

Implementation of EXABO – An Expert Advisory Board for the European Reference Network for Rare Respiratory Diseases

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Abstract. Rare conditions can make it difficult for physicians and healthcare providers to find the right answers and treatment for patients suffering rare diseases. The number of experts specializing in rare diseases in Europe is low. In order to ensure qualified diagnosis, treatment and care for these patients, the European Commission has founded the European Reference Networks (ERNs), which are virtual networks that include healthcare providers across Europe aiming to provide better care for patients across Europe. The European Reference Network LUNG (ERN-LUNG) has been established for patients with rare respiratory diseases seeking care and advice on all aspects of rare respiratory diseases. In the context of ERN-LUNG, the Expert Advisory Board (EXABO) was implemented. EXABO is a pan-European internet platform based on a question-answering system to support answering questions regarding all areas of rare respiratory diseases. This paper gives a brief overview of the first steps taken regarding the implementation of the EXABO platform, the challenges faced and the lessons that have been learned.

Keywords. Rare Diseases, rare respiratory diseases, ERN-LUNG, Expert Advisory Board

1. Introduction and Motivation

At present, the awareness of rare diseases is increasing. Diseases that affect less than 5 in 10,000 people are considered rare [1]. Between 6,000 and 8,000 rare diseases have been identified worldwide so far and affect 6% to 8% of the European population [1]. As a result, it becomes challenging for patients and their families to receive a confirmed diagnosis and adequate treatment for their condition, as the clinicians and healthcare providers often lack extensive experience in the majority of these rare conditions. Obtaining appropriate expert advice on a disease can be highly beneficial for patients as well as the clin-

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icians attempting to provide a targeted therapy. Launched in March 2017, the European Commission established the 24 European Reference Networks (ERNs) that work on a range of thematic issues [2]. Their main objective is to ensure and promote excellence in care and research for the benefit of patients affected by rare diseases. The European Reference Network for rare respiratory diseases (ERN-LUNG) addresses nine rare and complex pulmonary disease groups, including Interstitial Lung Disease (ILD), Cystic Fibrosis (CF), Primary Ciliary Dyskinesia (PCD), Pulmonary Hypertension (PH), nonCF-Bronchiectasis (nCF-BE), α 1-Antitrypsin Deficiency (AATD), Mesothelioma (MSTO), Chronic Lung Allograft Dysfunction (CLAD) and Other Rare Lung Diseases (ORLD), which are represented in nine Core Networks [3]. ERN-LUNG has 72 collaborating healthcare providers from 17 different European countries. Due to the lack of experts in the field of rare diseases, patients should benefit directly from expert knowledge, if they have a specific question regarding a rare respiratory disease. To provide the opportunity to address questions from patients and clinicians Europe-wide relating to any rare disease of the respiratory system to ERN-LUNG experts, the internet platform for an Expert Advisory Board (EXABO) was developed.

2. Methods

The concept of EXABO is based on the knowledge and experience with the former EU pilot project ECORN-CF², which is an online expert advisory board for Cystic Fibrosis. The key aspects of ECORN-CF were further developed and integrated into EXABO. While one area of rare respiratory diseases is covered in ECORN-CF, EXABO should be extended to all areas within ERN-LUNG. The experts must therefore be categorized based on their area of expertise and country. In each participating country, there is one expert group for each area of rare respiratory diseases. Each of these expert groups is organized by a moderator. The “superordinate moderator” takes on the task of organizing an area of rare diseases throughout Europe. In EXABO, the questions asked are distributed to the experts by moderators and the responses are monitored under quality aspects. Should an expert team not have the appropriate answer to a question, the superordinate moderator can reassign the question to the pool of Europe-wide experts [4].

Based on the stakeholder analysis and the concept, a prototype of EXABO was implemented. For the development of EXABO the waterfall model has been chosen. A two-staged testing process was used for testing. The results are significant for further development. In addition to the design and the technical realization of the Internet platform, the question-and-answer process, the internal communication between moderators and experts as well as the administration of the questions and users were of particular importance in the implementation of the prototype and the advancement to the present state. In the following the test phase is described and the improvements of the key features based on the evaluation of the test phase are highlighted.

2.1. Testing

The subject group, consisting of patients, relatives, physicians and programmers, was split up into the user roles questioner, moderator, superordinate moderator and administrator, so that a simultaneous interaction between them was possible.

²ecorn-cf.eu

In the quantitative test procedure, the subjects had to answer 30 questions regarding user friendliness, accessibility and navigation operating system based on a bipolar rating method using the four categories “do not agree”, “rather not agree”, “more likely agree” and “fully agree”. The neutral response option was excluded due to the fact that the test group for the EXABO prototype consisted of a very small number of persons.

The second stage was a qualitative test procedure, in which the subjects answered ten interview questions addressing improvement and weakness aspects.

2.2. Question-and-answer process

During the test phase, the question-and-answer process was tested for functionality and usability. The first step in the question-process in the prototype is selecting one of the eight rare and complex pulmonary conditions covered by ERN-LUNG: (1) ILD, (2) CF, (3) PCD, (4) PH, (5) nCF-BE, (6) AATD, (7) MSTO, (8) CLAD. In a next step, the questioner selects his desired language zone and inserts the question. The platform does not contain an automatic zone recognition, as it should be optional for the person using the EXABO platform to choose the language zone during travels. In the last step, personal data such as e-mail address, age, gender and country of residence are to be entered, whereby age and gender are not mandatory fields. For security reasons e-mail addresses are hidden even for logged-in users. The country of residence is essential for the assignment of questions as some languages are registered as official language in several countries. In consequence, a question that is asked in French will be sent either to a French or a Belgium group of experts, depending on the name of residency of the questioner.

The test phase has shown that a question cannot always be clearly assigned to a field of rare respiratory diseases in the beginning of the question-answering process. Above that, some questions may be so complex that it requires a different group of experts in the field of rare respiratory diseases. For this reason, the ninth Core Network “Other rare Lung Diseases” (ORLD) was set up. Furthermore, questions asked by a physician can be answered more specifically than those asked by laypersons, i.e. patients or their relatives.

Figure 1. EXABO question entry mask.

After the questioning process, each question entered is automatically forwarded to the responsible moderator, who is the leader of his disease specific expert group and initiates the response process. The moderator assigns each incoming question to one of the ERN-LUNG experts in his group to either give the answer to the question or start

a discussion with other experts before publishing the response. However, questions can be returned by the expert if they are not fully answered. Returned questions are then translated to English and forwarded to the superordinate moderator, who will forward the question to the rare respiratory disease specific panel group across Europe, where the question can be discussed and the answer sent back to the respective moderator. When the answer is translated back in the source language, it can be published and archived on the internet platform.

During the test phase, it became apparent that a discussion with several experts is not only beneficial in the level of the superordinate moderator, but can also be initiated by the moderators in each expert group. Additionally, experts as well as moderators can comment on questions and answers and discuss the questions in a panel group of rare lung disease experts. In this context, the system provides date time for chat messages as well as a chat history, which enables the involved ERN-LUNG experts to retrieve their communication history. If the communication between an expert and the moderator involves additional experts and experts across Europe, the moderator may censor parts of the communication, i.e. if an expert has not fully answered a question and hence, returns it to the moderator. The reason for not having answered the question and other aspects can be set invisible by the moderator. However, the expert's commentary may already contain further approaches which are of advantage for other experts or discussion groups. In this case, the related moderator has the opportunity to censor the commentary instead of hiding the whole commentary.



Figure 2. Moderator's welcome page with his jobs.

2.3. Administration of EXABO

An administrator manages the Internet platform and the user and role management. In the prototype implementation, the user interface of Keycloak [5] was used for the role and user management. The role distribution of EXABO is complex. In addition to experts, moderators and superordinate moderators, a user must also be assigned to a group of experts in a country with a specific field of expertise. Additionally, a user can be both an expert and a moderator, even for different fields of expertise or several countries. For example, a user can be an expert for cystic fibrosis and for primary ciliary dyskinesia, but is only the moderator for one of these fields. Accordingly, the responsible administrator who manages the user administration must work exactly to not forget or mix up a dependent role. If all roles are only listed without any structure, as is the case with the

prototype interface used, it will make it more difficult for the administrator to do his job correctly.

As an aid to the administrator, a completely new user interface with dependencies was programmed for the beta version. First, the actual role of expert, moderator, superordinate moderator and administrator is chosen, in the second step, the field of expertise is selected, whereby it is possible to make a multiple choice.

2.4. Technical realization

EXABO was implemented as a Spring Boot Java application and build with Maven. The front-end was realized with FreeMarker and Bootstrap [6]. The open-source single sign-on tool Keycloak [5] was used for the user and role management. The roles “experts”, “moderators” and “superordinate moderators” were included.

For the prototype a Web Application Resource (WAR) was used, so that an additional Tomcat server had to be installed on the server, in order to run the application. After the test phase and further development, it turned out that packaging with JAR and an integrated Tomcat server is the better choice for this application. The JAR is immediately executable.

3. Conclusion and Outlook

The generic aspect played a substantial role in the implementation of the EXABO Internet platform. As a result, new roles can easily be added in just a few steps and the platform can be enlarged for the implementation of other European Reference Networks.

The menu items are arranged in a logical manner, which makes the system user friendly and easy to use for laypersons as well as professionals. Translation into further European languages would allow a large number of other European citizens to enter their questions regarding rare lung diseases into the system and find more answers to their conditions. The internet platform is currently available in German and English in the beta version since March 2019 and is used by patients and care team members seeking advice on all aspects of rare respiratory diseases. The release of the full version is planned shortly. Special emphasis has been placed on a user-friendly interface/system/entry-points and an easy navigation operating system.

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