

## e-ENERCA: telemedicine platform for rare anaemias

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### Abstract

The creation of a telemedicine, tele-expertise platform opens a new challenge within the European Network for Rare and Congenital Anaemias (ENERCA; [www.enerca.org](http://www.enerca.org)). This is a cornerstone in the field of rare anaemias, in which national expertise is usually scarce and a significant number of patients remain undiagnosed. Experts in rare diseases are specially needed of shared knowledge platforms offering the possibility of a faster and more accurate diagnosis and the availability of a better patients' follow-up. The platform developed by e-ENERCA will be user friendly and intuitive so it will be used by the majority of professionals without requiring a specific formation. The idea of inter professional consultation is to bring medical experts together for collaborative involvement in activities that maximize the benefits and improvement in patient care.

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### Introduction

ENERCA Project started in 2002 with the global objective of increasing citizen's health by reducing inequalities in the diagnosis and prevention of major rare anaemias. The present telemedicine, tele-expertise ENERCA Project aims to contribute to this global objective in order to provide a new strategic collaboration environment.

ICT tools are used by networks to communicate and share their expertise in the distance (tele-expertise) and also to perform a remote diagnosis by tele-medicine. The idea of inter professional consultation is to bring medical experts together for collaborative involvement in activities that maximize the benefits and improvement in patient care. The practice of consultation and inter professional collaboration involves interdisciplinary relationships, preparation, and advanced

skill development within the specialty areas that tackle Rare Anaemias. This new form of medicine also arises some legal and ethical issues.

Objectives of the telemedicine/tele-expertise platform are to improve access to health services, to increase expertise of health professionals in rare anaemias, and to improve the quality of healthcare in those fields. Legal and ethical aspects are factors to be taken into account in the development of this tool.

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### Materials and Methods

In the field of anaemias, an internet platform will be developed. It will be an interface used in view to help, at a distance, non-expert physicians making, in a first phase a diagnosis (telemedicine) and to offer to experts the opportunity to discuss complex cases (tele-expertise). Diagnostics will follow a coding system in line with internationally recognised systems, for example International Classification of Diseases, assuring efficient sharing of data with other platforms with-in or outside the ENERCA network. All data will be anonymized. None of these services will be given in real time

Legal and ethical aspects were considered.

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### Results

Legal aspects of the telemedicine, tele-expertise platform have been indexed.

Decision trees for diagnosis of rare anaemias are under discussion and the platform is under construction; it fulfills the interoperability requirements and safety exchange of clinical patients' data.

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### Discussion

Our objective is to create a telemedicine (tele-expertise) platform for the diagnosis of (rare) anaemias with capacity of storage and sharing of clinical case information and allowing inter-professional clinical decision support and second opinions.

The challenges are to create a useful and easy to use tool. The physicians should get a response within a reasonable time and why not in their mother tongue. On the other side the experts should not be overwhelmed by simple cases or having to use an overly complex tool. Legal and ethical aspects are related to the healthcare service provided by telemedicine, the data protection, the legal protection of this platform as well as to the health professional liability.

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Key words: rare anaemias; telemedicine; ENERCA; patients; tele-expertise.

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Thalassemia Reports 2014; 4:4879

doi:10.4081/thal.2014.4879

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