

Conception of an Expert Advisory Board for the European Reference Network for Rare Respiratory Diseases

Désirée WALTHER^{a,1}, Olivia STEINMANN^b, Johanna SCHAEFER^a, Thomas OF WAGNER^b and Holger STORF^a

^a Medical Informatics Group, University Hospital Frankfurt, Frankfurt am Main, Germany

^b Frankfurt Reference Center for Rare Diseases, University Hospital Frankfurt, Frankfurt am Main, Germany

Abstract. Due to low prevalence of rare diseases and lack of expertise, patients suffering rare diseases are challenged with finding experts that are specialized and experienced in treating their conditions and get qualified answers. To address this issue, the approach of an interactive platform was made, which should allow affected patients or physicians the possibility to ask experts their specific questions to gather and improve their knowledge about their condition. This paper introduces the pan-European Internet platform EXABO, an Expert Advisory Board, which is developed within the framework of the European Reference Network for rare respiratory diseases (ERN-LUNG). The purpose of establishing this platform is initially dedicated to rare respiratory diseases in whole Europe, whilst the set-up is however, planned to be a generic tool for additional diseases or groups of diseases. This paper gives an overview of the concept and planning of the EXABO platform and shows how the platform is to be implemented.

Keywords. Rare Diseases, Rare Respiratory Diseases, ERN-LUNG, Expert Advisory Board.

Introduction and Motivation

The European Union (EU) considers a disease to be rare, if not more than 5 in 10,000 people in the EU are affected by one [1]. According to most recent estimates, there are approximately 5 to 8 thousand known rare diseases that affect the lives of 6% to 8% of the European population [1]. Due to the low prevalence of rare diseases, there is a deficiency of medical and scientific knowledge in this field and providing diagnosis and highly specialized treatment and care for patients with a complex health condition can be rather difficult for Healthcare Providers and costly for patients. For this reason, many patients suffering from rare diseases or conditions remain undiagnosed or without a sufficient treatment. In order to ensure a better and improved patient care and treatment, the EU established the European Reference Networks (ERN) in the fields of 24 thematic areas of rare diseases [2]. The project was launched in March 2017 and is a

¹ Corresponding Author: Désirée Walther, Medical Informatics Group, University Hospital Frankfurt, Theodor-Stern-Kai 7, 60590 Frankfurt am Main, Germany; E-mail: desiree.walther@kfgu.de.

non-profit, international, professional, patient-oriented and scientifically networked project. The main goal is the collaboration of EU Member States, which contributes to the pooling of experts and the dissemination of knowledge among healthcare providers across borders. The ERN-LUNG, which is the network for rare respiratory diseases, currently consists of 60 centers (health care facilities, health care providers) from 12 countries, which are specialized in rare respiratory diseases. ERN-LUNG includes 9 Core Networks that represent the diversity of the diseases and conditions affecting the respiratory system [3].

In order to provide patient access to expert advice on rare respiratory diseases and conditions, a web-based European cross-border Expert Advisory Board (EXABO) is being designed and set up for patients and physicians with individual questions regarding their health condition.

The system made use of the experience gathered with a similar system exclusively dedicated to the field of cystic fibrosis (ECORN-CF)², that had been operational ever since being funded by the European Commission as a pilot project. The aim is to disseminate expertise on rare lung diseases, identify new possibilities and techniques for treatments and care for patients and provide sufficient answers to complex questions regarding the respiratory system.

1. Methods

1.1. Requirement Analysis

In order to ascertain the requirements for the software solution, workshops with experts from the domain of rare diseases were organized to extract those needs and expectations in a structured manner. In addition, an analysis of the already existing ECORN-CF software has been made by interviewing the coordinators of ECORN-CF.

The main focus was set on filtering out the strengths and weaknesses of the solution. General experiences have been incorporated and refined. For example, the idea of distributing the user roles in ‘moderators’ and ‘experts’, like described in the following, has been adapted and further developed.

1.2. Conception of User Roles

Based on the results of the expert interviews and analysis of ECORN-CF, the following idea of structuring the user roles has been developed.

The fields of expertise within the ERN-LUNG can be split into eight groups: (1) interstitial lung disease, (2) cystic fibrosis, (3) primary ciliary dyskinesia, (4) pulmonary hypertension, (5) nonCF-bronchiectasis, (6) α 1-antitrypsin deficiency, (7) mesothelioma, and (8) chronic lung allograft dysfunction.

In EXABO, each group will be covered by ‘experts’ for the disease and ‘moderators’ for coordinating the questions and answers. For each field of expertise per participating country, there is an expert group with at least one English speaking ‘moderator’. For each field of expertise, the expert groups are linked via at least one ‘superordinate moderator’ across Europe. In consequence, each participating European country provides at least one ‘moderator’ and optionally a various number of ‘experts’

² <http://ecorn-cf.eu>

for each expert group. The members of an expert group are organized in a hierarchical way. In the following, the structure is visualized for the expert group for interstitial lung diseases (ILD) with one ‘moderator’ and one ‘superordinate moderator’ in a simplified way.

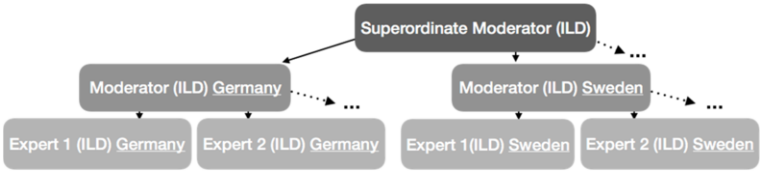


Figure 1. Hierarchical structure of members with different user roles for the expert group ILD.

Another user role is the ‘questioner’, who contacts the ERN via EXABO for receiving advices by the ‘experts’.

1.3. Conception of the Question-Answer-Process in EXABO

In general, questions can be submitted to the system via a web interface from any place by patients as well as by physicians. No registration process would be necessary. The submission of an e-mail address is obligatory, since the reply is sent via e-mail to the ‘questioner’. Due to the fact, that the addressed disease as well as the country must be chosen, the question will be assigned automatically to the appropriate ‘moderator’. The submitted question will then be checked for reasonableness. In the following, the question is assigned to an ‘expert’ for answering. The platform EXABO has got a filtering system that suggests ‘experts’ based on their area of expertise. This feature is not intended to automatically assign the questions to ‘experts’, but serves as a support to the ‘moderator’ without compromising the quality claim.

In case that the chosen ‘expert’ is not able to answer the question for some reason, the question can be returned to the ‘moderator’, who can reassign the question to other ‘experts’ or translate the question in English and send it to the ‘superordinate moderator’ of the same field of expertise. The history and comments attached to the questions will be stored and only visible to internal users.

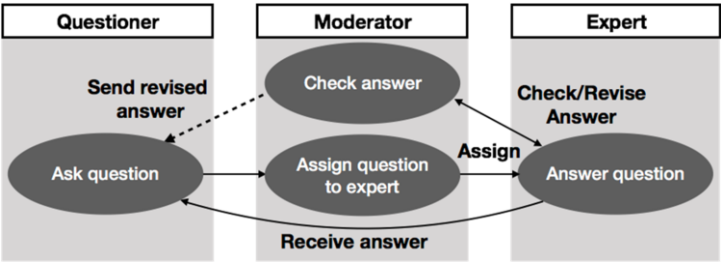


Figure 2. Process of questioning.

The ‘superordinate moderator’ has the possibility to assign the question directly to a single ‘expert’ or to an expert group of another member country with the same disease focus. A special feature of the platform is that a ‘superordinate moderator’ has the opportunity to open a discussion round in addition to the normal assignment to an ‘expert’ in order to be able to clarify particularly complex questions of rare diseases. In consequence, if a question cannot be solved by a group of experts in one country, it can

be reallocated across Europe or discussed by individual ‘experts’ from several other countries.

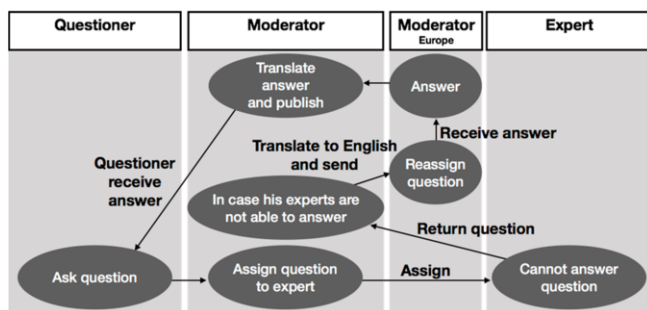


Figure 3. Process of questioning in cooperation with the ‘superordinate moderator’.

At the end of the question-answer-process, the ‘moderator’, who initially translated the question into English, receives the proposed answer from the ‘superordinate moderator’. Due to quality assurance reasons, the formulated answer is checked by the ‘moderator’ regarding formal aspects.

After approval of the answer, it will be translated into the origin language of the question. The answer then will be saved in the archive in English as well as in the origin language and ‘questioner’ will automatically receive the response to the question.

1.4. Implementation and previous Work

There are several options for the implementation of such a system. On the one hand, existing generic tools can be configured and used. This can be, for example, a common solution for a help desk software like OTRS³. First tests have shown that the configuration is not customizable in a sufficient way or too complex to handle. Help desk solutions like Zendesk are designed to provide a higher efficiency and quantity [4]. However, the focus of the project is on the quality of the response and not on the quantity of the questions answered.

On the other side, an individual realized solution could be used. For example, ECORN-CF is realized directly for covering explicitly that subject area of rare respiratory diseases and cannot be adapted to others that easy. Furthermore, the possibility of answering difficult questions in a pan-European discussion round is not available. An extension and technical upgrade of the ECORN-CF software or similar projects would come along with a high amount of effort, so that the decision has been made to conceptualize and implement a new software solution.

Nevertheless, the experiences made by the practical usage of ECORN-CF can be used for designing the new solution EXABO, especially the ideas of quality assurance, anonymization and the division of the user roles into ‘experts’ and ‘moderators’.

The platform will be implemented in form of a Java web application, utilizing the Apache Maven environment. For authentication, Keycloak, an open source authentication service, will be used. The user information is encrypted and the service runs on a local server [5]. Front-end development will be based upon the popular

³ <https://www.otrs.com>

Bootstrap framework. The open source toolkit Bootstrap is optimized for designing mobile web applications and provides a front-end component library [6]. The platform is intended to support mobile views and facilitate working with EXABO on mobile devices. To the actual date, a first prototype of EXABO has been realized, and will be enhanced stepwise in close cooperation with the medical experts of the ERN-LUNG.

2. Conclusion and Outlook

One major challenge is to plan EXABO as generic as possible from the beginning, so the transfer to other ERNs will be supported. Especially complex medical issues, which cannot be answered by the physician or expert in his own country, can be reassigned and discussed with other experts on that field or within other ERNs. The development of EXABO based on the representative example of ERN-LUNG provides an excellent condition for addressing this challenge.

The software should user-friendly with an appealing design to address people with various diseases and practitioners throughout Europe. Users who visit the platform for the first time should immediately know what the main goal of the internet platform is. To reach that goal, the possibility to ask a question must be placed centrally on the start page. The internal view for the ‘experts’ and ‘moderators’ has to be self-explanatory to ensure a small amount of additional work for those.

A Europe-wide expert board for answering questions concerning rare respiratory diseases does not yet exist to this extent. Only platforms, which are restricted to a special area of rare respiratory diseases. Concepts and experiences made within other projects like ECORN-CF can be utilized and analyzed, e.g. the concept of the hierarchy structure of the users. The feedback of the users will directly influence the development of EXABO and will ensure a high practical use.

As soon as the question-answer-process is realized in EXABO in a first version, user accounts for a subset of the experts of ERN-LUNG will be defined as well as roles and groups. In the following a scenario-based test will be performed and the feedback will be integrated in the further development. In the next step, this procedure will be repeated with other ERNs for testing the adaptability of the system.

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