

06 January 2021



Project: ERN-LUNG RD REGISTRY DATA WAREHOUSE

Population Registry Manual

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Co-funded by
the Health Programme
of the European Union

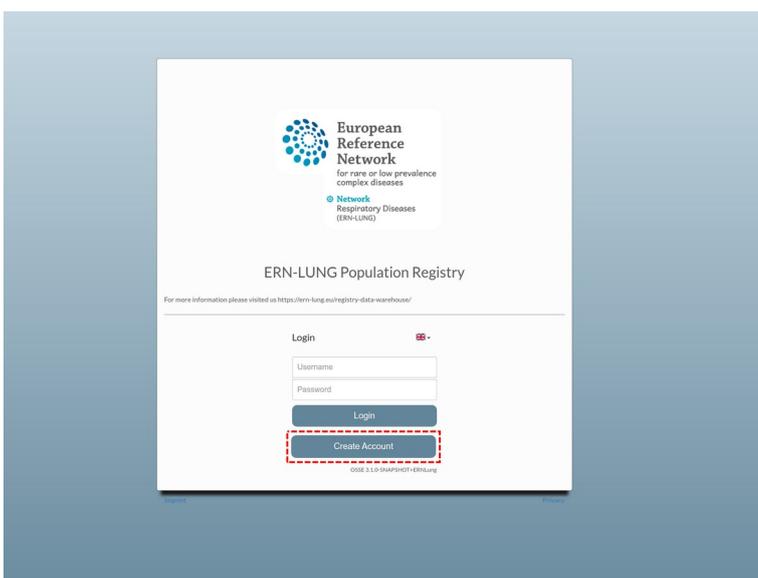
This user guide is part of the project / joint action '777295 / REGISTRY WAREHOUSE' which has received funding from the European Union's Health Programme (2014-2020).

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.

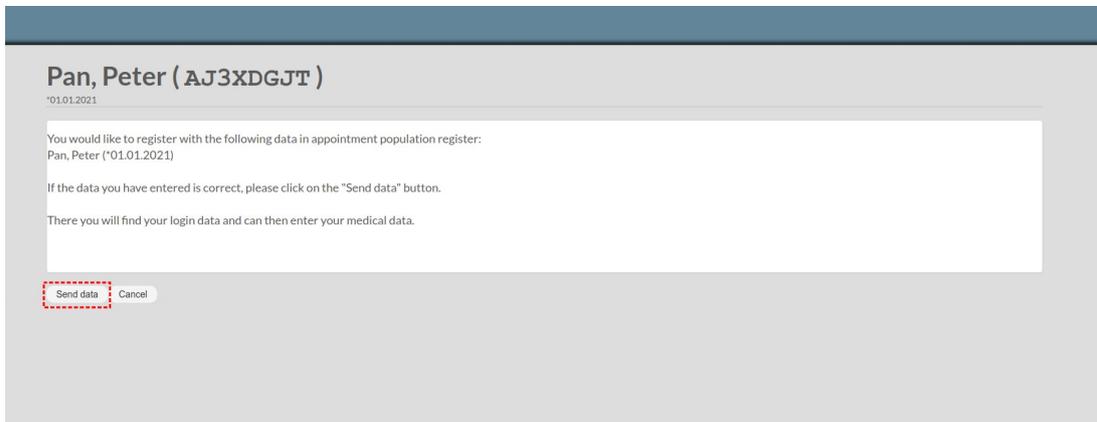
Patient Account User-Manual

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.



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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.



The screenshot shows a confirmation page for Peter Pan (AJ3XDGJT) with ID *01.01.2021. The page contains the following text:

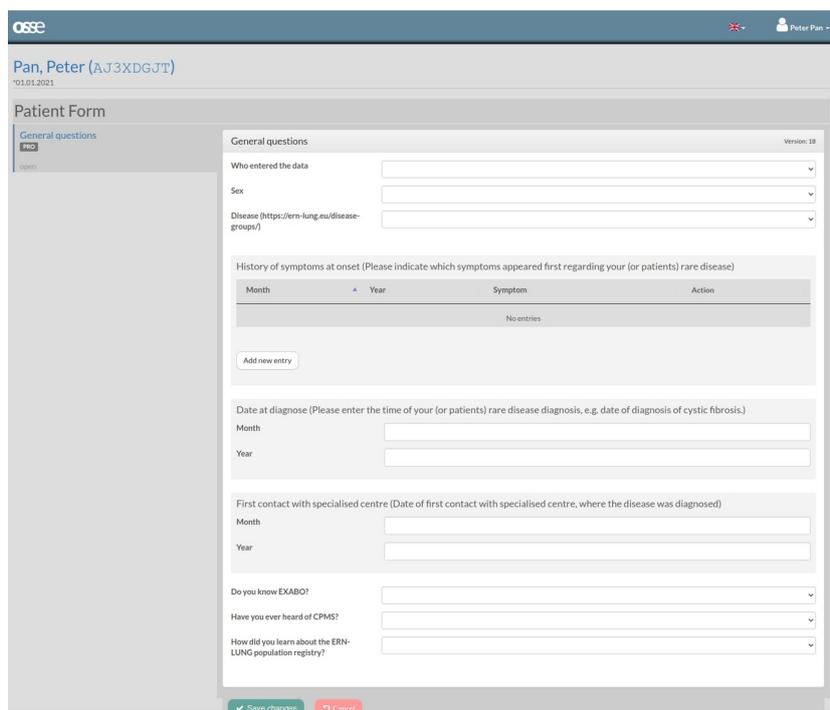
You would like to register with the following data in appointment population register:
Pan, Peter (*01.01.2021)

If the data you have entered is correct, please click on the "Send data" button.

There you will find your login data and can then enter your medical data.

At the bottom, there are two buttons: "Send data" (highlighted with a red dashed box) and "Cancel".

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 registrys) will be informed and may contact you if you agreed to be contacted.



The screenshot shows the "Patient Form" for Peter Pan (AJ3XDGJT) with ID *01.01.2021. The form is titled "General questions" and includes the following sections:

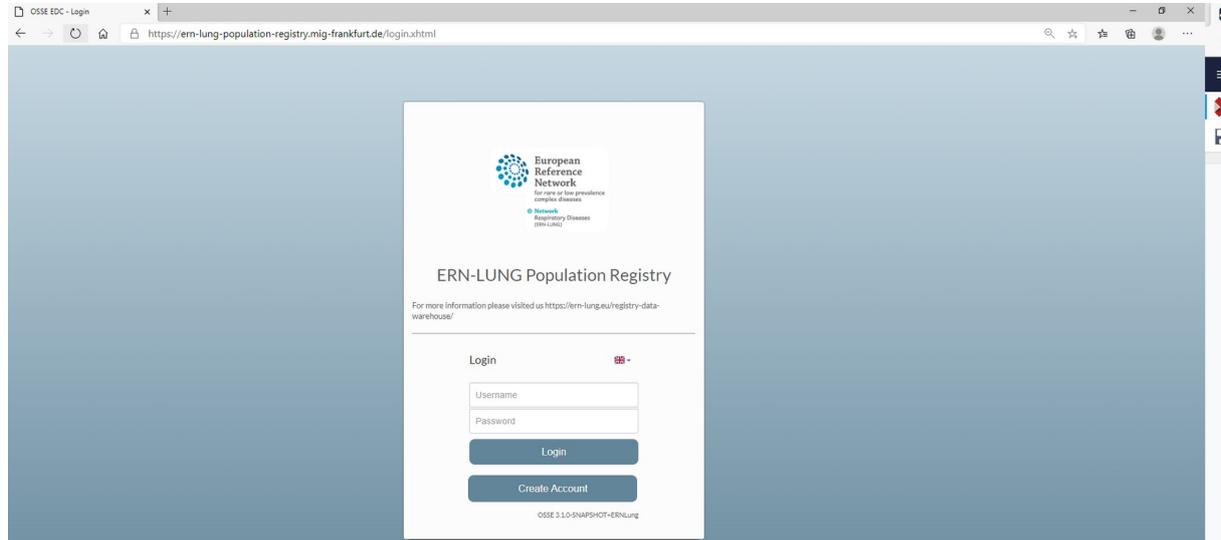
- Who entered the data: [Dropdown menu]
- Sex: [Dropdown menu]
- Disease (https://ern-lung.eu/disease-groups/): [Dropdown menu]
- History of symptoms at onset (Please indicate which symptoms appeared first regarding your (or patients) rare disease):
 - Table with columns: Month, Year, Symptom, Action.
 - Current state: No entries.
 - Button: Add new entry.
- Date at diagnose (Please enter the time of your (or patients) rare disease diagnosis, e.g. date of diagnosis of cystic fibrosis.):
 - Month: [Text input]
 - Year: [Text input]
- First contact with specialised centre (Date of first contact with specialised centre, where the disease was diagnosed):
 - Month: [Text input]
 - Year: [Text input]
- Do you know EXABO?: [Dropdown menu]
- Have you ever heard of CPMS?: [Dropdown menu]
- How did you learn about the ERN-LUNG population registry?: [Dropdown menu]

At the bottom, there are two buttons: "Save changes" (green) and "Cancel" (red).

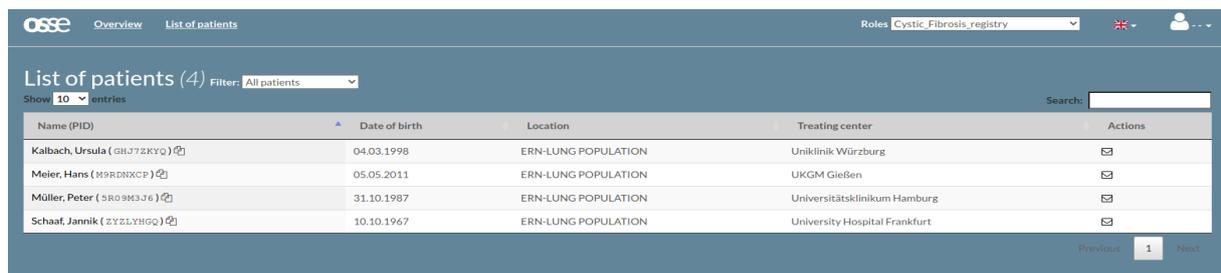
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Network Account User-Manual

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.



Name (PID)	Date of birth	Location	Treating center	Actions
Kalbach, Ursula (GBJ7ZKYQ)	04.03.1998	ERN-LUNG POPULATION	Uniklinik Würzburg	
Meier, Hans (M9RDNXCP)	05.05.2011	ERN-LUNG POPULATION	UKGM Gießen	
Müller, Peter (SR09M3J6)	31.10.1987	ERN-LUNG POPULATION	Universitätsklinikum Hamburg	
Schaaf, Jannik (ZYLLYHGG)	10.10.1967	ERN-LUNG POPULATION	University Hospital Frankfurt	

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.

The screenshot shows a web interface for OSSE. The top navigation bar includes the OSSE logo, 'Overview', 'List of patients', a flag icon, and a user profile icon for 'Jannik Schaaf'. The main heading is 'Your profile', with a 'BACK TO PATIENT LIST' link. The 'Patient Mail Content' section allows users to define text for contacting patients, with a preview showing a personalized email template. The 'Change password' section includes input fields for current and new passwords, and a 'Change own password' button.

OSSE Overview List of patients Jannik Schaaf

Your profile

[← BACK TO PATIENT LIST](#)

Patient Mail Content

Here you may define the text that will be used to contact patients if you choose to.

Dear User,

you have registered your self to the ERN Lung-Registry and gave your consent to be contacted for research purposes. We would like to invite you to #name#.

Best regards,

Your ERN-Lung Datawarehouse team

[Set mail content](#)

Change password

If you want to change your password, you need to provide your current password, and then enter the new password twice

Current password:

Password:

Repeat password:

[Change own password](#)

If you register with an email address you will receive an information mail when a new patient registers with your diseases of interest.