Project: ERN-LUNG RD REGISTRY DATA WAREHOUSE

Population Registry Manual

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Introduction

In the context of the European Reference Network for Respiratory diseases (ERN-LUNG), a registry was developed that allows patients or relatives to register themselves and enter medical data. This population registry therefore makes it possible to learn about patients who may not yet be present in the ERN-LUNG core network registries. Therefore, a function has been developed in the Population Registry that allows interested registry operators to be informed about the new registration of a patient. For example, if a patient with the disease cystic fibrosis registers, a defined group of people receives an e-mail notification and can view the patient in the registry. If this group of people determines that the patient is of interest to their own registry, they can contact the patient via an e-mail function in the Population Registry. The patient has agreed in the patient consent form that his/her data may be viewed and that he/she may be contacted. The Population Registry therefore enables specific disease registries to learn about and benefit from previously unknown patients. In the following section, the functions are presented from the user’s point of view.

Patient Account User-Manual

To register a new account in population registry you may press “Create Account” highlighted in the left image. The following form is designated for your personal data. To register you have to agree that your data will be stored in our database. You can also agree to be contacted for research purposes. If you choose to agree you might be contacted by one of our selected ERN partners.
To finish the registration you may press “send data” on the next page. In the next step the population registry team will process your registration and activate your personal account. Our goal is a processing time of two days. Subsequent to the activation you will receive an email with your account data.

If you use your personal login data to log into population registry you will get to your personal form. Please fill this form and press “save changes” to store your data. After you saved your data our ERN partners (e.g. specialised registries) will be informed and may contact you if you agreed to be contacted.
You will receive an email from the ERN-Lung administration team with access data. Use these to log in as shown in the figure below.

Next, a patient overview is displayed of all patients who have registered with a specific disease. For example, if you are only interested in cases for cystic fibrosis, only these patients will be displayed. If you choose to be informed regarding different diseases you can change your role/disease via the roles drop down menu. In the displayed table, there is also an "actions icon" represented by an e-mail symbol. This allows you to contact a patient by e-mail.

This mail can be customized in your profile. To do this, click on your user name in the top right-hand corner of the system. There you can and should also change your password.
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If you register with an email address you will receive an information mail when a new patient registers with your diseases of interest.