e-ENERCA: TELEMEDICINE PLATFORM FOR RARE ANAEMIAS
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6th EUROPEAN SYMPOSIUM ON RARE ANAEMIAS
1st Dutch-Belgian meeting for patients and health professionals
21st - 22nd November 2015
Amsterdam - The Netherlands
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<th>Disclosures</th>
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<td>Company name</td>
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**NOTHING**
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<tr>
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<th>Definite</th>
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<tbody>
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<td>Thalassemia’s</td>
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<td>Membrane disorders (e.g. sferocytosis)</td>
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<td>Enzym defects (e.g. PKD, G6PD)</td>
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<td>PNH</td>
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<td>Other forms of hemolytic disease</td>
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6th European Symposium on Rare Anaemias - 1st Dutch-Belgian meeting for patients and health professionals

+ 4 members
Non-ENERCA partners
Board of specialists
TELEMEDICINE PLATFORM FOR RARE ANAEMIAS

- National expertise on rare anaemias is usually scarce
- There are European experts in the field
Telemedicine

• Objective 1

  – To promote communication and sharing of clinical knowledge through the exchange of information and professional collaboration.
Telemedicine

- Objective 2
  - To allow professionals to share cases, opinions and comments easily and securely via Internet.
Telemedicine

• Objective 3
  – To facilitate research and education by providing the medical community with a tool that can store a large volume of data and images.

eENERCA platform
Why a Telemedicine?

- Since national expertise is usually scarce in rare anaemias, a significant number of patients remain undiagnosed or misdiagnosed. This makes impossible offering a proper prognosis, treatment and genetic counseling, increasing patient and patient’s family anxiety.

- Telemedicine platform facilitates remote diagnosis orientation of complex cases by building a bridge among health professionals in distant locations and experts in rare anaemias. This allows a faster and more accurate diagnosis driving to a better care of the patient.

Our Objectives

- Facilitate the access to diagnosis advice given by experts in rare anaemias in order to decrease the time needed for its achievement, resolve complex cases and reduce the number of patients remaining undiagnosed.

- Promote interprofessional consultation and sharing of knowledge through the exchange of clinical information resulting in the improvement of patient care.

- Foster research and education by providing the medical community with a platform to access a large amount of current information.

Your benefits

- Do not feel alone, share your complex cases easily and securely via Internet and increase your knowledge on rare anaemia diagnosis.

- When needed, a national expert will contact you and will present your case in a peer-to-peer expert group through the platform.

- You do not need a specific formation to use the platform since it is user friendly and intuitive.
Telemedicine: the tool

The applicant
Information asked via a template - -> Decisions trees and proposed diagnosis
No simple answer found?
A report is proposed

Automatic Email

Local expert “Moderator”
(In each country, a local expert is elected)

Automatic Email

ENERCA
Group of experts

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Telemedicine: the tool
Tele-expertise: the tool

Local expert “Moderator”
Propose a summary of the case
In view to keep it for teaching

Close the case
Tele-expertise: the tool
Telemedicine

Legal and ethical aspects

Interuniversity Chair in Law and the Human Genome

University of Deusto, University of the Basque Country

• e-ENERCA telemedicine platform, a second opinion given to the patient after his / her request?
  – No; does not fall into the scope of the Directive as a healthcare service.

• Confidentiality:
  – All the professionals must aim to ensure that patient confidentiality and data integrity are not compromised.
Telemedicine

Legal and ethical aspects

• Legal responsibility
  – As the platform establishes a relation between professionals and patients not involved in this relation,
    • Responsibility of the diagnosis, treatment and follow up concerns the physician in charge of the health service to the patient.
    • Actors must be well identified.
Schedule
2014 - 2016

Specifications
Decisions trees
Legal issues

Open access e-platform
2016
Telemedicine

Conclusions

- Implementation of a telemedicine platform involves:
  - Health workers
  - IT

- Legal and ethical aspects are part of the process.