



6 months after project launch of the ERN on rare respiratory diseases, we are pleased to having been able to make some progress on our project tasks and deliverables. After having gathered a good overview on ongoing clinical research thanks to Isabelle Fajac, from the FC Research and Clinical Trials, who worked out a questionnaire and evaluated it.

Further, we are currently in the process of working on an online expert advice tool with the help of the team of the “Medical Informatics Group” at the University Hospital Frankfurt, who is implementing a software program for an online expert advice tool for ERN-LUNG. We aim to provide a tool that can be used for each disease and in each language. We will keep you updated on this.

Above that, the FC “Guidelines and Best Practice of Care Committee” has set up a questionnaire on Gap analysis of available expertise and existing guidelines for diseases covered by and within all ERN-LUNG countries and coordination with overlapping ERNs to develop a 5-year roadmap of guidelines to be created and updated. This will provide us with knowledge of the existing gaps of expertise and address new possible applications to cover the field of expertise. Currently, we are still in the process of gathering information from the Core Networks. Many thanks to Nazzareno Galie and Helge Hebestreit, who made great efforts to set up and design the questionnaire.

Further, one of the first deliverables in our work programme is to develop a dissemination strategy, which includes the set-up of a ERN-LUNG public website, which provides an easy way to learn more about rare lung diseases, the network itself, and what it aims for. The website is partly still in a planning stage, and we are constantly updating the website to keep you posted on news and developments regarding ERN-LUNG. We eventually would like to add photographs of all participating members to our website.

Despite the fact, that we are currently lagging behind schedule with our project deliverables, we are happy to say that we have managed to set up a sufficient project management plan now, with all our individual tasks and subtasks, which we have assigned to the persons with the relevant responsibilities, and despite the delays during project set-up, we can say that we are on track of our tasks now, and that everyone seems to be highly motivated. Nevertheless, it was necessary, to suggest to the EU to revise the project timeline and change the project deliverable due-dates, as some of them have already passed, resulting from the set-up delay.



Though we are behind with some deliverables or others, we still managed to complete a few tasks and we are sure that we will be able to complete all due project deliverables by the end of the year.

1. Announcement of new ILD Core Network Lead

We are very sorry to announce that Francesco Bonella has decided to resign from the position of Core Network Leader of the ILD Core Network. The ILD CN proposed that Antje Prasse, Hannover, Germany, should be the future Core Network Leader. The MSC approved this decision of the ILD CN, i.e. Antje Prasse will now serve as the CN leader together with Michael Kreuter, Heidelberg, Germany as the deputy.

2. Medical Steering Committee - First meeting in Milan

In the context of the ERS International Congress this month in Milan, Italy, the Medical Steering Committee held its first meeting to discuss the status of project progress and project-specific topics. The meeting minutes can be found at:

<https://cloud.ern-lung.eu/index.php/s/KOg3i1ZNLWi6Dk3>

3. Patient Representatives on Basecamp

As discussed at the ePAG meeting in the context of the MSC meeting in Milan in September, we have added all ERN-LUNG Patient Representatives to our project management tool Basecamp. That way, they have the possibility to actively participate in message board activities.



4. EPHA petition: EU do more for health!

In the context of the first meeting of the MDC, the members expressed their full support of this initiative (see below):

EU: do more for health!

WHAT ARE WE ASKING FOR?

We call on the European Commission to step up coordinated EU action to tackle cross-border health challenges.

By signing this petition, you are expressing your support for the letter sent to Jean-Claude Juncker calling on the European Commission to step up coordinated EU action to tackle cross-border health challenges. We want the EU to do more for health! (>> Read the letter here <https://epha.org/eu-health-collaboration-crucial-for-europe-future/>)

WHY DOES IT MATTER?

European Commission President Juncker presented earlier this year a white paper on the future of Europe, outlining 5 scenarios.

In these scenarios, the option to "do less" on some policy areas is contemplated. This could lead to less EU action on health after 2020.

The European Public Health Alliance (EPHA), the European Patients' Forum (EPF) and a coalition of organisations have teamed up to express their concerns in a letter to European Commission President, Jean Claude Juncker.

WHO CAN SIGN THIS PETITION?

We count on the support of organisations and Members of the European Parliament.

>> Read more at <https://epha.org/eu-do-more-for-health-campaign/>

REGISTER YOUR ORGANISATION BELOW, AND APPEAR ON THE LIST OF SUPPORTING ORGANISATIONS! For your logo to be included in the letter, please send a .PNG or .JPEG file to giulia@epha.org after you signed up.



5. ERN-LUNG Standard Operating Procedure (SOP)

If, for example, a work group of a Core Network (CN) of ERN-LUNG has performed a systematic review and has also achieved a consensus within the members of the ERN and also with external experts and the patient advisory group [this is still the example] how can this be published in a way that it is officially badged as an ERN-LUNG output?

For this case, the NCT composed a SOP with the title „How to officially badge a publication as an ERN-LUNG output?“

You can find the SOP under following link in our ownCloud:

“How to officially badge a publication as an ERN-LUNG output?“

<https://cloud.ern-lung.eu/index.php/s/v7hGdoGnZuMZNpN>

6. ERN-LUNG Operational IT-Helpdesk

On behalf of ERN-LUNG we have submitted the application for funding of “ERN-LUNG Operational IT-Helpdesk” in the context of the call “2017 CEF Telecom Call - eHealth (CEF-TC-2017-2)”. Scope and Objectives of the proposed action:

THE EUROPEAN REFERENCE NETWORK FOR RARE DISEASES OF THE RESPIRATORY SYSTEM (ERN-LUNG) has been established to develop innovative care models and improve cross border care for patients suffering from rare lung diseases. ERN-LUNG will develop and provide eHealth tools, will contribute to medical solutions and device development, and will offer services such as cross border health care for those affected by rare diseases of the Respiratory System. ERN-LUNG will boost research through large clinical studies and contribute to the development of new pharmaceuticals, and will lead to economies of scale and ensure a more efficient use of costly resources, which will have a positive impact on the sustainability of national healthcare systems, and for tens of thousands of patients in the EU suffering from rare and/or complex diseases and conditions. The main objective of this application is to support members of ERN-LUNG to ensure adequate and efficient use of the European Reference Networks Collaborative Platform and Clinical Patient Management System IT solution. With this effort, the introduction, implementation, and sustained utilization of the ERN IT Platform throughout ERN-LUNG will be possible in a timely manner increasing the efficacy of the efforts going into this European initiative of bringing together the best centers of care and clinical research in the attempt to improve patient centered care for rare lung diseases.



7. FC Registries and Biobanks: Survey open

As a part of the deliverable “Data gathering” in the ERN-LUNG work program 2017, Olivier Sitbon and Angelo Corsico from the Functional Committee “Registries and Biobanks” set up a survey on local patient data registries, to distinguish existing registries and biobanks. The Survey will be open until October 15, 2017.

8. Webinar?

In the next days, we will send you a survey regarding the idea of a webinar you can fill in and comment on.



**European
Reference
Network**
for rare or low prevalence
complex diseases

 **Network**
Respiratory Diseases
(ERN-LUNG)

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