Rare Disease Portal Implementation

Carlos Luis Sánchez Bocanegra

Tutor: Luis Fernandez Luque

Table of Contents

Introduction

Rare Disease Video Portal is a Content Management System (CMS) that recolects valid html tags (iframe) with included videos and exposes in a portal web. These videos belong to several channels in Youtube about rare diseases.

In our case we got all videos from that channels and embebed in our portal system, during the analysis & develop of this project we found some difficulties that were described and added in the taskfreak manager.

The main problems funded were related to the design and re-adapt some Drupal's module for showing the desired results by the client. For example, to adapt the visualization of the videos. Gantt time project was re-calculated three times and finally we need one extra week for finish it (see taskfreak).

Instalation

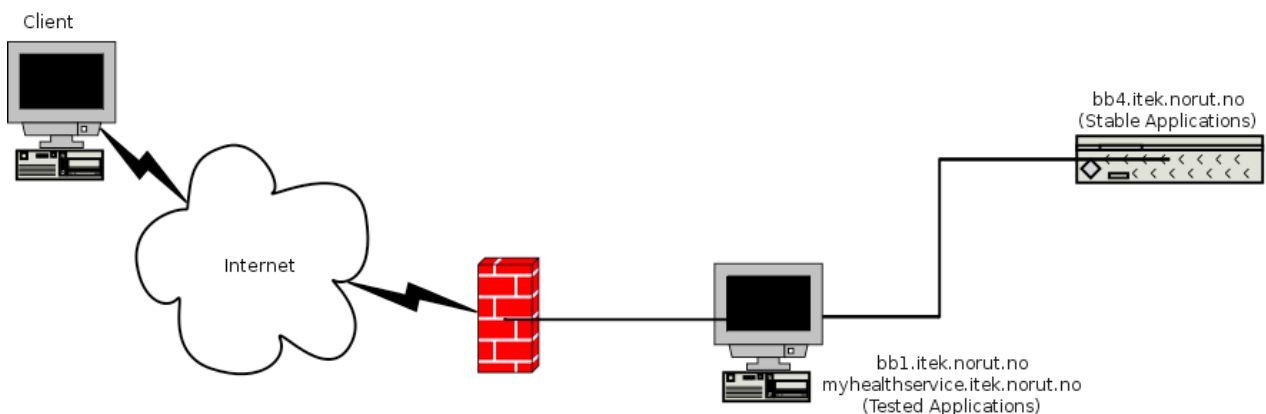## Infrastructures

Tipology

Figure 1: Topology structure

As seen on Figure .1 we have two server through firewall, bb1.itek.norut.no is a tested application server, there we will check new updates for including on production. bb4.itek.norut.no is the stable application server where we have all tested and approved products.

Port used

- **myhealthservice or bb1**: 80, 443 (ssl), 8080 (tomcat), 8081 (tomcat), 22 (ssh), 110 (pop), 143 (imap), 25 (smtp).

- **bb4**: 80, 443 (ssl), 8080 (tomcat), 22 (ssh only intranet), 110 (pop), 143 (imap), 25 (smtp).

IMPORTANT

- If we act on **mhs** server and this action could give any dangerous in the system, please execute the file **/saluteca/backup/myhealthservice/bat/mhs** for creating a snapshot of the system before

- If we act on **bb4** server and this action could give any dangerous in the system, please execute the file **/saluteca/backup/myhealthservice/bat/bb4** for creating a snapshot of the system before

- NOTICE: we have an increase disk space on bb4.itek.norut.no, in our case we have 16 Gb on /data directory, we decide to move all /saluteca/* data to /data/ directory (including backup), after this we will erase /saluteca and make a simbolic link /saluteca → /data**.**

Subversion policies

- As we know, svn server are closed for Internet, only we can access by intranet norut, or even in localhost host on each other. In this case our point of view we propose the following steps:
  - Work on mhs locally: in this way only we checkout in the same host where subversion exists.
  - Work remotely: for now, we must get the subversion code and pass to our client Desktop, work with it, after this we need to generate a differential code for transfer via ssh and adding on mhs host.
  - Stable code: checkout on main Ståle's[1] server.

Source code

We were thinking to upload all Drupal code on mhs subversion, but this isn't efficient. After a little time i prefer to propose a clean code make by us, excluding all rest Drupal code, in this way we sign the version of Drupal (6.2) and sub-directory (module) for our contribution.

Reusing code make this project results in a few period of time, in this case we use some commodities for this project including modules where Drupal forum and contribution make more easy and quick results for this project.

Following the reusability, we have the next modules on this Drupal:

- Views module[2].

- Ctools module[3].

- Cck module[4].

- Emfield module[5].

---

[1] Stålle server is the main subversion server in norut
[2] Views module: http://drupal.org/project/views
[3] Ctools module: http://drupal.org/project/ctools
[4] Content Construnction: Kit http://drupal.org/project/cck
[5] Embbed Media Field: http://drupal.org/project/emfield

- Media_youtube module[6].

- Reptag module[7].

- Video_filter module[8].

Finally w prefer to show on svn-web because we don't compromise our password, for this reason we will put code on a public subversion for the 1.0 version release.

Changes on infrastructures

We find some system problems, basically on norut server, their security policies make our project management chosen (redmine), exactly for cross-site scripting policies make some redmine features dysfunction.

We change our strategy and aim to taskfreak project management together with dokuwiki store in lab-virtual.scc.uned.es server.

Software used

- ⚔ Taskfreak project management.
- ⚔ Dokuwiki.

Port used

- **lab-virtual.scc.uned.es:** 80, 22 (ssh)

---

[6] Media Youtube: http://drupal.org/project/media_youtube
[7] Replacement Tags: http://drupal.org/project/reptag
[8] Video Filter: http://drupal.org/project/video_filter

Portal preview
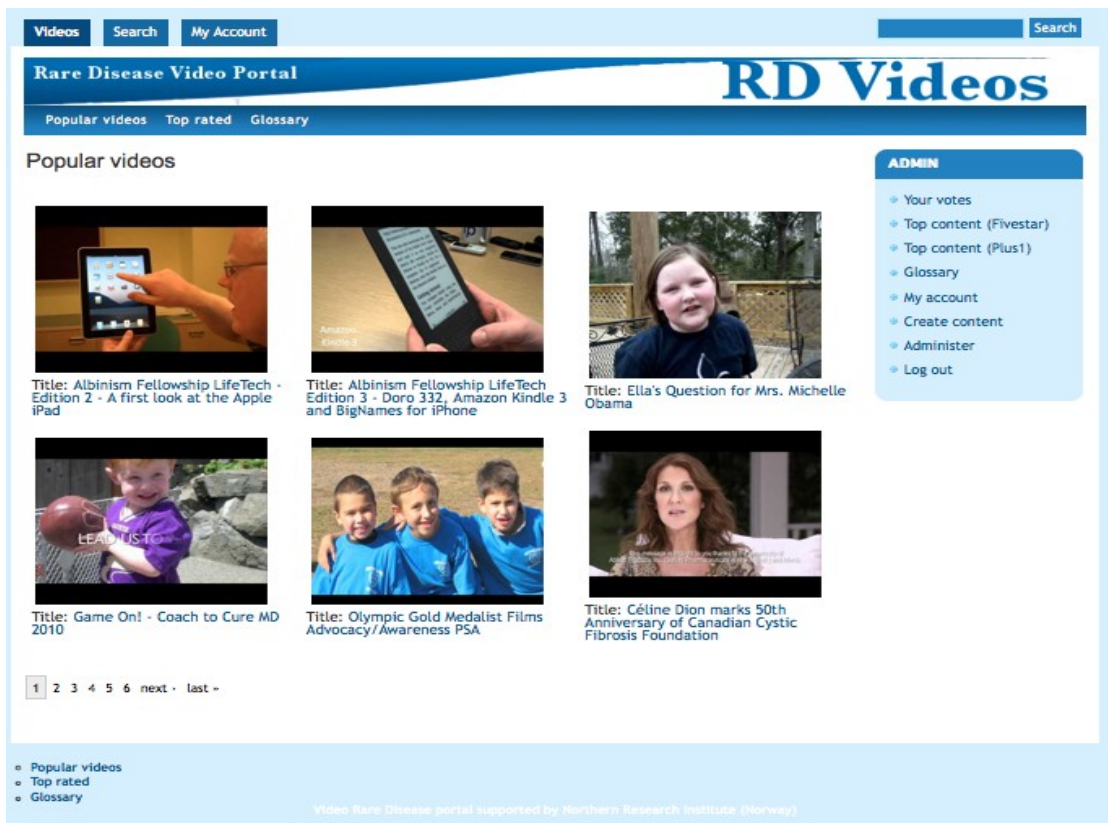
Figure 2: Main view

Figure 2 show the first page with the results of videos. We decide to show in a 3x2 grid with 9 images preview of the videos, each image link to the html5 video of Youtube with description.

We put a basic search engine at the right corner, together with some related links.

Top bar shows basic possibilities for show some videos with some characteristics, including glossary. Right bar have an administrative menu with more options (e.g. fivestart ratings).

Figure 3: Glossary

Figure 3 shows the portal that give add-ons like glossary where we could find videos order by first caption letter.

Figure 4: Rating portal

Figure 4 & 5 show how we can rate each video, this rating belongs to the portal no to Youtube. Each person on the platform can sign and rate videos. Average ratings are displayed with the videos.
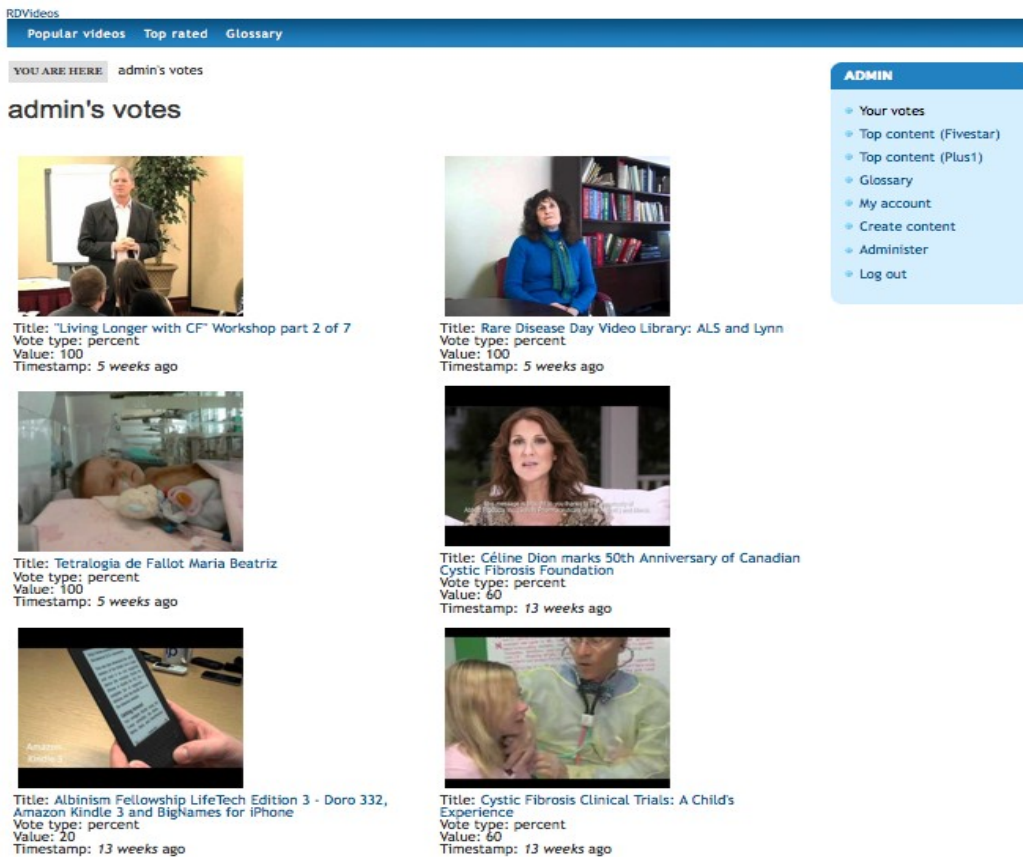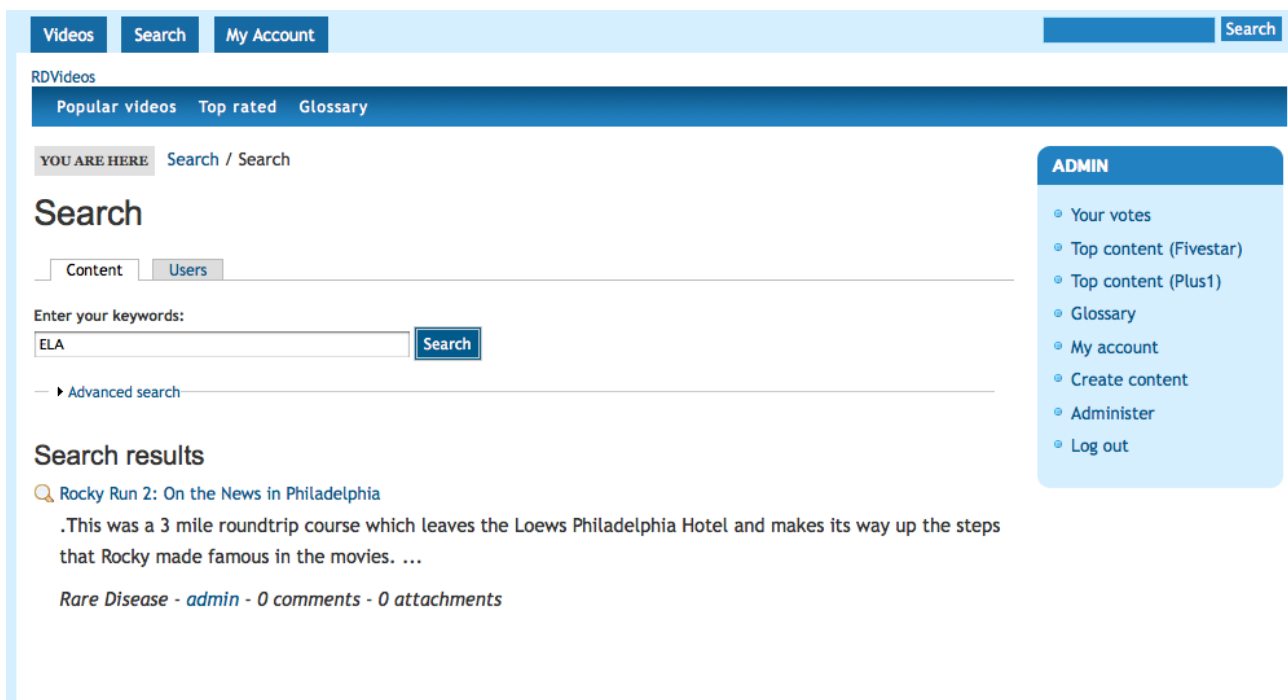
Figure 5: Votes

Figure 6: Search

Figure 6 shows our search engine, this engine include an advanced search where we could find a more detail searching options.

Figure 7: Show video

Figure 7 let user to show video in html5 format with it description capture from YouTube API.

Results

We have 379 videos getting through 12 channels of YouTube. Each of one belongs to a hospital and send messages for a kind of disease. This gives to the portal a entity of an 'rare disease data bank' where health professional can learn and catch experiences and patients grow up on their disease.

- AlbinismUK
- CCFFadmin
- CysticFibrosisUSA
- Eurordis
- HFHealthcare
- MoreThanHemophilia
- NHFvideo
- NOAHAlbinism
- ParentProjectMD

- Rarediseaseday
- Raredisorders
- WFHcommunications

We include rate valuation, this rating give to patients hope and one way for not stay alone with their disease.

In other hand, We can find health professionals where could introduce on their investigation this data bank for a good quality evolution of their patients. This give a more near approximation of the status of each patient and send alternatives for chronic disease where were localized in other point of the world.

In short we try to join and communicate experiences around the world that combine the efforts of the improvement in disease recollecting from YouTube channels avoiding all possible spam.

Conclusions

Rare disease is one of the lost objectives of this society, we must know how we can help and give hope on a wellness evolution of this disease, even more, try to aim for a better solutions.

We think that this solution and a better quality really have the own patient, so in this case we reflect videos of other persons with similar disease where could give clues for improve their possibilities.

On the technical view we consider the social impact and follow that responsibility for a better product adapted for the patients basically. This gives us a way for seeking some more improvement on the platform, e.g. accessibility, usability and design.

We begin a long tail project proud of the results but really this project need to grow up on the next 3 years.

Besides, we don't forget semantic web implication on a future challenge through YouTube metadata and own data by the portal, include improvement in our way of communication through YouTube API and Drupal API.

This project was a challenging experience for me, mainly because I have had a rare disease for nearly 40 years. This project gave me an opportunity to improve myself an overcome my challenge, on my point of view I learned my weakness like English languages and how to make memories on English language (really very different than in Spanish).

Working together with Luis Luque gave me a new point of view on how to see the problems, Mr. Luis has a consolidate experience on project management, but he never got involved on this kind of project.

Acknowledgment