

# Resource creation for neuromuscular disease information management

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## SUMMARY

The new vision of health introduced by the WHO in 2001 substantially broadens the field traditionally attributed to this area. In consonance with this new perspective, the dissemination of available knowledge on disease amongst society as a whole becomes a significant element in improving not only care but also the quality of life of patients and their relatives.

Taking this approach as our starting point, and with the aim of disseminating the oft-demanded knowledge on neuromuscular disease in Spanish, we have set up a multidisciplinary team, whose members are drawn from the Spanish and Galician Federations for Neuromuscular disease (ASEM and ASEM-Galicia), faculty from the University of Vigo and physicians from Meixoeiro Hospital, for the purpose of creating documentation and tools that will provide Spanish speakers with access to information on disease of this kind.

This poster presents the principal lines of the project in which we are currently involved and highlights some of its main outcomes to date:

- Translations into Spanish, basically from texts written in French, which have made available to society as a whole a considerable number of representative documents reflecting the state-of-the-art of scientific and social aspects of neuromuscular disease;
  - MYOCOR: a web-based search engine with texts in both French and Spanish that provides access to proven and coherent information on these diseases.
- The resources we are creating will be of use to:
- patients and their relatives;
  - health professionals;
  - scientific and technical translators, interpreters and writers.

The direction taken by the project and the teams involved in its development make it possible to:

- respond to a social demand
- establish a link between academic research and the social reality in which this takes place.

## INTRODUCTION AND BACKGROUND

Our work springs from the desire of the Spanish and Galician Federations for Neuromuscular disease (ASEM and ASEM-Galicia), to disseminate amongst Spanish speakers knowledge on:

- neuromuscular disease
- current research
- the situation of patients in other countries
- the assistance and benefits currently available

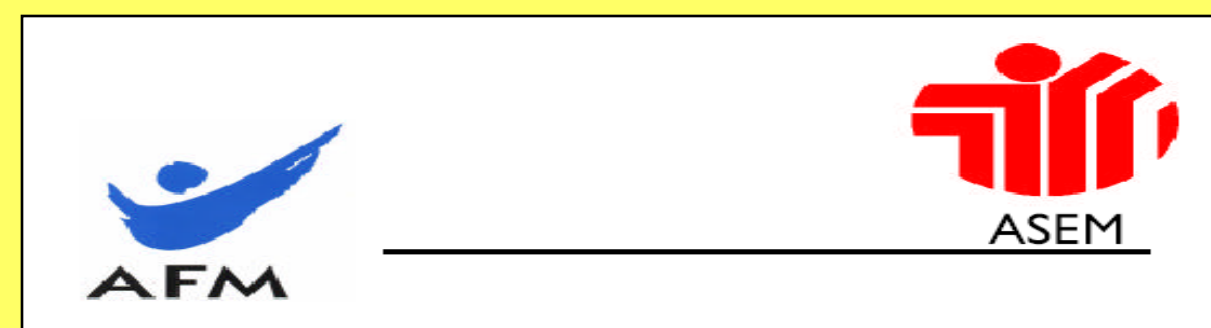
Our interest in making this knowledge known is based on the conviction that a wider awareness of all the above aspects will help to:

- improve patients' quality of life
- make society more aware of these disease

A clear forerunner of our project are the well-known texts produced by the Association Française contre les Myopathies (AFM).

This association has published a large number of works written by persons and institutions of all kinds involved in the sphere of neuromuscular disease. These therefore include texts written by physicians or other health professionals with different degrees of specialisation (biologists, nurses, physiotherapists, etc.), by researchers and by a variety of institutions. Similarly, the intended readers of these publications also form a wide range that includes not only the health professionals referred to above and patients, but also society as a whole.

The Galician Association for Neuromuscular Disease is the beneficiary of an agreement that makes all these texts available to it for the purpose of using them for the good of patients on a not-for-profit basis.



## OBJECTIVES AND STARTING HYPOTHESIS

The general objective of the project is to:

- ✓ Contribute to a better quality of life for patients with neuromuscular disease and their relatives through the dissemination of knowledge in this field.

In order to improve the situation of those affected by neuromuscular disease we have to:

- increase awareness amongst health professionals of the need to provide care swiftly;
- increase awareness amongst the authorities of the need for effective and coordinated action;
- increase awareness amongst society as a whole of the need to become involved in order to give patients a better quality of life.

### Starting hypothesis:

- ✓ The new vision of the concept of health introduced by the WHO in 2001, which brings together two opposing models: the traditional 'medical model' and the new 'social model'. The former sees health as an individual problem that is directly related to a disease that requires specific medical treatment, whilst the latter, the social model, places it in a wider context that refers back to situations that originate, at least partially, in the social setting and involve society as a whole. This approach stresses the importance of considering health implications in all manner of social discussion forums.

According to this new vision of health, the dissemination of knowledge on neuromuscular disease in all its aspects (identification, characteristics, cutting-edge research, technical assistance, reference centres, etc.) helps to:

- enhance quality of life for patients and those close to them
- to raise awareness of diseases of this kind in society as a whole.

The present situation of patients will only begin to change:

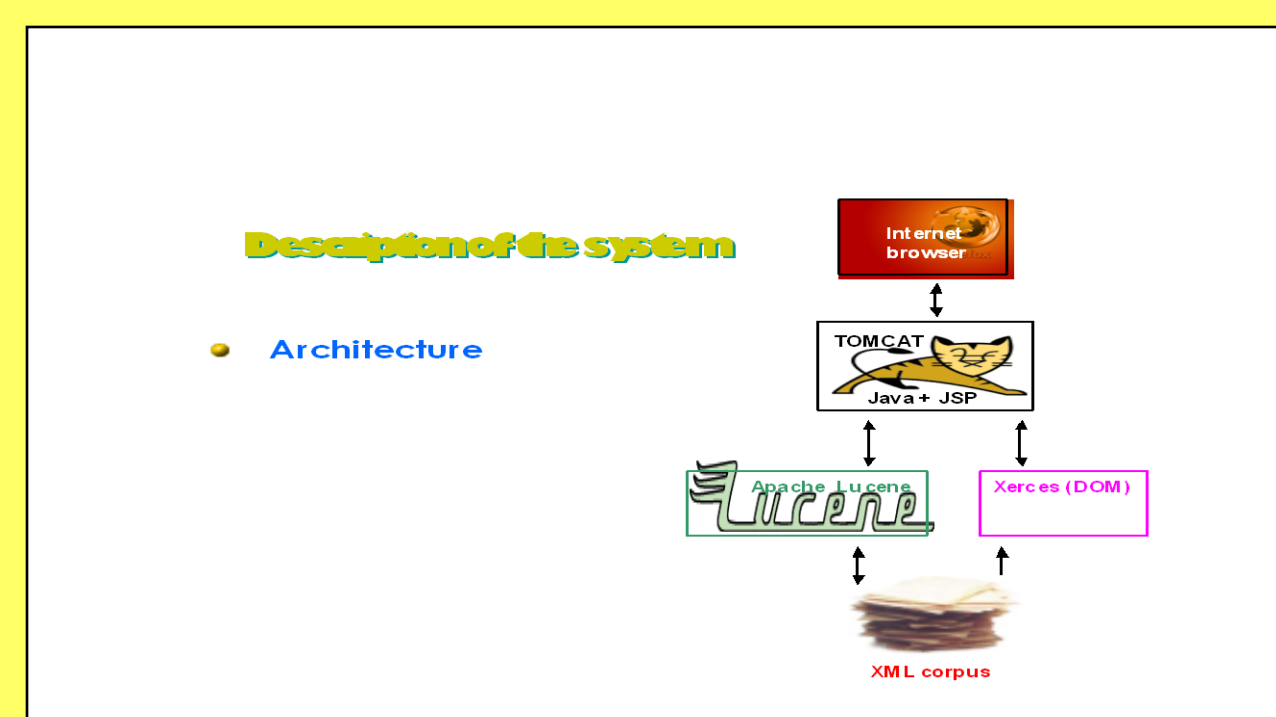
...when everyone is familiar with the meaning of MYOPATHY or MUSCULAR DYSTROPHY (a progressive loss of muscle strength) just as they are now familiar with the meaning of FLU, DOWN'S SYNDROME or ALZHEIMER'S. (ASEM 2002:3)

In this task of creating awareness in order to achieve the stated purpose, the availability of resources in Spanish that make it possible to disseminate knowledge and provide access to information on these diseases is an essential component.

## METHODOLOGY

In order to develop our project, from a methodological standpoint we have followed the following lines of work, which are interlinked:

- Selection of texts dealing with neuromuscular disease according to the following criteria: their quality (i.e. from accredited sources), representative nature and currency.
- Translation of the selected texts into Spanish.
- Construction of a corpus of texts on neuromuscular disease that is standardised, documented and marked up in XML according to the code proposed by TEI (Text Encoding Initiative)
- Putting the corpus to use through the creation of a web-based search engine.



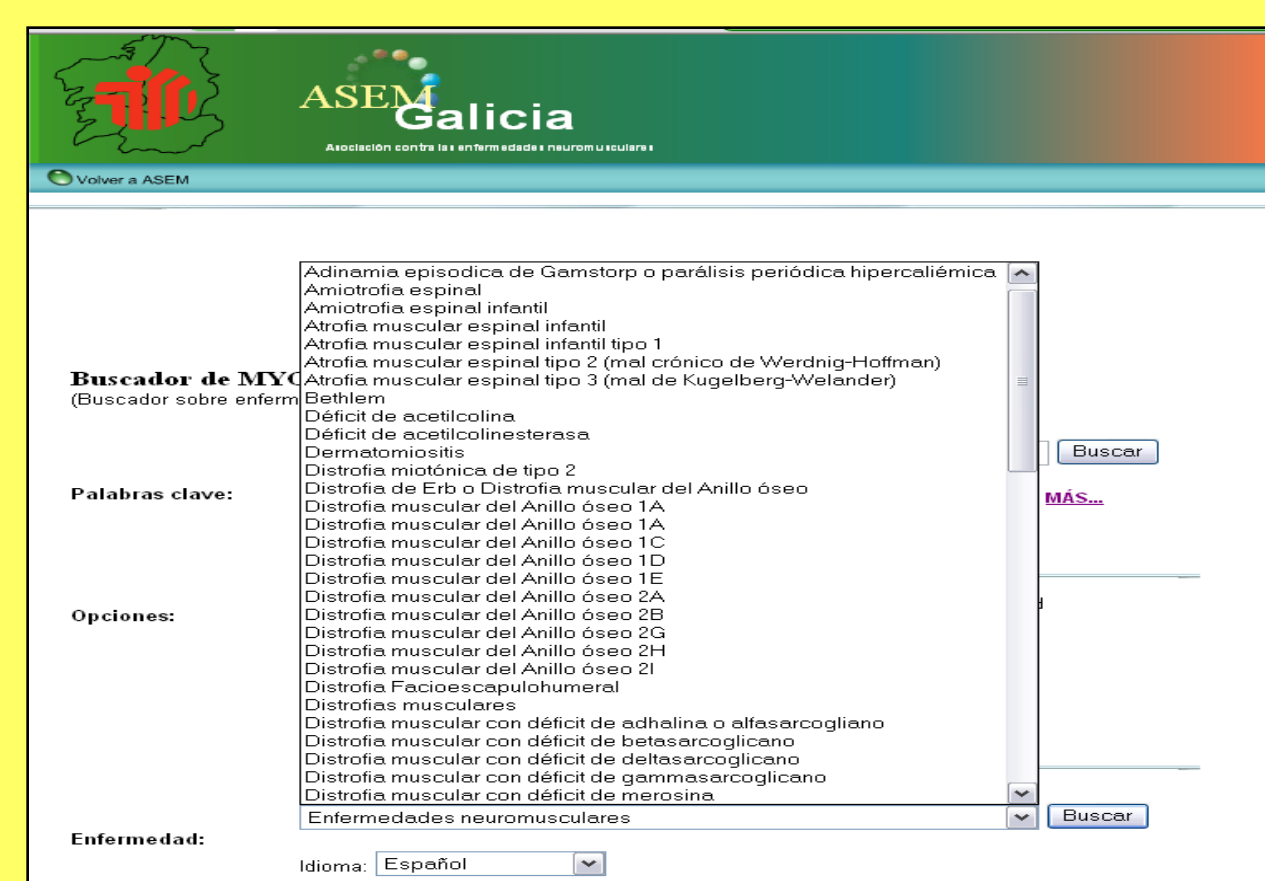
- Creation of a dedicated website to make the resources available to interested users.

## RESULTS

- Translation into Spanish of over 100 texts, mostly written in French, from a variety of genres (monographs, research papers, legal documents, etc.), that have been presented in numerous health forums (hospitals, conferences, etc.) and been sent to a large number of professionals working in the field of health (GPs, paediatricians working in health clinics, neurologists, nursing staff, etc.).



- Creation of the MYOCOR search engine: a tool for consulting information on neuromuscular disease in French and Spanish.



## RESULTS (contd.)

- Creation of the ASEM-Galicia web page (<http://www.asemgalicia.com>): a platform that brings together the combined experience of all the initiatives working in the field of neuromuscular disease.



## CONCLUSIONS

The project we are currently working on provides an innovative approach as much for its end objective as for the methodology used or the nature of the project team itself (a multidisciplinary team composed of researchers specialising in translation, computer science and medicine).

The resources now being created constitute a source of multilingual documentation on:

- neuromuscular disease,
- the high number of specialist areas of medicine that come together in this sphere (neurology, genetics, haematology etc.)
- many other health areas such as physiotherapy, orthopaedics or psychology that are also involved in the subject, given the serious consequences of diseases of this nature, which are usually progressive and extremely disabling.

The resources are of interest to a wide range of target readers:

- those directly concerned, i.e. patients and their relatives
- the professionals involved, such as physicians and other health workers
- other professionals, such as translators and others working in the sphere of communications.

La platform that has been built:

- brings together the experience of all the initiatives working, directly or indirectly, in this area of medicine
- involves those who produce the information and its end users.
- makes it possible to provide better information for the general public, patients and professionals
- enables better advice to be given on medical content, thereby preventing low quality information from filtering down to end users.

The project creates a link between research activity in various disciplines and the social reality in which this takes place, thereby facilitating a convergence much demanded by a variety of social agents.

## FUTURE WORK

- Continuation of the lines of work on which we have embarked, expanding the number of resources and improving the quality of those in existence.
- A broadening of the number of working languages to include English, Portuguese and Galician, initially.
- Extension of the thematic sub-domain: we are beginning to develop a line of work dealing with rare diseases.
- Creation of the necessary ontologies and metadata, implementing them in a semantic search engine for the sub-domains concerned.
- Creation of multilingual resources, whether of a terminological nature, translation memories or tools to assist machine translation.
- Collaboration with other research teams interested in developing the lines of research we have presented with a view to setting up a coordinated pan-European research team.

## ACKNOWLEDGEMENTS

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