

User Manual EXABO

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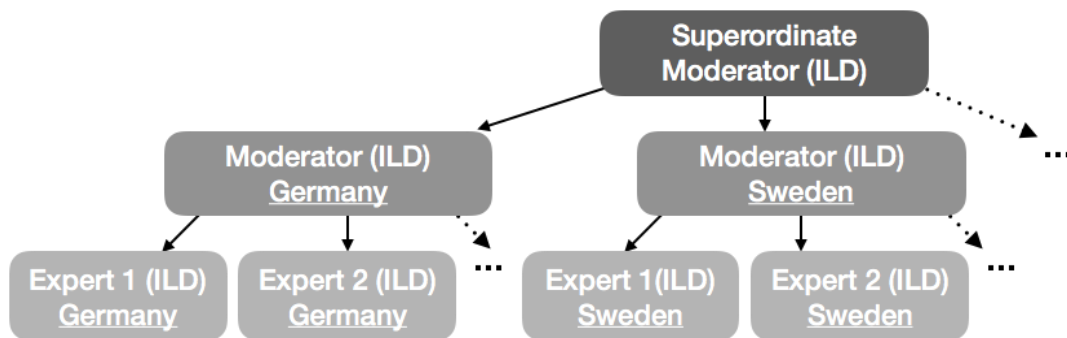
1 Introduction

The internet platform EXABO has been developed in the context of the European Reference Network for rare respiratory diseases (ERN-LUNG). EXABO aims to reach a wide range of patients that are affected by rare lung diseases, their relatives, and the physicians who are treating these patients. ERN-LUNG is an alliance of more than 60 centers of expertise (Healthcare Providers) distributed across 12 European Member States with experts who are focused on the treatment of patients affected by rare lung diseases. ERN-LUNG currently consists of nine lung disease specific thematic areas (Core Networks). The current Core Networks are (1) Interstitial Lung Diseases, (2) Cystic Fibrosis, (3) Pulmonary Hypertension, (4) Primary

Ciliary Dyskinesia, (5) non-CF Bronchiectasis, (6) Alpha1-Antitrypsin Deficiency, (7) Mesothelioma, (8) Chronic Lung Allograft Dysfunction, and (9) Other Rare Lung Diseases (e.g. respiratory malformations, Ondine syndrome). The EXABO platform classifies these subgroups into Core Networks. The lung disease specialists, who are members of ERN-LUNG and are assigned to answer the incoming questions via the EXABO platform, are assigned to at least one Core Network on the basis of their expertise. Given the fact that EXABO is planned to be used throughout Europe, and the questions can be posed in different European languages, a group of experts will be formed for each participating country or language zone respectively per Core Network with these experts. For example, there is a group of experts for the Core Network "Cystic Fibrosis" in Germany and a group of CF experts in France. The questions that are asked in German are automatically allocated to the group of experts for Cystic Fibrosis, whereas questions asked in French are assigned to the French group of experts for Cystic Fibrosis. However, the questions must be assigned to the relevant expert group in an organized manner. For this reason, at least one moderator must be in charge of every expert group. This moderator assigns all the questions that are allocated by the EXABO system to an expert or he has the possibility to discuss an answer to the question with the whole group or several of the experts. If the question is assigned to a single expert, the person asking the question will receive the answer to his question via email. Internally, however, the moderator has to approve the answer before it is forwarded to the person asking the question. Should the moderator feel the answer should be amended, he can send the answer with his comments back to the expert. This process will continue until the moderator gives his approval for sending the answer to the questioner, publishing and archiving it. However, an expert can also return the question. In this case, it is redistributed by the moderator. If the question cannot be answered by an expert from a country with the relevant area of expertise, it can be reassigned within Europe or discussed in English. Each Core Network has a superordinate moderator, who is responsible for reassigning the question (Figure 1). The administrator is responsible for user administration and assigns the internal roles such as expert, moderator and superordinate moderator. The person asking the question does not receive a user account, as a login process is not required for asking.

Important Notice:

We will start EXABO in English only and at a limited level of differentiation: There will only be the role of the moderator (TOF Wagner and the NCT) and they will distribute all incoming questions to the resp. CN leader (or the person identified to be responsible for this task within the CN). Therefore, in the following, the user groups "Expert" and "Moderator" of the internet platform EXABO are presented and the tasks and functions are described in detail.



2 Role: Questioner

The questioner can first browse the homepage to find general information regarding the project or use the archive tab to search already released questions and answers, filtered by language and area of specialization, in order to find an answer to a similar question to his/her own that has already been answered via the system. If no similar question has been asked, the questioner can enter the question via the button on the start page or via the "Ask question" tab. The questioning process consists of four steps: "Select range", "Select language", "Ask question" and "Personal data". The first step is to select the ERN-LUNG Core Network, which means the area of rare lung diseases in relation to the question that is going to be asked. All nine Core Networks are supported: (1) Interstitial lung diseases, (2) Cystic Fibrosis, (3) Pulmonary Hypertension, (4) Primary Ciliary Dyskinesia, (5) non-CF Bronchiectasis, (6) Alpha1-Antitrypsin Deficiency, (7) Mesothelioma, (8) Chronic Lung Allograft Dysfunction, and (9) Other Rare Lung Diseases (e.g. respiratory malformations, Ondine syndrome).

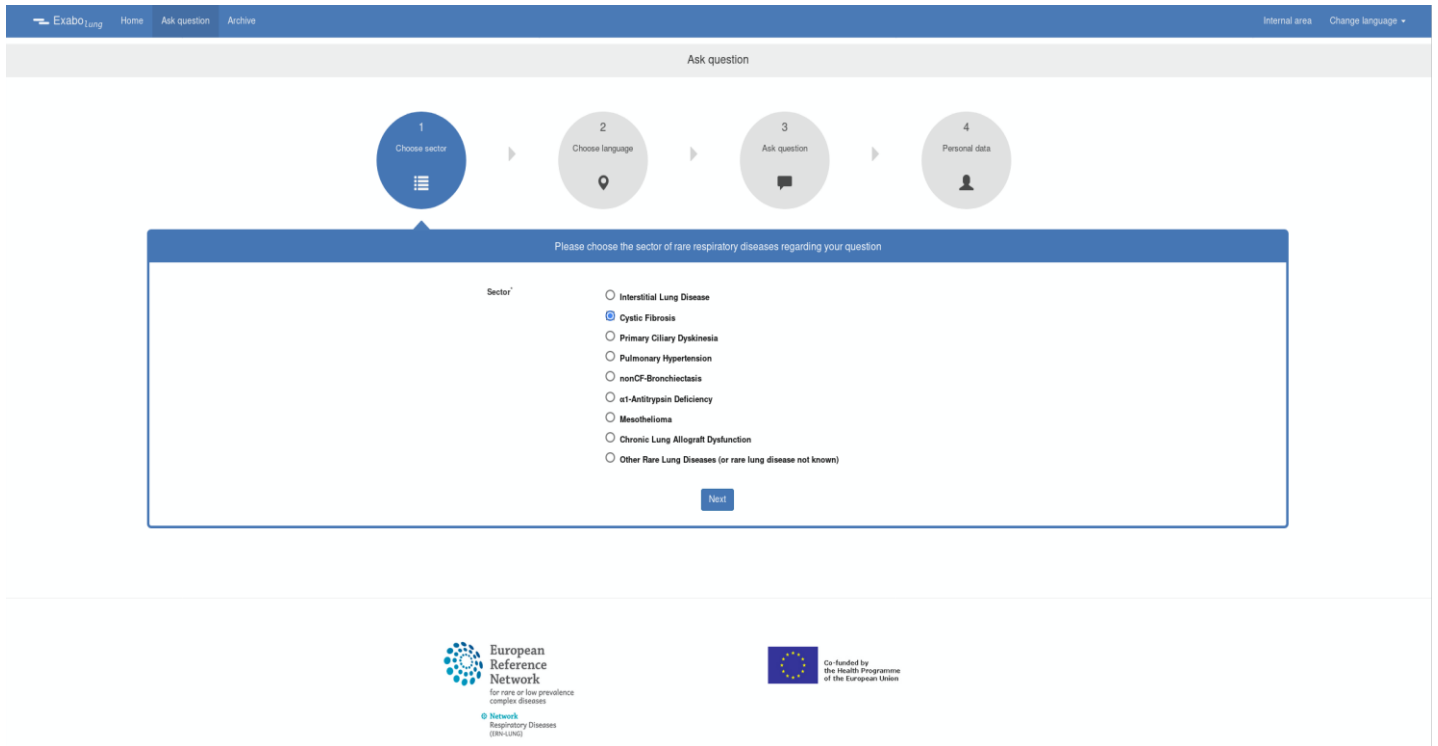


FIGURE 1: INQUIRY PROCEDURE: SELECT FIELD OF EXPERTISE OF RARE LUNG DISEASES

The next step is to specify the language (Figure 2, limited to German and English for the time being). The language cannot be determined by using IP information, as there should be the option to select the desired language for asking a question. For example, if you wish to ask a question whilst travelling, it is important to be able to manually choose your desired language. Currently, questions are supported in English and German.

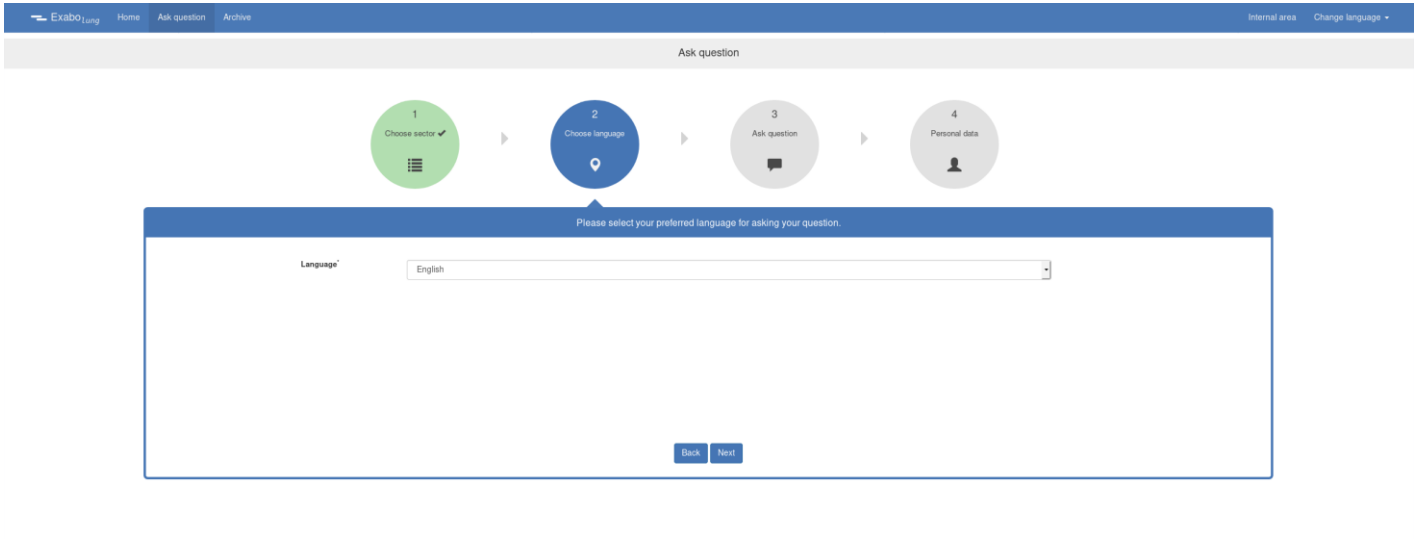


FIGURE 2: INQUIRY PROCESS: LANGUAGE SELECTION

Once the desired language is chosen, the request to enter a question (Figure 3) in step three of the inquiry process follows. The subject is required to categorize the questions later on. Personal data must not be included in any of the questions.

FIGURE 3: INQUIRY PROCESS: INDICATE SUBJECT MATTER AND ENTER QUESTION

In the last step of the inquiry process, personal data such as age, gender, address and email will be collected (Figure 4). While age and gender can be helpful information for selecting an appropriate expert and eventually answering the question, the address and email address are required for allocation and notification within the EXABO system and are therefore mandatory fields. The address is needed if the question is to reach a specific group of experts from a multilingual country, e.g. if French is selected but the questioner's address is located in Belgium. Based on the questioner's address, this question will be directed to a Belgian expert rather than a French one. The moderator's task is to assign the questions that were allocated to his expert group to one expert or to open a discussion round, in which several experts from the moderator's expert group can jointly pose an answer.

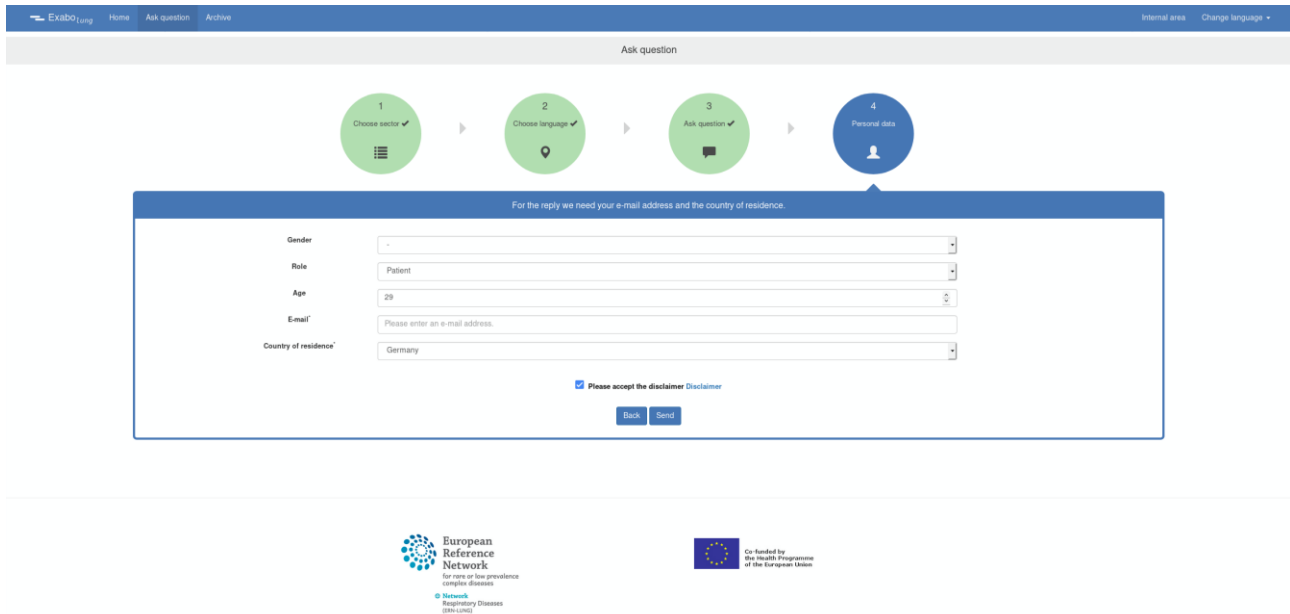


FIGURE 4: INQUIRY PROCESS: PROVIDE PERSONAL INFORMATION AND ACCEPT DISCLAIMER

3 Role: Moderator

The moderator’s task is to assign each question that has been allocated to his expert group to one expert or to open a discussion round, in which several experts from the moderator’s expert group can jointly develop an answer. The user logs on via the login-button, which is located at the top right-hand corner of the EXABO-webpage. In a next step, the user can enter his/her login details in order to get to the moderator’s welcome page.

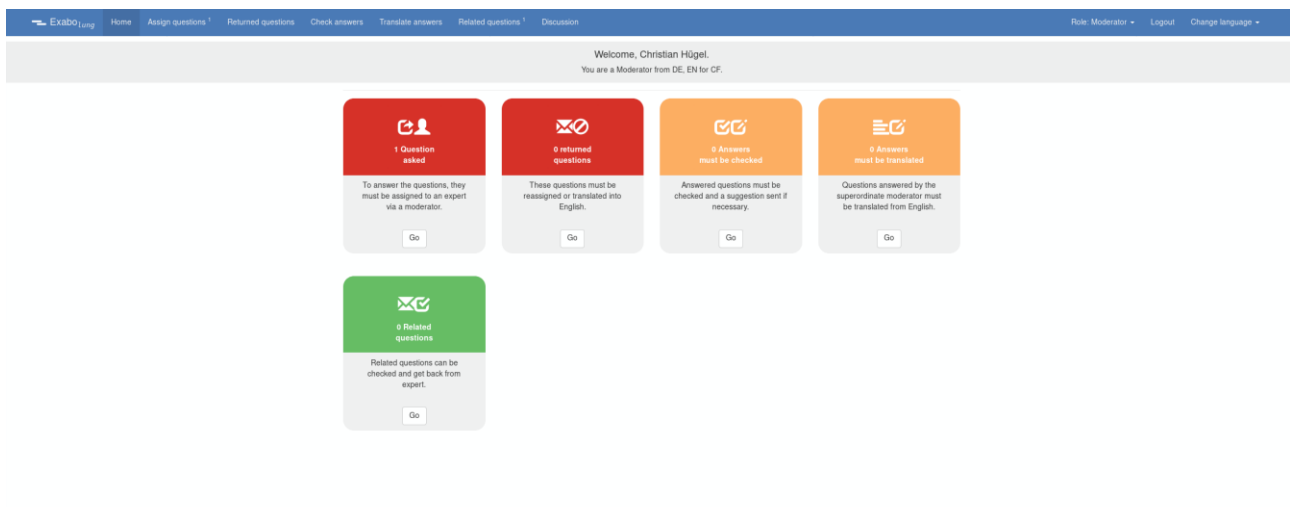
3.1 Subpage/moderator’s welcome page

The Moderator’s welcome page shows all respective tasks (Figure 5), which are displayed in containers. These containers represent the number of tasks with explanatory texts. The tasks can be viewed by clicking on the container or via the corresponding tab in the menu bar.

The "moderator" has the following main tasks:

- Assignment of questions to the "experts"
- Review answers
- Reassignment of questions (if necessary)
- Translation of question into English and forwarding them to the “superordinate moderator” if necessary

- Translation of answer back into original language after having received a revision from the superordinate moderator
- Reclaim questions from "experts" if they do not answer a question in-time or after having been asked several times.
- Participation in discussions, should he be invited to join them or feel the need to create



- one himself

FIGURE 5: MODERATOR'S WELCOME PAGE

3.2 Subpage „assign question to „expert“

The subpage "assign questions to an expert" lists the questions to be assigned, with the questions sorted in chronological order. The top "question container" is extended at start up, which enables a quick beginning. The questions are scrollable in the container only when expanded. During this process, the remaining containers are retracted for reasons of clarity.

If the "question container" is extended, the moderator has the option to recommend the question to be deleted, i.e. for questions that are not related to the specific topic or not respectful. Clicking a specific button will trigger a popup window which will open and show a modal window with a confirmation text message. If a question is proposed for deletion, the question is hidden from the view of the "moderator", but exists in the database and is finally deleted by the "administrator" only.

3.2.1 Subject

The question's subject can be edited, in case the core of the matter is not clear enough. The iconic symbol for changing the subject is a pencil. The subject can be edited in a popup, which will return back to the same position after expansion.

3.2.2 Anonymize question

A question can be edited for anonymization matters. There is the possibility of reversing the editing of the question in case the moderator i.e. has deleted a sentence by mistake which he didn't plan to anonymize.

3.2.3 Assigning a question

The questions are basically displayed in a balloon and throughout the system in a consistent manner. Below, the "moderator" can now select whether he wants to assign the question to a single "expert" (Figure 6) or start a discussion round with several "experts". The "moderator" however can have a discussion with only a single "expert" in order to answer the question. If the "moderator" enables the button "send question to expert", a pop-up will appear, displaying the available "experts" arranged in a drop-down-menu, containing a profile picture of the "experts" as well as information on their expertise. The pop-up for starting a discussion has a similar structure, but on the right side next to each "expert" a selection field appears for adding the "expert" to the discussion (Figure 7). After the discussion the "moderator" formulates an answer and publishes it in the archive.

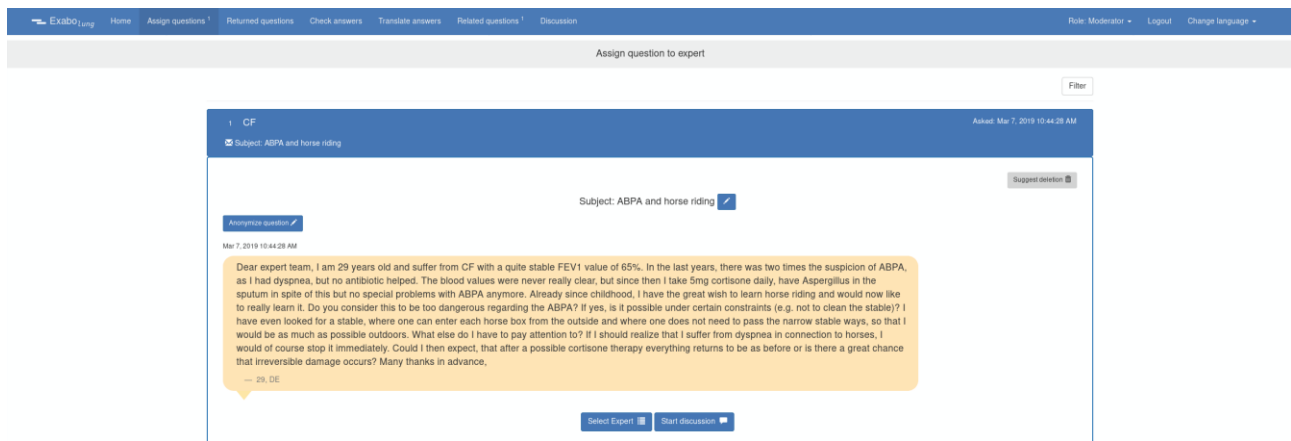


FIGURE 6: SUBPAGE "ASSIGNING QUESTIONS TO EXPERTS"

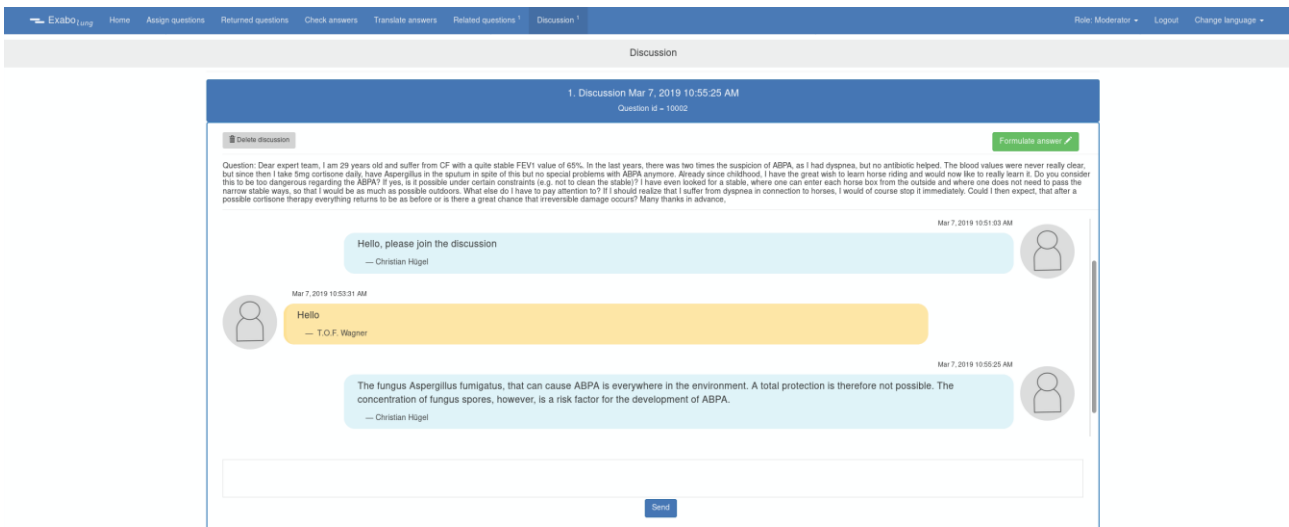


FIGURE 7: "MODERATOR" BEGINS A DISCUSSION IN ORDER TO FIND AN ANSWER TO A QUESTION

3.3 Subpage "returned questions" by expert

Should an "expert" not be able to answer a question, it can be returned to the "moderator". The "moderator" will then reassign the returned question on the subpage "returned questions" either to another "expert" from his group of experts or he can translate the question in English and send it back to the "superordinate moderator". The "expert" has to comment on why he has returned a question. There is the possibility to create private notes or comments that are only visible to him and not viewable for the "superordinate moderator". If the "expert" is not able to answer the question due to time constraints, and notifies the "moderator" via email, he can make his comment privately. Another scenario would be if personal information was written in the commentary. In this case, it would make sense to hide the "expert's" comment and write a separate anonymized comment with the given information. For this reason, the "moderator", when writing his own comment, is shown the "expert's" comment in a free field for the entering of a comment, which can be edited or deleted (Figure 8).

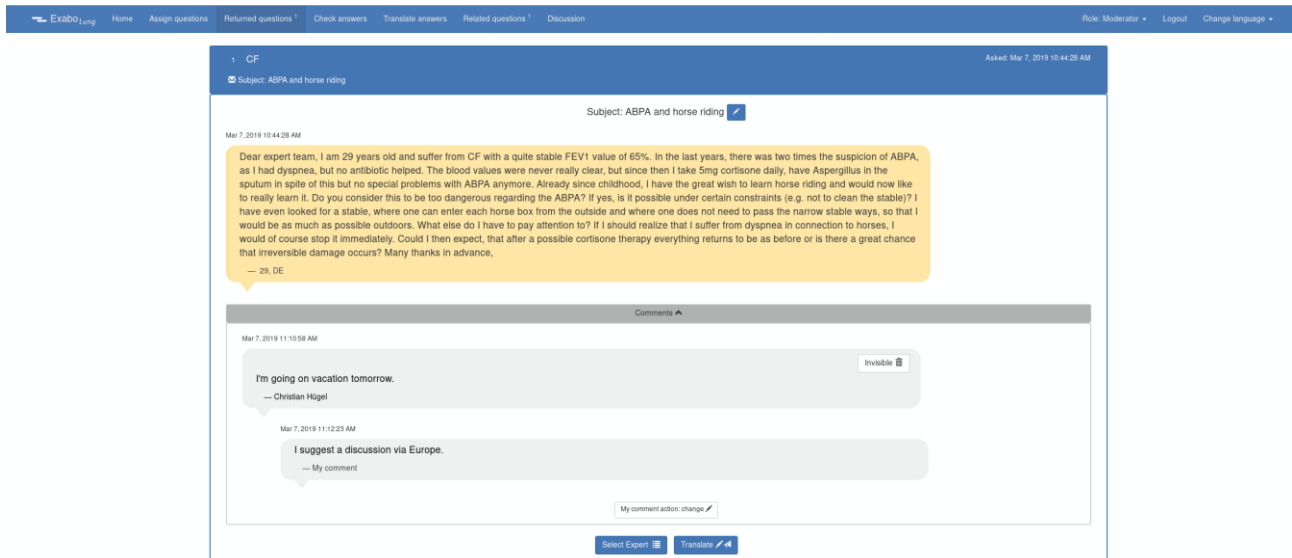


FIGURE 8: THE "MODERATOR" ASSIGNS THE RETURNED QUESTION TO ANOTHER "EXPERT" OR SENDS IT TO THE "SUPERORDINATE MODERATOR"

3.4 Subpage "check answers"

If an "expert" has given the answer to a question, it is reviewed by the corresponding "moderator" (Figure 9). He can either grant approval or propose an amendment of the answer. The "expert" will see the proposal and can react to it. The process is repeated until the "moderator" declares the answer completed and publishes it. A message is sent to the "expert" by means of a pop-up, whereat the "moderator" is provided with the current answer of the "expert" as a suggestion for editing (Figure 10).

ExilDOLang Home Assign questions Returned questions Check answers Translate answers Related questions Discussion Role: Moderator Logout Change language

Check and publish the answers from the experts

Filter

1 CF Asked Mar 7, 2019 10:44:28 AM
Subject: ABPA and horse riding

Mar 7, 2019 10:44:28 AM

Dear expert team, I am 29 years old and suffer from CF with a quite stable FEV1 value of 65%. In the last years, there was two times the suspicion of ABPA, as I had dyspnea, but no antibiotic helped. The blood values were never really clear, but since then I take 5mg cortisone daily, have Aspergillus in the sputum in spite of this but no special problems with ABPA anymore. Already since childhood, I have the great wish to learn horse riding and would now like to really learn it. Do you consider this to be too dangerous regarding the ABPA? If yes, is it possible under certain constraints (e.g. not to clean the stable)? I have even looked for a stable, where one can enter each horse box from the outside and where one does not need to pass the narrow stable ways, so that I would be as much as possible outdoors. What else do I have to pay attention to? If I should realize that I suffer from dyspnea in connection to horses, I would of course stop it immediately. Could I then expect, that after a possible cortisone therapy everything returns to be as before or is there a great chance that irreversible damage occurs? Many thanks in advance.

— 29, DE

Mar 7, 2019 11:18:55 AM

Hello, the fungus *Aspergillus fumigatus*, that can cause ABPA is everywhere in the environment. A total protection is therefore not possible. The concentration of fungus spores, however, is a risk factor for the development of ABPA. Therefore it is not recommendable to stay in areas with a high fungus spore load. The riding stable, and here possibly especially the horse box, stable ways and riding hall, can have a high load with fungus spores. These arguments are on the one side, and on the other are the special conditions of the stable, that you already found. You could mostly be outdoors. It would be favorable that you should not do the cleaning. You have the great wish to learn horse riding, the sport would be favorable. The severity and the course of an ABPA are not predictable and can vary between light symptoms with a good therapeutic response and a severe course. In the end, your personal weighing of possible benefits of the riding sport on the one hand and on the other hands the potential risks plays an important role. Best regards.

— Christian Högel

Answer is not ok ✖ Answer is correct ✔

FIGURE 9: VIEW OF "MODERATOR": CHECK ANSWER

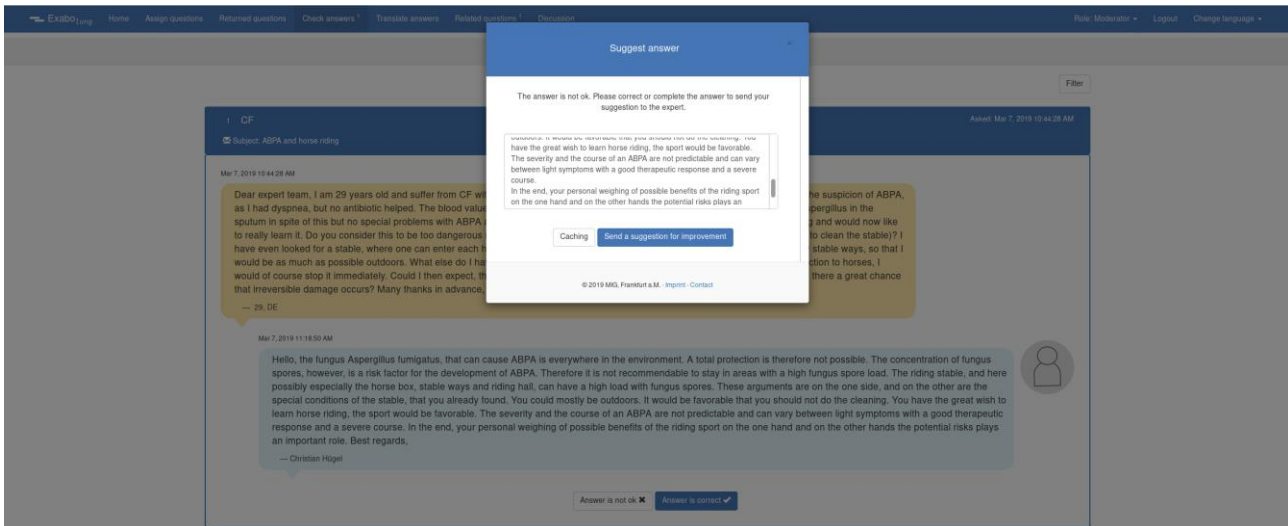


FIGURE 10: VIEW OF "MODERATOR": CHECK ANSWER: SEND SUGGESTION FOR IMPROVEMENT

3.5 Subpage "translate answers"

In case the questions regarding rare respiratory diseases cannot be answered within an expert group of a country, they will be reassigned by the superordinate overarching Europe-wide moderator or discussed with selected "experts", so that an answer will be formulated in English by the "superordinate moderator". The "moderator" who previously sent the question to the "superordinate moderator" is now prompted to translate the answer he receives from the "superordinate moderator" into the language in which the question was asked and publish it in the archive.

3.6 Subpage "Related questions"

This subpage serves the "moderator" as an overview of his corresponding questions. He can view which questions were assigned to the "experts" and whether those questions have been answered. Timestamps are set for the complete log of questions, assignments and the "expert's" answers can be viewed for each question. In case an "expert" hasn't answered a question over a long period of time, the "moderator" can retrieve the question and it will appear on the subpage "assign question to expert" once again. In consequence, the question will be withdrawn from the "expert". The view of the containers resembles the archive. The containers that have a green frame, should include the questions that have been answered, checked and published in the external archive. The containers that were given a yellow frame, include questions that have been answered, but still need to be approved by the "moderator". Containers with a red frame indicate that there questions which have been assigned but have not yet been answered. This is meant to signalize that the experts may have to be reminded that there are questions for them to be answered, or in case they haven't responded for a longer period of time, the question may be withdrawn.

Questions that have a gray frame have neither been assigned nor have experienced any interactions with an "expert" yet (Figure 11).

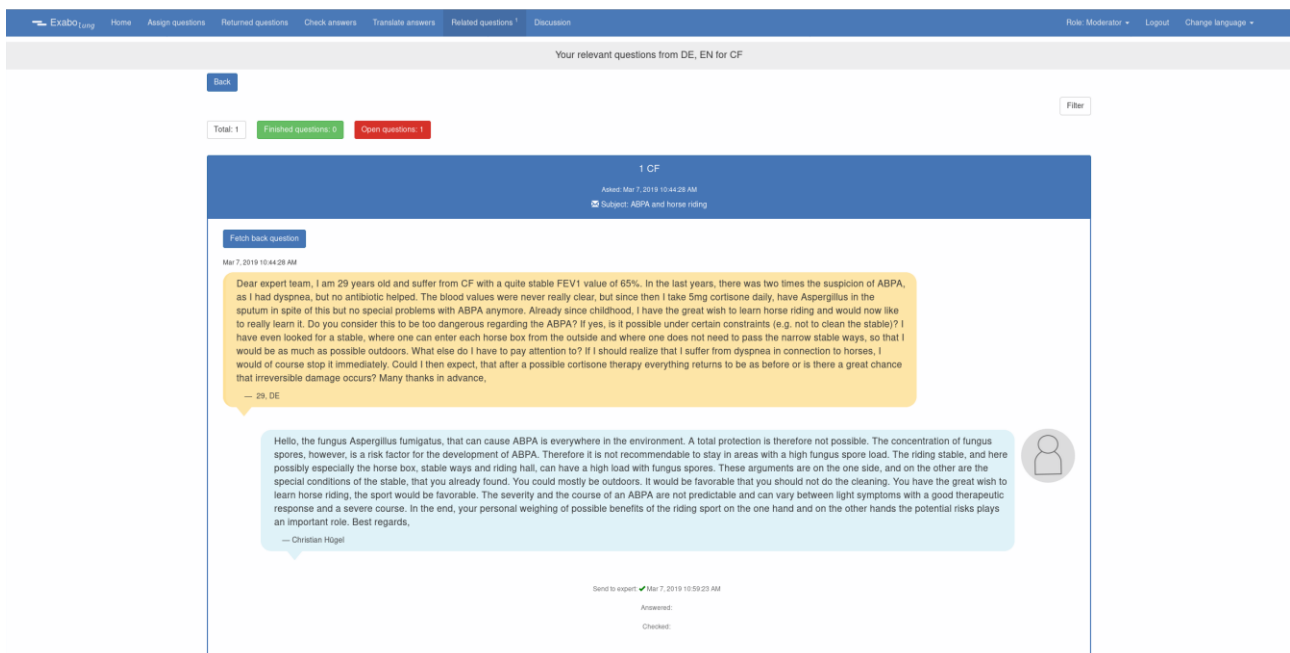


FIGURE 11: MODERATOR VIEW: RELATED QUESTIONS

4 Role: Expert

The task of the "expert" on the EXABO platform is to answer questions on specific topics of rare respiratory diseases. The questions may be asked by patients or their relatives, general practitioners, and other care team members. An "expert" should relate to at least one area of rare respiratory diseases. For example, an "expert" can answer questions regarding Cystic Fibrosis. As the questions are language-specific, the "expert" belongs to a group of experts of a specific country for a Core Network. Certainly, an expert can be assigned to several roles. In example, the expert may have the expertise for several Core Networks, which makes him a member of several expert groups. After logging onto the welcome page of the EXABO internet platform, he can access his welcome page using the login data he received (Figure 12).

4.1 Subpage "expert's home/welcome page" of expert

The welcome-page serves the orientation of the "expert". On the upper part of the page the Core Networks are listed, to which the experts belong; on the bottom are the tasks an "expert" will be expected to fulfil. Similar to the welcome page of the "moderator", the "expert" receives information texts regarding his tasks, which are displayed as containers. The "expert's" main task is to answer questions. Further, there is

the possibility for him to attend discussion rounds which are initiated by the "moderator" or the "superordinate moderator", should he be proposed to participate in the discussion. If the "expert" is active in more than one discussion, the number of discussions will be displayed in the navigation bar. The welcome page displays the amount of questions that have been answered and the number of answers that have to be corrected, as well as appropriate answers, that have been reviewed and published by the "moderator".

Accordingly, the tasks of an "expert" are:

- Answer questions
- Improve answers
- Take part in discussions to find adequate answers

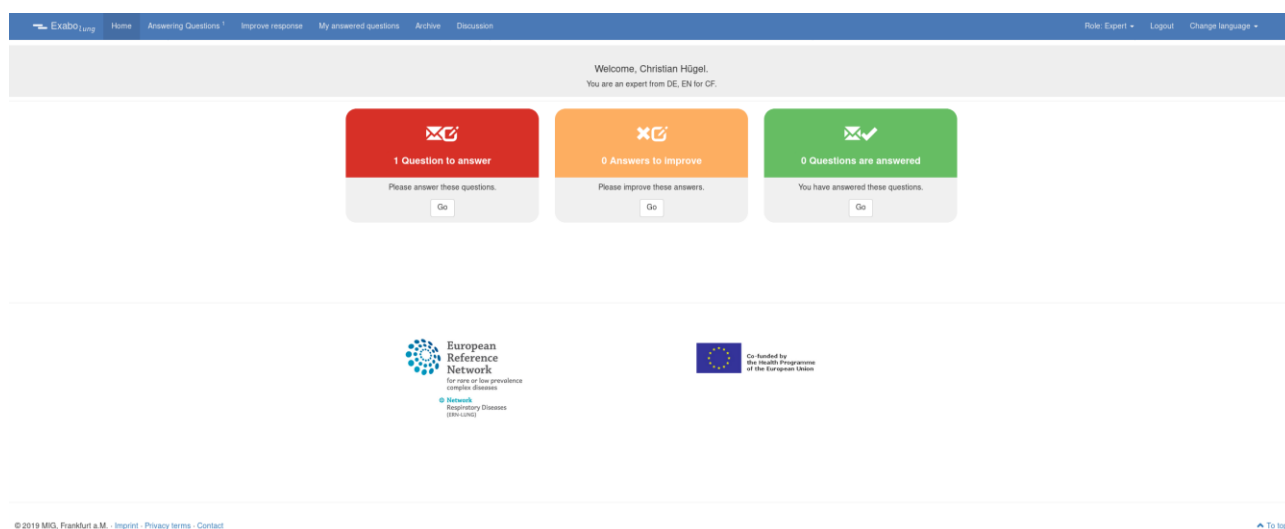


FIGURE 12: WELCOME PAGE OF "EXPERT"

4.2 Subpage "answer questions"

An "expert" is assigned by ERN-LUNG to answer questions from his subject area that are mainly asked in his national language (Figure 13). It is possible, however, that a "superordinate moderator" assigns a question to the "expert" in English, if it could not be answered by the expert group from the respective country/language zone. The questions translated into English appear together with those assigned to him from his circle of experts on the "answer questions" subpage, whilst the translated questions are

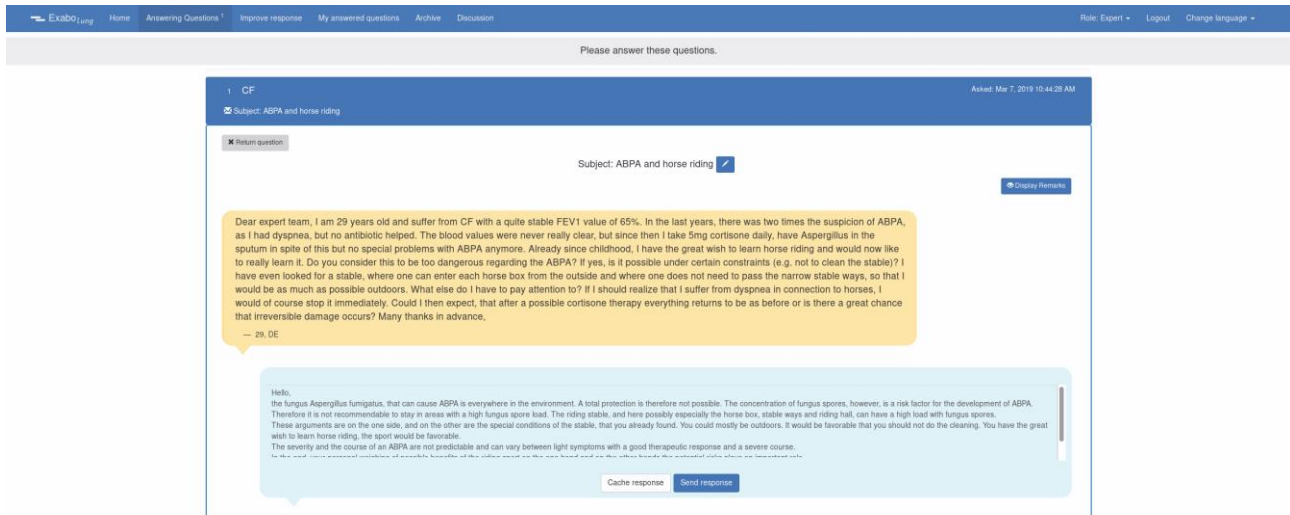


FIGURE 13: EXPERT VIEW: ANSWER QUESTIONS

highlighted. Questions that are assigned to the "expert" directly by the "superordinate moderator", may contain comments, that can help the "expert" in the answering process. The question with the oldest timestamp is located at the top, and the box, which contains the questions and answers, is extended. This box may include further questions, which are sorted in the order of timestamp, which means the questions are listed in chronological order. The answers can be cached and edited at a later point in time. The "expert" can return a question he is not able to answer. By clicking on the button "return question", a pop up will appear, suggesting the "expert" to leave a comment for the "moderator" as the reason for returning the question. The comment may help the "moderator" in the reassignment of the question.

4.3 Subpage "Improve question"

The "expert's" submitted answer always has to be approved by the "moderator" before it can be published. If the "moderator" feels that the answer should be improved, he comments on it and then sends the answer back to the "expert", who edits the question and sends it back to the "moderator" again for approval. The subpage is adapted to the design of the other pages and resembles the subpage for writing a reply, with the only difference, that comments are available by the "moderator" to expand the response in each case.