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European Reference Network for rare respiratory diseases (ERN-LUNG)

JA2015 - GPSD [705038]

START DATE: 01/03/2019

END DATE: 28/02/2022

DURATION: 36 month(s)

CURRENT STATUS: Ongoing

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: Multiannual Grant Agreements for European Reference Networks

TOPIC: ERN Specific Grant Agreements 2019 - 2021

EC CONTRIBUTION: 589163 EUR

KEYWORDS: Centers Of Expertise, European Reference Network, Lung, Network, Rare Diseases, Respiratory Diseases

Project abstract

ERN-LUNG is a network of European patients and healthcare providers dedicated to ensuring and promoting excellence in care and research to the benefit of patients affected by rare respiratory diseases. ERN-LUNG's vision is to be a European knowledge hub for rare respiratory diseases and to decrease morbidity and mortality from rare respiratory diseases in people of all ages. ERN-LUNG is a European Reference Network (ERN), a non-profit, international, professional, patient centred network. ERN-LUNG is focused on rare respiratory diseases and is made up of nine core networks representing the diversity of diseases and conditions affecting the lungs. The current core networks (sub-thematic areas) are interstitial lung diseases, cystic fibrosis, pulmonary hypertension, primary ciliary dyskinesia, non-CF bronchiectasis, alpha1-antitrypsin deficiency, mesothelioma, chronic lung allograft dysfunction, and other rare lung diseases. In addition to the sub-thematic groups, ERN-LUNG is also organized in functional committees tackling horizontal topics, affecting all of the current and future core networks of ERN-LUNG. These functional committees are Research and Clinical Trials, Ethical Issues, Registries and Biobanks, Patient Recorded Outcomes and Quality of Life, Quality Management, Physical Fitness and Training, Social Services, Guidelines and Best Practice of Care, Communication and Outreach, Cross Border Care, and Professional Training and Continued Medical Education. In building up on and learning from mature networks of recognized international excellence, ERN-LUNG will continue to grow, to establish registries and clinical trial networks, and add value for patients, healthcare providers, and professionals through dissemination of knowledge, enhancement of general expertise by learning from the best centres in rare respiratory diseases in Europe, and improvement of standards of care, quality of life and prognosis for the whole spectrum of rare pulmonary diseases.

Work package

Work Package 1: Management

Start month: 1

End month: 36

Work Package Leader: UKF

Task 1 – Improve quality and reduce quantity of communication by tailoring the Basecamp project management system to the specific needs of teams and working groups

In the first year of its establishment, ERN-LUNG has gone through a number of administrative steps to establish a strong communication and exchange between members and the Network Coordination Team (NCT). We have been and will be using 'Basecamp', a project management tool, which is a free software for educational purposes. This is causing a large number of messages to all active members, the amount of activities (tasks and deliverables) the members are involved in triggers the number of emails that are sent by the Basecamp. The management of this tool continues to lie with the NCT to restrict sub-project communication to active members (teams) and try to tailor the communication to actual needs of the resp. members.

Related deliverable(s): 1.1a (M18), 1.1b (M36),

Target groups: Network Coordination Team, all ERN-LUNG members

Task 2 – Organization of the ERN-LUNG Board meeting and an additional Medical Steering Committee meeting

The Board meetings of the ERN-LUNG Board are expected to take place in Frankfurt late February or the beginning of March of each year (expected number of participants: approx. 80 to 100). The Coordinator and the Network Coordination Team will prepare the agenda for the Board meetings as well as for meetings of the other bodies of ERN-LUNG (Patient Board and Medical Steering Committee in particular), sort out the logistics (date, venue, travel and accommodation for participants), identify items requiring votes (e.g. change of by-laws), ensure that key materials are developed for discussion and approval at the meeting and prepare a post-meeting report with full minutes of discussions.

A meeting of the Medical Steering Committee (expected number of participants: approx. 12 to 20) is also planned to take place in September of each year of funding, during the ERS Congress, to discuss progress, approve plans developed during the first semester the resp. year and review activities to be undertaken by M12, M24, or M 36.

This includes Milestone1 which will only be met if a list of gaps and SOPs for inclusion of Supporting Partners and/or Contact Points have been consented.

Related deliverable(s): 1.2a (M9), 1.2b (M21), 1.2c (M33)

Target groups: all members of ERN-LUNG, patient group representatives

Work Package 2: Dissemination

Start month: 1

End month: 36

Work Package Leader: UKF

Task 1 - Dissemination Plan - update

ERN-LUNG has developed a five-year dissemination plan, including internal and external communications. The ERN-LUNG Advisory Board has been established to aide ERN-LUNG in achieving dissemination of its activities and raise awareness about its services.

As identified in the ERN-LUNG five-year plan, the external communication activities will be towards scientists, patients and other laypeople as well as political decision makers to create more awareness of ERN-LUNG. It will entail publications in scientific journals, the use of the ERN-LUNG webpage (www.ern-lung.eu), and creation of dedicated social media channels, special features in the lay press, organisation of sessions at medical congresses, etc. Translation in various languages to increase the accessibility of content created within the Network will also be supported. This will be made feasible with the assistance of Patient Representatives who can support further dissemination of work done within ERN-LUNG (e.g. through social media) and with support from HCPs involved in the Network who all have a good command of English and can serve as country liaison to ensure knowledge is shared at national level.

Related deliverable(s): 2.1a (M6), 2.1b (M18), 2.1c (M30)

Target groups: medical community, patients, general public

Task 2 – Report on activities and achievements related to recruitment of Supporting Partners and/or Contact Points to fill the gaps in geographical coverage of ERN-LUNG

ERN-LUNG's Year 3 to 5 programme in accordance with the five-year plan will focus on adding more supporting Partners, Affiliated Partners and – if the next call should be published during this year – will add more members to the network as to cover all Member States. The addition of top-level experts in the respective fields will increase our potential but will not automatically help in disseminating this knowledge to the best of the patients. We have therefore decided that the addition of as many Contact Points and collaborating partners as possible is a logical next step for the development of our network. The many Health Care providers who do not have the same level of knowledge have to be connected to the network and its services as well. Only with both top-level experts and the many other Health Care providers we will be able to reach the entire population of patients affected by rare respiratory diseases.

Related deliverable(s): 2.2a (M9), 2.2b (M21), 2.2c (M33)

Target groups: all ERN-LUNG members and partners, medical community and

patients inside and outside of ERN-LUNG

Work Package 3: Data Gathering

Start month: 1

End month: 36

Work Package Leader: UKF

Task 1 - Integrate ERN-LUNG Registry Data Warehouse into ERN-LUNG and among its members (report)

With the positive evaluation of the ERN-LUNG registry application (RD REGISTRY DATA WAREHOUSE, EU project 777295) ERN-LUNG has the chance of achieving full interoperability of all its Core Networks' registries and establish fully interoperable registries for those diseases or disease groups where no registries exist. The starting date of this 3rd Health Programme project was July 1st 2018. The NCT and all members will have to contribute to make sure this will not remain a project of registry specialists in Paris, Dundee, Münster, and Frankfurt but help develop into another cross fertilizing and interconnecting activity of ERN-LUNG instead.

The NCT will support the integration of other funded projects clearly by separating all activities and taking care not to have any double funding nor undue overlap between the projects.

Work Package 4: Quality of Care

Start month: 1

End month: 36

Work Package Leader: UKF

Task 1 - Clinical care pathways including cross-border Online Expert Advice System, cross-border online consultations, cross-border referral

Clinical care pathways are being developed to help standardize the way patient requests and presentations are harmonized throughout the whole network.

This includes Milestone 2 which will be the consensus among all stakeholders about the clinical pathways. The ultimate goal is, that clinical pathways across all Core Networks are consented and implemented.

Task 2 Establish cross-border Online Expert Advice System (EXABO)

Task 3 will establish cross-border online consultations which will enable all member HCPs to participate in cross-border online consultations.

Task 4 will consist in establishing cross-border referrals

A patient management workflow (patient pathway) will be developed defining criteria when advice (level 1), consultation (level 2), or referral (level 3) will be used for RD patients. After setting up the infrastructure within ERN-LUNG for cross-

border advice (level 1; see above Activity 2, Task 2), consultation (level 2) and referral (level 3) constitute the main ways to achieve one central objective of ERN-LUNG: Cross-border care for patients with respiratory diseases. ERN-LUNG will offer these services to all patients and care team members across all EU Member States. Level 1: Online expert advice systems require relatively little European resources, since the major workload is offered as “good will” activity on a national (language zone) basis. European resources are only needed for coordination and cross-border quality control.

Level 2: When establishing cross-border consultations, a CPMS like the one established for all ERNs is a prerequisite. Preparing and coordinating such cross-border consultations is one of the major steps to be taken during year two.

Not all prerequisites for cross-border consultations have been established, i.e. we do not know how the HCPs involved will get paid for these services.

Level 3: The last level of cross-border care is the referral of patients for face to face consultations in one of the ERN’s HCP in- or out-patient facilities.

Related deliverable(s): 4.1a (M21), 4.1b M36)

Target groups: all ERN-LUNG members and partners, medical community, patients
Task 2 - Establish cross-border Online Expert Advice System (Level 1 of cross-border services)

While the CF Core Network already has many years of experience with an Online Expert Advice System (ECORN-CF; this was started as a European pilot project), other Core Networks will have to implement and learn how to make best possible use of this technology.

The system has been developed during year 1 of ERN-LUNG and will be rolled out for all Core Networks and their teams during year 2. Each Core Network will have to establish coordinating teams according to language zones, and cross-border quality control has to be implemented by the NCT.

Related deliverable(s): 4.2a (M21), 4.2b M36)

Target groups: all ERN-LUNG members

Task 3 - Establish cross-border online consultations (Level 2 of cross-border services)

The ERN CPMS has been developed to support the ERNs in offering online video consultations etc. Care team members of member HCPs can upload pseudonymised patient data or imaging which then can be discussed by expert panels within the ERN. The system (CPMS) is available. The consultations will mainly be within the borders of Core Networks. During the process of the gathering of patient cases to be discussed, we realized that it will be necessary to tailor specific expert panels with individual selections of experts for the cases we have on our list. Not all prerequisites for this type of cross-border care have been clarified, yet. The remuneration of the time spent for these consultations is not clear at the time of writing this proposal

Related deliverable(s): 4.3a (M21), 4.3b M36)

Target groups: all ERN-LUNG members

Task 4 - Establish cross-border referral (services)

One key

Work Package 5: Training

Start month: 1

End month: 36

Work Package Leader: UKF

Task 1 – Liaise with ELF and patient academy (for patients) and with ERS (for clinical care team members) for organizing meetings, workshops, and training programs (schedule/report)

Milestone3: Liaison has been fixed (report)

This activity contains the Milestone 3 being the finalized agreement with ERS and ELF. The Coordinator will collaborate with the Patient Board and Professional Training and Continued Medical Education Functional Committee to create a program for training and education activities within ERN-LUNG for patients and healthcare professionals. For the care team members the NCT has the option to participate in the activities of the European Respiratory Society as well as some of the European disease specific scientific or clinical Societies. They all have lots of educational activities which can easily be used for education in the field of rare respiratory diseases. The same is true for patient education activities, where the European Lung Foundation (ELF) offers numerous generic and specific education programs, and they have offered to join forces with ERN-LUNG.

Work Package 6: Research

Start month: 1

End month: 36

Work Package Leader: UKF

Task 1 - Webinars, workshops, and hands-on training labs on Clinical Trials Network development

This activity contains the Milestone 4 which entails consent to the webinar/seminar program.. During year one ERN-LUNG members have identified that the development of Clinical Trials Networks within ERN-LUNG according to the template of the CF Clinical Trials Network (ECFS CTN) is one priority of ERN-LUNG. ERN-LUNG in close cooperation with the ERS will present a webinar about the chances and pitfalls of Clinical Trials Networks and will organize workshops, and hands-on training labs on Clinical Trials Network development together with the CF Core Network and the European Cystic Fibrosis Society.

Related deliverable(s): 6.1a (M9), 6.1b (M21), 6.1c (M33)

Target groups: all ERN-LUNG members, medical community, other ERNs, patients

Task 2 –Annual report on research projects - update

Regular reporting of research activities within and outside the network as well as dissemination of knowledge to other stakeholders is in the primary focus of ERN-LUNG. The updated specific yearly research report will be put together by the NCT together with the Communication and Outreach Functional Committee and the Research and Clinical Trials Functional Committee.

Work Package 7: Evaluation

Start month: 1

End month: 36

Work Package Leader: UKF

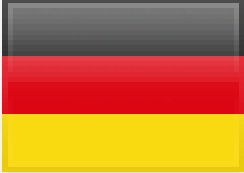
Task 1 – Liaise with EURORDIS (Eurobarometer: Rare disease awareness survey) for patient 'satisfaction' analysis

In the first year, the deputy Coordinator, the Network Coordination Team, with support from the Advisory Board, the Patient Board, and the Patient Recorded Outcomes and Quality of Life Committee have developed an evaluation plan for ERN-LUNG, which includes tools for monitoring and reporting on the network's progress towards implementation of the annual and multi-annual plans and specific performance and outcome indicators for Healthcare Providers. Due to the fact, that the network will only start to offer clinical services to patients in the second year, the evaluation will have to be adapted during the following years. Patient satisfaction is a key issue and monitoring and evaluation will be developed together with the ERN Coordinators Group (Working group on monitoring and quality improvement). Together with representatives from EURORDIS, we will seek to implement ERN specific questions within the well-established 'Eurobarometer: Rare disease awareness' survey to address a large number of patients from all over Europe with a wide spectrum of diseases.

Task 2 – Comprehensive ERN-LUNG report

The Coordinator and the Network Coordination Team will be in charge of developing the 18-monthly report of ERN-LUNG which will cover information about each activity including research projects and clinical trials.

COORDINATOR



KLINIKUM DER JOHANN WOLFGANG VON GOETHE
UNIVERSITAET (Uniklinik FFM)

Theodor Stern Kai 7
60590 FRANKFURT

Germany
WEBSITE: <http://www.kgu.de>

PARTNERS

No partners related to the current project

ERN-LUNG management report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Improve quality and reduce quantity of communication by tailoring the Basecamp project management system to the specific needs of teams and working groups

ERN-LUNG Board and Medical Steering Committee meeting reports Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Organization of ERN-LUNG Board and Medical Steering Committee meetings

ERN-LUNG Board and Medical Steering Committee meeting reports Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2021

Organization of ERN-LUNG Board and Medical Steering Committee meetings

Other meetings report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2021

Develop and organize other meetings together with ERS and other Scientific Organizations or Societies (schedule/report)

Other meetings report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Develop and organize other meetings together with ERS and other Scientific Organizations or Societies (schedule/report)

Dissemination report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/09/2021

Dissemination Plan – update

ERN-LUNG growth report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Report on activities and achievements related to recruitment of Supporting Partners and/or Contact Points to fill the gaps in geographical coverage of ERN-LUNG

ERN-LUNG growth report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2021

Report on activities and achievements related to recruitment of Supporting Partners and/or Contact Points to fill the gaps in geographical coverage of ERN-LUNG

ERN-LUNG Registry Data Warehouse report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Integrate ERN-LUNG Registry Data Warehouse into ERN-LUNG and among its

members

ERN-LUNG Registry Data Warehouse report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2021

Integrate ERN-LUNG Registry Data Warehouse into ERN-LUNG and among its members

Clinical care pathways report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Clinical care pathways including cross-border online expert advice system, cross-border online consultations, cross-border referral

Clinical care pathways report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Clinical care pathways including cross-border online expert advice system, cross-border online consultations, cross-border referral

EXABO report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Establish cross-border Online Expert Advice System (report)

EXABO report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Establish cross-border Online Expert Advice System (report)

cross-border online consultations report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Establish cross-border online consultations

cross-border online consultations report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Establish cross-border online consultations

cross-border referral report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Establish cross-border referral

cross-border referral report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Establish cross-border referral

Education and training report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Liaise with ELF and patient academy (for patients) and with ERS (for clinical care team members) for organizing meetings, workshops, and training programs

Education and training report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Liaise with ELF and patient academy (for patients) and with ERS (for clinical care team members) for organizing meetings, workshops, and training programs

CTN report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2020

Webinars, workshops, and hands-on training labs on Clinical Trials Network development (schedule/report)

CTN report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/12/2021

Webinars, workshops, and hands-on training labs on Clinical Trials Network development (schedule/report)

ERN-LUNG research report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2021

Annual report on research projects – update

ERN-LUNG research report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Patient satisfaction report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2021

Liaise with EURORDIS (Rare Barometer survey) for patient 'satisfaction' analysis in cooperation with ERN Coordinators' Group

Patient satisfaction report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Liaise with EURORDIS (Rare Barometer survey) for patient 'satisfaction' analysis in cooperation with ERN Coordinators' Group

Comprehensive ERN-LUNG report Y5

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Expected on: 01/03/2022

Comprehensive report after 18 and 36 months

ERN-LUNG management report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 10/12/2020

Improve quality and reduce quantity of communication by tailoring the Basecamp project management system to the specific needs of teams and working groups

Dissemination report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 10/12/2020
Dissemination Plan – update

Comprehensive ERN-LUNG report Y4

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 10/12/2020

Comprehensive report after 18 and 36 months

ERN-LUNG research report Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 17/03/2020

Annual report on research projects – update

Patient satisfaction report Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 17/03/2020

Liaise with EURORDIS (Rare Barometer survey) for patient 'satisfaction' analysis in cooperation with ERN Coordinators' Group

Other meetings report Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 16/03/2020

Develop and organize other meetings together with ERS and other Scientific Organizations or Societies (schedule/report)

ERN-LUNG Registry Data Warehouse report Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 20/12/2019

Integrate ERN-LUNG Registry Data Warehouse into ERN-LUNG and among its members

CTN report Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 17/12/2019

Webinars, workshops, and hands-on training labs on Clinical Trials Network development (schedule/report)

ERN-LUNG Board and Medical Steering Committee meeting reports Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 09/12/2019

Organization of ERN-LUNG Board and Medical Steering Committee meetings

ERN-LUNG growth report Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 09/12/2019

Report on activities and achievements related to recruitment of Supporting Partners and/or Contact Points to fill the gaps in geographical coverage of ERN-LUNG

Dissemination report Y3

UKF

European Reference Network for rare respiratory diseases (ERN-LUNG) (ERN-LUNG)

Published on: 23/10/2019

Dissemination Plan – update