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Vice Coordinator: Prof. Marc Humbert

Requirements for joining the ERN-LUNG PH Core Network

ERN-LUNG comprises 10 Core Networks (CNs), each responsible for developing disease-specific action plans aligned with the network's overall strategy. Each CN defines minimum requirements for patient volume, multidisciplinary team composition, infrastructure, and clinical procedures.

Interested in joining the ERN-LUNG PH Core Network?

Contact the network coordination team at info@ern-lung.eu for information on the application process and to connect with network members.

Network Coordination Team:

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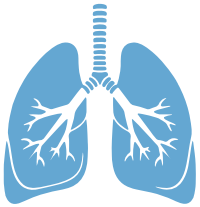
European Reference Networks | ERN-LUNG
RARE RESPIRATORY DISEASES
for rare or low prevalence complex diseases

Funded by the European Union

ERN-LUNG Core Network:

Pulmonary Hypertension (PH)



July 2026

Indicator	Minimum Number required/HCP/year (Adults)	
	Adults	Children
Minimum number of TOTAL patients (visited, treated, or followed) per year	200	30
Minimum number of NEW patients per year	50	10
Key diagnostic procedures per year		
Acute vasoreactivity challenge	50	10
Right heart catheterization	50	10
Doppler echocardiography	100	30
Ventilation/perfusion lung scan (V/Q lung scan)	50	0-10
Lung function tests with DLCO	100	20
Cardio-pulmonary exercise testing	20	0-10
6 min walking test	200	30
Biomarkers: BNP and troponin	200	30

Core Multidisciplinary Team
Adult-and Childcare

- Pulmonologist
- Radiologist
- Nurse
- Study Nurse
- Social Worker
- Cardiologist
- Medical Secretary
- Data Typist
- Psychologist

ERN-LUNG Actions

The ERN-LUNG PH Core Network, composed of both pulmonologists and cardiologists, is one of three partners of a Task force on CTEPH, along with ERS and the International CTEPH Association. CTEPH is an important treatable form of PH and we are interested to produce a clinical statement. We are working on updating the current ESC / ERS guidelines on PH, to have 3 types of guidelines for experts, non-experts and patients, with the aim to have a new publication in 2022. An ERS Clinical Research Collaboration (CRC) on PH/PAH has been approved, acronymed PHAROS, with the objective of setting up a platform for clinical research in PH in close collaboration with ERN LUNG, to coordinate research on topics not of immediate interest to the industry. Some of the initial projects will focus on establishing an inventory of existing and local PH registries and look at interoperability, on evaluating patient access to care across Europe, on characterising PH patients with failing right ventricle, and on phenotyping and treatment of patients with PH due to lung diseases. Our research priorities in general include the improvement of screening and early diagnosis of heritable pulmonary hypertension, the development of risk stratification instrument in pulmonary hypertension, defining the best treatment strategies of PAH and CTEPH.

Competence Requirements

Clinical Follow-Up

- Hospital admissions
- Mortality at 2 years
- Pulmonary endarterectomy, in-hospital mortality, in %
- Survival (3 year survival data from national audit) connective tissue disease-associated PAH
- Survival (3 year survival data from national audit) congenital heart disease associated PAH
- Survival (3 year survival data from national audit) PH due to Left Heart Disease
- Survival (3 year survival data from national audit) PH due to Lung Disease
- Survival (3 year survival data from national audit) Chronic Thromboembolic PH
- Sepsis in patients on IV therapy with Hickman Catheter –
- Proportion of patients with PAH/CTEPH who have a baseline NYHA/WHO functional class, exercise test (6 minute walk or cardiopulmonary exercise test), and right heart catheterization recorded before they begin any pulmonary hypertension drug therapy
- Proportion of newly seen patients who underwent complete assessment
- One-, two- and three-year survival of incident idiopathic, heritable and drug-induced PAH in the applicant center in the last 3 years
- Number of patients under the applicant center treated with at least one pulmonary hypertension drug therapy during each year in the last 3 years
- Median survival of IPAH/HPAH/Drug-toxin associated (last 10 years)
- Baseline NYAH/WHO FC (%)
- Baseline 6MWT (%)
- Right Heart Catheterization (%)

Where are our PH member institutions located?

Full Member Affiliated Partner Supporting Partner