

Target Groups

The main target group is all patients affected by rare respiratory diseases. The more we know about these patients and their disease the better we will be able to help them. The project will not only give detailed information on patients already known but will attract new patients to self-register in the ERN-LUNG POPULATION REGISTRY and will help closing the gap of knowledge conc. the number of patients affected. The scope of the project is such that we expect to cover all patients in the entire field of respiratory disorders (same coverage as ERN-LUNG) in all Member states. All members of the care teams involved are considered a secondary target group since they are the connectors between the registries and the use cases and are important motivators and multipliers for data acquisition and maintenance.

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**European
Reference
Network**

for rare or low prevalence
complex diseases



Network
Respiratory Diseases
(ERN-LUNG)

**ERN-LUNG
RD REGISTRY
DATA WAREHOUSE**

Background

The RD REGISTRY DATA WAREHOUSE is a virtual combination of different use cases making the best possible use of data in different settings.

The WAREHOUSE is the data manager in charge of knowing where data are stored and how they could be used. Data, though, will only be made available for a specific purpose if the patient has given his or her consent to that utilization. It will be of no importance which part of entry the data takes as long as the patient has consented to making the data available for different registry purposes etc.

The RD REGISTRY DATA WAREHOUSE has three major elements:

1. ERN-LUNG REGISTRY

ERN-LUNG REGISTRY (new; basic data set plus health care and economic data, plus (inside and outside the ERN) respiratory disease specific registry data (Cystic Fibrosis (CF), Non-cystic fibrosis bronchiectasis (NCFBE), Primary ciliary dyskinesia (PCD), Pulmonary arterial hypertension (PAH) and all other rare lung diseases)).

2. ERN-LUNG POPULATION REGISTRY

Rare Respiratory Disease Registry (ERN-LUNG POPULATION REGISTRY; new; basic data set, patient driven, patient recorded data).

The new POPULATION REGISTRY is collecting data from patients directly, irrespective of the fact whether they are seen either in the ERN-LUNG member HCPs or in any other highly specialized institution. This offers access to patients otherwise not reached especially since patient self-recording of the data will be encouraged.

3. DISEASE SPECIFIC REGISTRIES

Disease specific registries (new and/or amended and/or bridgehead-connected existing registries for CF, PCD, NCFBE, and PAH) - registries of CF, NCFBE and PCD horizontally linked with each other for benchmarking purposes etc. These registries have been in existence and will remain outside the ERN but will be connected (will share data) with the POPULATION REGISTRY and the ERN-LUNG REGISTRY by a search broker etc.