E L C A N O: European and Latin-American Countries Associated for a Networked database of Outstanding guidelines in unusual clinical cases *

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Abstract. The morbidity and mortality of unusual clinical cases ranges from five to sixfold times those of usual clinical cases. Noneless, there is an acute lack of structured information sources on the best managing practices for those cases. The general objective of ELCANO is to build and exploit a multilingual *Virtual Library* of outstanding clinical guidelines to manage unusual cases. This *Virtual Library* will be distributed across The Internet from the partners servers and accessed by specialists and specialists in training. Gastroenterology will be the initial area of the clinical practice to be addressed. The unique and innovative aspects of ELCANO are its orientation toward unusual cases, the framework embracing countries from Europe and Latin-America, the structured pre-validation of the cases and its multilingual contents as well as their indexing and codification using internationally accepted standards. An immediate benefit from ELCANO will be the availability of critical clinical information in places where there is a lack of experience coming from places where this experience is commonplace. ELCANO is to be regarded as a exploratory measure, to test the implementation of North-South and South-North collaboration in telecommunication of clinical information. When successful, a broader range of medical specialities and more countries in both regions as well as new regions are foreseen to be involved.

1. Introduction

It has been widely accepted that the morbidity and mortality of unusual clinical cases ranges from five to sixfold times those of usual clinical cases. Depending of the accepted definition of the term unusual, this figure may account for as much as 60% of all clinical complications in a Service of an University Hospital. Noneless, there is an acute lack of structured information sources on the best managing practices (diagnosis, treatment, patient information, prevention and prognosis) of those unusual cases. Clinicians usually rely in clinical reports or other colleagues stories to gather information about those cases [1]. An unusual clinical case might be one of a rare disease (extremely low prevalence in the area), an unusual form of presentation of a usual disease or an unusual clustering of concurrent clinical conditions in a patient.

The prevalence of some diseases widely varies among geographic areas, specially among different hemispheres and differently developed areas. The Internet provides an unique opportunity to share critical clinical information between dispair geographic areas about the best guidelines to manage clinical cases.

Apart from the general benefit obtained by sharing information about universal unusual cases, there is the added benefit of sharing information about cases being commonplace in one site and highly unusual in others.

2. Objectives

The general objective of ELCANO is to build and exploit a multilingual *Virtual Library* of outstanding clinical guidelines to manage unusual cases. This *Virtual Library* will be distributed across The Internet from the partners servers and accessed by specialists and specialists in training. Gastroenterology will be the initial area of the clinical practice to be addressed. ELCANO is to be considered an exploratory measure to use telecommunications technology to link separate regions sharing clinical information. More medical specialities and more countries/regions are planned to be involved in the forthcoming years.

Specific objectives are relative to user needs, technologies and methodologies. Regarding the user needs, ELCANO will acknowledge a common strategy to define unusual cases, taking into account its absolute (i.e.: universal) prevalence as well as distinct prevalence among different geographic areas. The technologies area will deal with the definition of a common style to report clinical cases with multimedia contents, adapted for its dissemination in HTLM format through the World Wide Web of The Internet; adopting an internationally accepted standard to code and index the cases and building and validating an Internet World Wide Web Server specifically optimised to deal with queries to a clinical cases database. The methodologies to be followed are facing the validation of new clinical cases and monitoring the use of the database, and its impact upon the clinical practice by its clients. Also, a methodology for a quasi-simultaneous translation of the newly reported clinical cases between the languages (English and Spanish) of the participating countries will be in place.

3. Background

3. 1 Medical Part

In the medical literature, it has been repeatedly reported that the morbidity and mortality concentrates in those patients presenting with unusual clinical cases [2]. Being them low prevalence diseases, unusual presentation of common diseases or unusual combinations of diseases in a single patient, the experience of the clinician in similar situations is of paramount importance in successfully managing the case [3] [4]. Whilst there is a growing body of information regarding the management of common diseases, increased by the progressive advent of clinical guidelines, there is little or none structured sources of knowledge about the management of unusual cases (other than the sporadic and clinical reports scattered among the medical literature).

Moreover, the dispair incidence of diseases among the participating countries provides a unique opportunity to share the cumulated experience in one area about a locally common disease which is a rarity in other countries (i.e.: Chagas Disease, common in South America is seldom seen in ES; Inflammatory bowel disease, common in UK is unusual in AR; Tuberculosis, common in AR constitutes a low prevalence disease in UK; complications from AIDS are regularly seen in ES and uncommon in AR).

3.2 Technological Part

The HTLM format and the World Wide Web of The Internet constitutes a growing forum for the interchange of medical knowledge [4]. A good example of the capabilities of the system to report clinical cases are the Virtual Hospitals initiatives that start to appear in the WWW [5]. The majority of initiatives in this forum, however, are taking place in an individual, non-structured, non-controlled way, and seems to be driven more by a local impulse to be networked than by a real need to share structured information about illustrative cases.

The technology needs of this project are in its majority already in place [6] [7]. The HTLM (and the forthcoming HTLM II) format is simple and versatile enough to hold the multimedia contents of a report of clinical cases. Database servers linked to HTLM query documents are being used by a variety of projects [7], ranging from on-line polls to remote consultation of library catalogues. Monitoring the access and use of a WWW Server is a straightforward process when managing a server.

4. Choice of approach

The main issue of the project is to share medical information through a global network. We choose WWW and The Internet because is, by far, the most sensible approach in terms of universality, low cost and growing

potential. Other networking alternatives will face the wall of dissimilar infrastructures between Europe and Latin-America and will represent a less open approach to the dissemination of medical knowledge.

We choose to build a Virtual Library of clinical cases of unusual presentation because the potential utility of this cumulated knowledge outweighs that of a common cases library [8] [9] [4].

We choose to share this information over a network (as opposed to CD ROM distribution for example) because the on-line validation, on-line management of translations and foremost, the acquisition and dissemination from and to third parties is only possible through a global network.

5. Innovative aspects

Neither to report clinical cases nor to use The Internet's WWW to disseminate information constitutes a use of a cutting-edge innovative technology. What is unique and innovative in ELCANO is the orientation toward unusual cases, the framework embracing countries from Europe and Latin-America, the structured pre-validation of the cases, its multilingual contents and the indexing and codification of cases using internationally accepted standards.

6. Challenges

6. 1 Definition of unusual cases

To acknowledge what will constitute a valid case to include it in the Virtual Library. Some categories emerge so far as potential candidates: 1) Clinical cases with universal low prevalence. 2) Clinical cases with dissimilar incidence among UE and Latin-American areas 3) Clinical cases with unusual clusters of symptoms 4) Clinical cases with unusual constraints for its treatment 5) Clinical cases with documented management errors from which to learn 6) Clinical cases with unusual combinations of different diseases.

6. 2 Definition of a style to report clinical cases

To acknowledge in the sections, style and conventions to be used in a generic case report in order to offer a set of guidelines to build a consistent structure of the clinical report. Concrete issues to be addressed are: Which fixed sections a case report must have. How many and which optional sections might be included. Which will be the preferred grammatical construction and style [10]. Choose a unique way to report laboratory values and microbiological terminology. To acknowledge on a preferred medical vocabulary to use in intra-text description of symptoms, diseases, examinations and treatments.

6. 3 Format of the graphical part of the report

Adopt a standard for clinical image representation. The task will be devoted to analyse existing standards for image representation and compression suitable for inclusion in HTLM documents to be distributed over The Internet. Inputs to this task will be the chosen standards by existing libraries of clinical images and the experience gained by partner ES in building and maintaining a database of clinical images. Standards to be considered for still images include JPEG-2, GIF, Still QuickTime and fractal compression of DIB format. Standards for video sequences include MPEG/MPEG II and QuickTime. The election of a preferred image format will imply the testing of available image managers to be made available from the servers to visualise those images.

The analysis will take into account the quality/size ratio of different compression technologies as well as the desirable size and resolution for each category of clinical images (i.e.: Chest x-ray needs a widely different size and resolution than a foetal ultrasound or a pathology specimen). The task will set-up a minimum ground for including images and a recommended range of resolutions for each category. The task will define a standard method to implement the guidelines to preserve the privacy of the patient.

6. 4 Adoption of a standard to index and retrieve clinical cases

In order to be useful, the Virtual Library of case reports must be fully indexed. As it is multinational as well as multilingual the adoption of an internationally accepted standard is mandatory [11]. The task will address two aspects of the indexing of the clinical reports, namely the actual standard for coding and the structure of the database and its associated query system [12].

To choose the most appropriate international standard in the health care information systems to adopt in the coding of the reports of clinical cases. The standard adopted must be adapted to represent clinical data in detail [11] (as opposed to coding oriented towards cost-related retrieval or epidemiological analysis) and must agree (or cross-reference) with the CEN published documentation regarding the representation of clinical data [13]. A detailed analysis of the GALEN project is in order to explore potential interaction with their methodology to include medical terms.

6. 5 Database and Query system

To design and implement a database structure to allocate the clinical cases description and codes. This structure will be capable to process the queries obtained from HTLM query forms [6]. Its reports will be formatted accordingly to HTLM format conventions, ready to be sent over WWW as a report page. To design and implement a secondary database to handle the validation and monitoring of the Web Server, with special emphasis on automatic reporting of the use, hit rate, queries processed and feed-back from Web Clients.

6. 6 Design, build and validate an Internet World Wide Web Server

To design and implement the structure of the World Wide Web Server. Specifically this task will address the logical structure of the Web sites with their associated database [8], the pages, their relationships, the conventions used to establish intra and inter page jumps and in-page inclusions of images. The sections of each page will be defined and implemented. Templates for each page will be provided. Multilingual versions of each page with templates will be provided.

6. 7 Create and implement a methodology to acquire and validate new clinical cases

This is a task to be performed once all preceding tasks are accomplished, and its course will span through the rest of the project life time. It is an ongoing task involving all participating partners. The acquisition of new cases, following the guidelines for authors, will take place in two phases:

1) Seeding Phase: In which the participating partners will directly input cases into the Virtual Library, recruiting clinicians at their respective sites to build clinical reports. In this phase, Clinico-patological conferences, mortality and morbidity conferences and locally published clinical reports should provide the most directly available sources for new cases. Also, the list of preferred cases for diseases of asymmetric prevalence among partners should be considered to an excellent source for an easy to produce initial repository of clinical cases. Members of the participating partners institutions will guide the input of those initial cases in order to adhere to the guidelines of the Virtual Library

2) Harvesting Phase: Once a significant number of cases is available, a dissemination strategy will be followed, indexing the Home Page of ELCANO in as many WWW searchers as possible in all continents. The Virtual Library will encourage the submission of new clinical reports to the Virtual Library, delivering an "acceptance" certificate for each clinical report accepted. The intention is this certificate be of similar curricular importance for the author as that of a clinical report accepted for publication in a medical printed publication. Each case will be peer-reviewed (see WP9) before its acceptance. Each consultation of an individual case will be reported to the author, implementing thus a real "impact factor" audit for each submission.

6. 8 Validation of new cases

Each new case will be peer-reviewed in a similar manner of a peer-review process for clinical reports submitted for publication in printed form to a scientific publication [14]. Each partner will set-up an Editorial Board of Reviewers to whom the newly submitted cases will be forwarded. Recommendation about scientific contents will be passes onto the authors. Each partner will set-up a local Technical Board of Reviewers to whom each newly submitted case will be presented in order to check for the adherence to the guidelines for authors in terms of distribution of the material, images format, privacy preservation. Each validated case will be coded following the adopted standard by the receiving site.

6. 9 Create and implement a methodology for translation

Once validated, each case will be translated to English and Spanish. Taking into account the actual abilities of each partner to translate clinical material a provisional redundant strategy has been devised to translate the validated clinical reports.

6. 10 Create and implement a methodology to monitor the Virtual Library use

To continuously monitor the access and use of the Virtual Library of clinical cases, obtaining a periodic report of its utilisation, with details per region, country, disease group and type of query.

7. Expected benefits

ELCANO will harness the collaboration activities between project partners, in order to share knowledge and to develop a single resource which will draw dispersed medical expertise by means of a collective and joint effort to put together a peer-reviewed set of clinical cases.

ELCANO will enhance the research and development capabilities of the partners in relation to innovative uses of global networking technologies for the promotion of healthcare and education by exploring and implementing Internet World Wide Web based, low cost solutions. ELCANO will encourage North-North, North-South and South-South collaborative activities, in synergy with EU policies on development and economic collaboration by taking advantage of the summation of medical knowledge and research capabilities from all partners.The immediate effects can be regarded in two fronts:

1) Technological front: The implementation of existing global network technologies linking separate world regions will we a working demonstration of the feasibility of such technology to share clinical information. As an important part of the project ELCANO deals with the standardisation on the format to report and represent clinical information on the WWW, it might represent an important point of reference for future work in transmitting clinical information over the Internet.

2) Medical front: The sharing of medical guidelines to manage clinical cases among partners with different degree expertise will be a direct benefit for the partners participating, as well as for any third party user willing to make a consultation to the Virtual Library of Clinical Cases and/or contributing with new cases to the library.

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