

THE INTERNET PLATFORM EXABO – FROM BETA TO FULL VERSION

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INTRODUCTION

Due to the small number of experts, it is often difficult for patients suffering rare conditions to access quality diagnosis, treatment and care. To ensure patient access to the right therapy and care, the European Commission has established the European Reference Networks (ERNs), which are virtual networks involving Reference Centers of expertise across Europe which consist of a network of healthcare providers and patient organizations, aiming to provide Europe-wide care for all patients suffering rare diseases. The European Reference Network LUNG (ERN-LUNG) represents the network that covers the diversity of rare conditions that affect the respiratory system.

The experts from ERN-LUNG are split into expert groups for a participating country based on their expertise in rare respiratory diseases. Each expert group is hosted by a moderator, who can assign the question to an expert from his team or formulate a common answer with several other experts in a group discussion provided by the system. If a question cannot be answered in the relevant subject-based expert group of a specific country, it may be discussed and answered by Europe-wide experts.

The internet platform was launched as a beta version and tested by ERN-LUNG members, and all processes are constantly being improved.

Figure 1: Visualization of the initial patient survey

METHODS

In the context of ERN-LUNG, the Expert Advisory Board (EXABO) was developed and implemented basing on a generic approach. EXABO is a pan-European internet platform enabling patients, their relatives and physicians to ask specific questions relating to any rare conditions of the respiratory system and receive qualified answers from experts who are specialized in this field.

CONCLUSION

After having released a successful beta test phase, EXABO is now being transformed to a full version. Furthermore, due to the generic implementation approach, it is possible to adapt the internet platform EXABO to European Reference Networks for other rare diseases.

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