registry for Rare Endocrine Conditions’ – EuRRECa (one of the 5 successful applications out of >20) which will address the gaps raised in the above survey by developing and implementing an e-reporting programme and a core registry for all rare endocrine conditions covered within Endo-ERN.

Structural alliance with European Scientific Societies as reflected by distinct Endo-ERN symposia at the respective adult and paediatric European scientific society meetings in 2017 (Lisbon and Washington)

In the first year, Endo-ERN focused on a subset of the stakeholder groups identified for the five-year plan, namely patients, families and caregivers, healthcare providers, insurers, policy makers, scientific community and the general society.

Achieved outcomes compared to the expected outcomes

All deliverables were met as expected. In the trajectory towards achieving the deliverables the response rates to the developed surveys was not always as high as wished, but the approval of the registry application and the structural linkage to the scientific societies was very successful.

Dissemination and evaluation activities carried out so far and their major results

Dissemination activities that have been accomplished and are ongoing include: implementation of Endo-ERN social media activities, establishment and development of public Endo-ERN website, dissemination of EU Commission ERN logos within Endo-ERN, including user guide, and development and dissemination of Endo-ERN specific logo, multiple versions, a monthly Endo-ERN Newsletter reporting on the ongoing ERN and Endo-ERN specific activities,
development of a newsletter subscription database. Developing of a database of experts within Endo-ERN, including contact information per Main Thematic Group and/or Work Package, Establishment & further development and implementation of Endo-ERN Collaborative Platform. Establishment & further development and implementation of document management system CircaBC. Development of Endo-ERN physical dissemination materials (including Endo-ERN pens, notebooks, USBs, and Endo-ERN stickers.

The dissemination activities range over several different platforms each with its own target audience, ensuring the widest possible dissemination reach. For example, providing presentations or posters at scientific congresses or events is specifically targeted towards the scientific community, whereas providing information on the Endo-ERN website is aimed at reaching a more broad audience and patients. The investment of building a network of expertise now and developing a database will ensure that in the future the network has a strong foundation of motivated and engaged persons carrying out the different activities.

Evaluation activities:
Performance of electronic registration and periodical analysis of
- website visitors
- social media followers
- opening/reading of periodical newsletters
- registrations/active usage of the collaborative platform.
Work package

Work Package 1: Education & Teaching
Start month: 1
End month: 12
Work Package Leader: LUMC

The activities of this WP are aimed to coordinate a survey of education gaps in the member states and analyse the data. The survey aims to identify geographic differences and targets all lines of care, patients and their families. The analysis of the data will provide the basis for the multi-annual educational agenda.

Work Package 2: E-Health & ICT
Start month: 1
End month: 12
Work Package Leader: LUMC

To coordinate the creation of an inventory of ICT and E-Health solutions, analysing these data and formulating a strategy on how to move forward on these aspects in the remainder of the ERN and to allow the development of common platforms. This will involve expert, administrative input and virtual & face-to-face meetings. Over Year 1 it is also envisaged that thematic groups will identify their individual needs for Technology Enabled Care (TEC) in the three categories (professional to professional, professional to patient, patient to patient). It is also likely that over this Year 1, the future EU landscape for proving TEC across its member states will also become clearer.

Work Package 3: Research & Science
Start month: 1
End month: 12
Work Package Leader: LUMC

The central and original feature of the network is to create a consortium of paediatric and adult specialists of rare endocrine diseases. It is recognised that the transition from childhood/adolescence to adulthood is critical and poses unanswered questions in rare conditions diagnosed in children and lasting for the entire life. Such questions arise from practice and the general objective of the Research & Science activities to support the scientific validity in the approach towards addressing those issues.
Work Package 4: Quality of Care & Patient View
Start month: 1
End month: 12
Work Package Leader: LUMC

Within the operational activities we aim to provide excellent care for patients with rare or complex endocrine diseases, improving time to diagnosis and correct treatment, as well as psychological support for patients and families, and prophylactically anticipate the chronic specific co-morbidities of many of these diseases, harmonising care across HCPs to improve equality throughout the EU.

Work Package 5: Diagnostics & Laboratory Analysis
Start month: 1
End month: 12
Work Package Leader: LUMC

The first year will be spent on collection of information regarding the eligibility of laboratories for the ERN accreditation, the establishment of communication infrastructure (web-based information technology, modalities of shipping of samples, etc) and standardisation of the employed diagnostic procedures, covering all paediatric and adult endocrinology aspects as these require different analyses and methods.

Work Package 6: Management
Start month: 1
End month: 12
Work Package Leader: LUMC

Overall management and coordination of the execution of the work-plan activities. Many tasks are aimed at the initial inventory and surveying activities. Endo-ERN will setup a specific communication and dissemination strategy aimed at all stakeholders involved in the rare endocrine disease field to ensure awareness and engagement.
COORDINATOR, LEADER CONTACT AND PARTNERS

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PARTNERS

No partners related to the current project
Report on EU network creation
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 20/06/2018
Report on the followed strategy and progress of EU network creation, current and pending members, and guidelines and strategy for the coming years based on lessons learned.

Report on accreditation and quality control measures
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 20/06/2018
Report on the accreditation measures that have been decided, how those will be measured and how external quality control of network members will take place before and after joining the network.

Year 1 annual ERN report
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 20/06/2018
Report on aspects related to management, dissemination and communication of the ERN.

Dissemination tools
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 20/06/2018
Tools such as newsletters, contact database, website, etc.

Dissemination material
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 20/06/2018
Educational strategy
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 19/06/2018
Report on EU educational gaps based on survey performed during year 1, with an analysis of the data and educational strategy for the following years of the ERN based on this analysis.

ICT and E-Health strategy report
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 19/06/2018
Report on data about EU ICT and E-Health solutions collected over year 1 as part of WP2 activities, analysis of these data and a strategy for the following years of the ERN based on these data.

Science and Research strategy report
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 19/06/2018
Report on 1st year survey of research needs and available sources, an analysis of the data and a strategy for the next years of the ERN work programme based on this.

Quality of care and Patient view strategy report
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 19/06/2018
Data report on Quality of Care and Patient view, analysis of results and strategy for the remaining ERN years formulated based on the analysis. Report on outcomes of the discussions set up in task 4.3.

Dissemination strategy
LUMC
European Reference Network on Rare Endocrine Conditions (Endo-ERN)
Published on: 18/07/2017
Report describing detailed dissemination plan including month-by-month activities and partner responsibilities.