

The ERN-LUNG Registry Data Warehouse in the European Reference Network for Respiratory Diseases

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Introduction

The European Reference Network respiratory diseases (ERN-LUNG) is a patient-centric network of healthcare providers and patient organisations [1,2]. ERN-Lung will connect pre-existing registries of rare respiratory diseases by using a Registry Data Warehouse (RDW). It is a combination of existing registries that are brought together in a comprehensive registry landscape. The aim is to connect registries of different respiratory Rare Diseases.

Methods

To develop the RDW, we used the Open-Source Registry System for Rare Diseases (OSSE) [3]. We involved clinicians to develop a common-dataset, which faces the interoperability between the registries. For increasing the interoperability, a strong connection to the European Rare Diseases Registry Infrastructure (ERDRI) is realized [4].

Results

The RDW includes several components: The ERN-Lung Registry, which includes a basic data set as well as disease specific registry data. This registry is making use of the same minimal data set as all other registry applications. The second component is the ERN-Lung Population Registry which is

collecting data from patients using self-recording. We also aim interoperability between registries of patient organizations in the future. To make data interoperable, the Meta Data Repository (MDR) of ERDRI is used. A ERN ID Management System will be used to create unique pseudonyms in an untraceable manner.

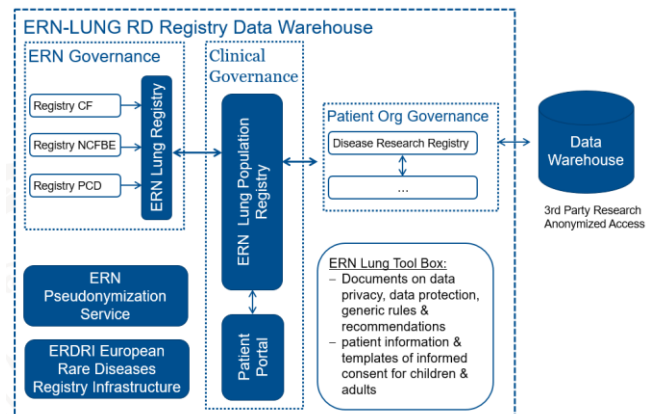


Figure 1: Components of the Registry Data Warehouse

Conclusion

The RDW will serve as a model to help the RD community make the best possible use of the precious patient data collected. By including a patient portal and enable patients to self-registration, will actively contribute to RD research and thus enables patient empowerment.

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