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

H Storf1*, J Schaaf2, J Chalmers3, H Omran4, O Sitbon4, M Dugas5, S Riepenhausen5, TOF Wagner6

1 Medical Informatics Group (MIG), University Hospital Frankfurt, Frankfurt, Germany
2 Scottish Centre for Respiratory Research, University of Dundee, Dundee, United Kingdom
3 Department of General Pediatrics, University of Münster, Münster, Germany
4 Centre de Référence de l'Hypertension Pulmonaire Sévère, Assistance Publique - Hopitaux de Paris, Paris, France
5 Institute of Medical Informatics, University of Münster, Münster, Germany
6 Frankfurt Reference Center for Rare Diseases (FRZSE), University Hospital Frankfurt, Frankfurt, Germany

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.

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.

Acknowledgements
The project “777295 / REGISTRY WAREHOUSE” is co-funded by the Health Programme of the European Union (2014-2020).

Contact:
Dr. Holger Storf
holger.storf@kgu.de
Medical Informatics Group (MIG), University Hospital Frankfurt
www.mig-frankfurt.de

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