Development of a Web Application for consulting resources on Rare Diseases

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Abstract

Despite the wide range of diseases that are classified as Rare Diseases (RDs), they have classically received few resources to investigate these pathologies. As a consequence of the lack of information for the diagnosis and treatment of RDs, patients often receive 2-3 misdiagnoses, requiring visits to different doctors and specialists to converge on a lasting diagnosis. Identification and diagnosis take an average of 5 years, requiring at least 10 years in 1 in 5 cases to obtain a correct diagnosis.

Patients affected by this type of disease see altered both their physical and mental capacities, influencing their sensory and behavioral capacities. In certain cases, life expectancy is not limited although, most affected patients deal with the disease throughout their lives. Early diagnosis improves medical care helping provide a better quality of life and extend their life expectancy.

As a continuation of previous projects, the current objective is to facilitate access to all RDs resources. With the use of Django framework, a Web Application was designed. Through a Graphical User Interface (GUI), the access to this information has been improved, serving researchers, doctors, and patients equally.

1. Introduction

Rare diseases (RDs) are disorders that affect a small percentage of the population. The definition of a RDs varies internationally; the European definition is any disease with an incidence of less than one in 2000 [1]. However, the distribution of these conditions varies between regions and some RDs are more common in certain countries than others. The scale of the RDs challenge is staggering, with more than 8,000 types of RDs described and an estimated 6 to 8% of the total population. In Europe, RDs are estimated to affect between 27 and 36 million people [2], where in most of the cases, these disorders are considered chronic diseases, drastically affecting the quality of life and/or life expectancy of the patient [3].

In general, most affected patients deal with the disease throughout their lives. In some cases, the symptoms appear from the first years of life, however there are also RDs that become clinically evident only in adulthood. In certain cases, life expectancy is not limited, although affected patients may eventually need some specific medical attention during their lives, coinciding with outbreaks of the disease. Although most RDs have a genetic origin, some are caused by infections or appear following an autoimmune pathway [4].

The resources allocated to investigate these diseases have been inversely proportional to the large number of pathologies that are classified as RDs. This has implied less scientific knowledge of the mechanisms underlying these diseases, resulting in an increase in adverse conditions associated with the disease.

As a consequence of this lack of information, patients usually receive 2-3 erroneous diagnoses. Correct identification and diagnosis take an average of 5 years, requiring in certain cases at least 10 years [5] [6] [7]. The drawn out diagnosis process can have serious implications for individuals with RDs (health management, finances, work, personal stress, and many other aspects of life) [8]. So, it is necessary to know every single symptom and signs of each RDs, as well as all the new updated information. Although most RDs do not have curative treatment, early diagnosis helps to extend life expectancy, providing a better quality of life.

In the last decade, a great effort has been made worldwide to stimulate research on RDs. Firstly, with the aim of making a correct diagnosis of patients who still do not know what disease they have, and secondly, developing and marketing specific therapeutic agents. This has produced to the emergence of numerous information resources that allow people to change their behavior, learn about their disease [9], obtain support from similar people [10] or track information about themselves [11]. However, there are not many methods that bring together all this information in a single platform that can be of help to researchers, physicians, and patients.

In previous projects, the review and classification of the resources on RDs contributed by the organization Health On the Net (HON) [12] was carried out. The results of these projects were stored in a database. The objective of this project is to facilitate access to all these resources. For this, a web application for queries on rare diseases was implemented.

2. Database

As results of previous works, the bibliography for rare diseases resources from specific and non-specific rare diseases resources, such as medical center, website, organization, editorial, medical magazine, charity organization or application, was analyzed and classified. They were summarized, first, in an excel file with 1344 RDs with the name and information of each one, and finally stored in a database [13].

The database has 4 entities which are: Resources, Diseases, URL and ResourcesType. According to the data model, Resources can have associated more than one Diseases, URL or ResourcesType associated with it and vice versa, giving a total of seven tables. These tables and fields are:

- Resources table: 351 entries (idResources / Name / Finality / Access / Price)
- Resource´s type table: 15 entries (idType / Type / Description)
- URL table: 353 entries (idURL / Language / Address / Location)
- Diseases table: 1344 entries (idDisease / Name / Prevalence / Affected system / Diagnosis / Treatment / Summary of the disease)
- Resource_ResourcesType table: 353 entries (idResource / idResourcesType)
- Resource_Diseases table: 351 entries (idResource / idDisease)
- Resource_URL table: 352 entries (idResource / idUrl)

The database was created with MySQL version 8.0.19, counting additionally with a consulting application for searching information of the database. This application has been created with Eclipse IDE, with version 4.14.0. The application also allows the user to insert new resources or delete the ones that are no longer available. It does not have a graphical design and the interaction, between the user and the application, is just through console commands. Therefore, the creation of a web graphical interface was the aim of this project, thus facilitating interaction with the database.

3. Django

The realization of the platform managed through a graphical interface requires considering the two stages of web development; the first corresponds to the design of the Graphical User Interface (GUI) with which the user interacts with the data (front-end), and the second, the management of user requests to the database that has the information stored on rare diseases (back-end). Taking these two phases into account, it was decided to use a framework that would allow manipulating the behavior of the web page on a single platform. Django framework was the selected one, with support for databases in MySQL [14].

Django is an open-source web development framework, using Python as a programming language, allowing the use of it in all parts of the framework, including settings, files, and data models. Django follows a model–template–view (MTV) design model based on the model–view–controller (MVC) software architecture pattern.

This design pattern separates, on the one hand, the components for the representation of the information, and on the other hand, the interaction of the user, dividing these into three modules called the model, the view, and the controller. The model corresponds to the information data, the view corresponds to the representation of the information and user interaction, and finally, the controller is the module in charge of managing events and communications between the view module and the model module. In this way, it is aimed to separate the concepts, facilitating the application development task, making it more functional, maintainable, and scalable, by allowing the addition of new functionalities by modifying a single module without altering the operation of the rest.

As mentioned, Django respects the MVC pattern to develop the model-template-view MTV design pattern, dividing them into a model module, template module, and view module. The template module replaces the view module, maintaining the functions of managing the interactions between the user and the computer, taking the information, and presenting it to the user (via HTML, for example), where the URL configuration system is also part of this layer. The view module replaces the controller module, maintaining the functions of managing the requests of the template module, while maintaining direct communication with the model module, which manages the logical operations and information of the database.

Additionally, Django allows the development of the different functions that a project has, by blocks. These blocks are called Applications, where they allow to manage the different functions offered in the web project in a modular way, facilitating the individual handling of each functionality and the reuse of these, separately in different projects (see Figure 1).

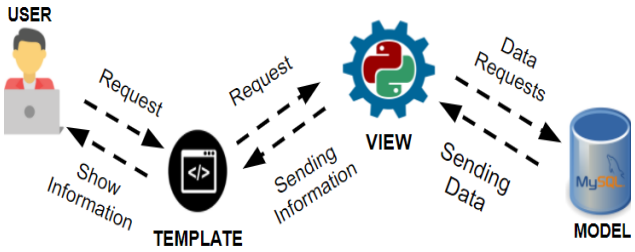

Figure 1. *MVT diagram*

4. Results

The current project allows to show, sort, and search the contents of the database. In addition, an asynchronous communication system was created between the user and the administrator of the website. These correspond to the news and contact sections, which allow managing the functions of publications and sending messages to the administrator. This is an additional feature that allow the Create, Read, Update and Delete (CRUD) of each post entries though a graphical interface for the administrator.

Figure 2. *Homepage*

The website consists of 5 sections. These are:

4.1. HOME

This section describes the Home section which corresponds to the homepage indicating the structure to be followed throughout the entire web page. This features a background image, navigation bar, an information box, and footer as show in the Figure 2.

4.2. BOARDS

This section has the function of displaying the database dashboards related to RDs, resources, resource types and urls. It indicates the fields of each table and their relationships. It has an additional option bar, which allow switching between diseases, resource, resource type, and urls boards.

Boards:

- **diseases**: Shows through a table the parameters of each entry (ID / Name / Prevalence / Affected system / Diagnosis / Treatment / Summary of the disease), in turn they have a link to the information disease through the feature Name.
- **resources**: Shows through a table the parameters of each entry (ID / Name / Finality / Access / Price), in turn they have a link to the information resource through the feature Name.
- **resources type**: Shows through a table the parameters of each entry (ID / Type / Description), in turn they have a link to the information resources type through the feature Type.
- **urls**: Shows through a table the parameters of each entry (ID / Language / Address / Location), in turn they have a link to the webpage through the feature URL.

4.3. BROWSER

This section has the browser function inside the database and show it to the user through a dashboard. For the introduction of the search fields, it has a search bar. As the BOARDS section has an additional option bar under the navigation bar, which allows switch the search between the boards (see Figure3).

Figure 3. *Search page*

Search results are shown in a simplified table with the same links as the previous section (see Figure 4).

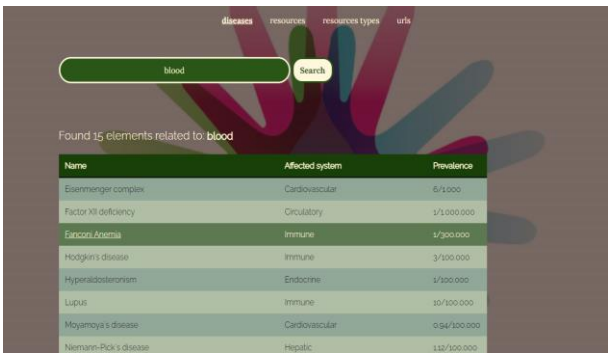

Figure 4. *Search result page*

4.4. NEWS

This section has the post function, aims to show the advances in RDs. These are displayed as a list of all the posts (image with brief description, title, link to the news, and the author of the post) (see Figure 5). Additionally, allows to show the posts related to a certain category. New tables were created to store the posts, which allow the CRUD of each entry though a graphical interface.

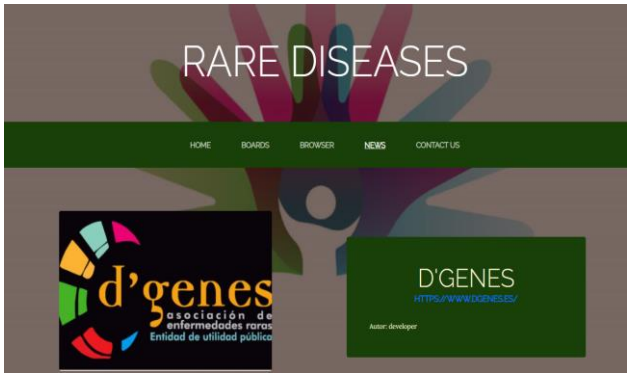

Figure 5. *News page*

The posts are created by the administrator of the page through the Django administration console. Access to this administration site is restricted by username and password (see Figure 6).

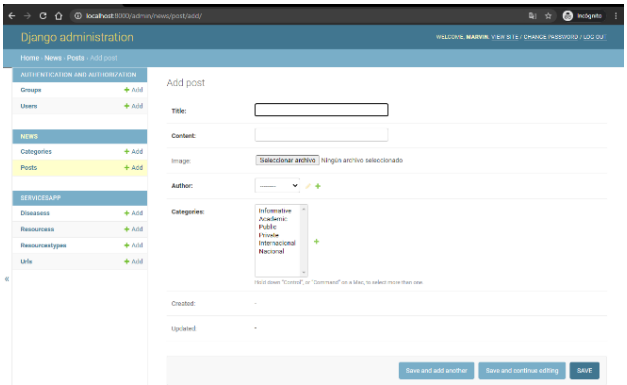

Figure 6. *Administration site*

4.5. CONTACT US

This section works as a communication method between users and the administrator. It has a form, which the user will fill it out indicating name, contact email address, and

finally the text of the message (see Figure 7). This will be sent by email, showing only on the screen a verification message of "information sent correctly, thanks" or failing that "information not sent correctly, sorry", in case of possible error. The form will be sent as an email text in the mailbox showing as sender "rdiseaseswebproject@gmail.com" and "Rare Diseases web project Django" as mail subject.

Figure 7. *Contact us page*

5. Discussion

Thanks to the use of a framework, the design of the Graphical User Interface (GUI) and the management of user requests to the database, that has the information stored on rare diseases, could be developed on a single platform. The use of Django allowed to manage the development of the project in a modular way, using Python as a programming language.

The use of a webpage as a GUI, improves the consultations and information searches of RDs, making these an intuitive handling, and practical for the user. Additionally, the NEWS and CONTACT US sections were developed. The former allows to keep users updated. By means of a post board, relevant news about RDs can be indicated. The latter establishes a communication mechanism for the users, allowing them to send any request for modifications, comments, or information through a form.

6. Conclusions and future lines

To improve the prognosis of rare diseases, it is necessary to optimize the time of diagnosis. The lengthy diagnostic process can have serious implications for people with rare diseases. Therefore, it could have a very positive impact to have a platform where all the symptoms and signs of each rare disease are found, as well as all the new updated information, useful for researchers, doctors, and patients.

With the use of Django, a Web Application was developed, which allows the retrieval and consultation of the information stored in the database of resources on Rare Diseases. Through a GUI the access to this information has been improved with respect to previous projects, creating a more intuitive environment for the user. Additionally, a communication mechanism was created between users and the administrator of the website, allowing the publication of news and the sending of inquiries.

With the performance of this project, I have been able to see broadly the field of web development. This has given me knowledge of front-end and back-end development through the Python programming language. Leaving the interest to continue with the exploration of this world.

Future lines of this project could be adding and updating information, improve the design of the web page, and create a user registration system that allows managing the different levels of access, such as creating a post or making CRUD on the RDs database.

7. References

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