Needs & Proceedings In Rare Disesase Portal

Carlos Luis Sánchez Bocanegra

Tutor: Luis Fernandez Luque
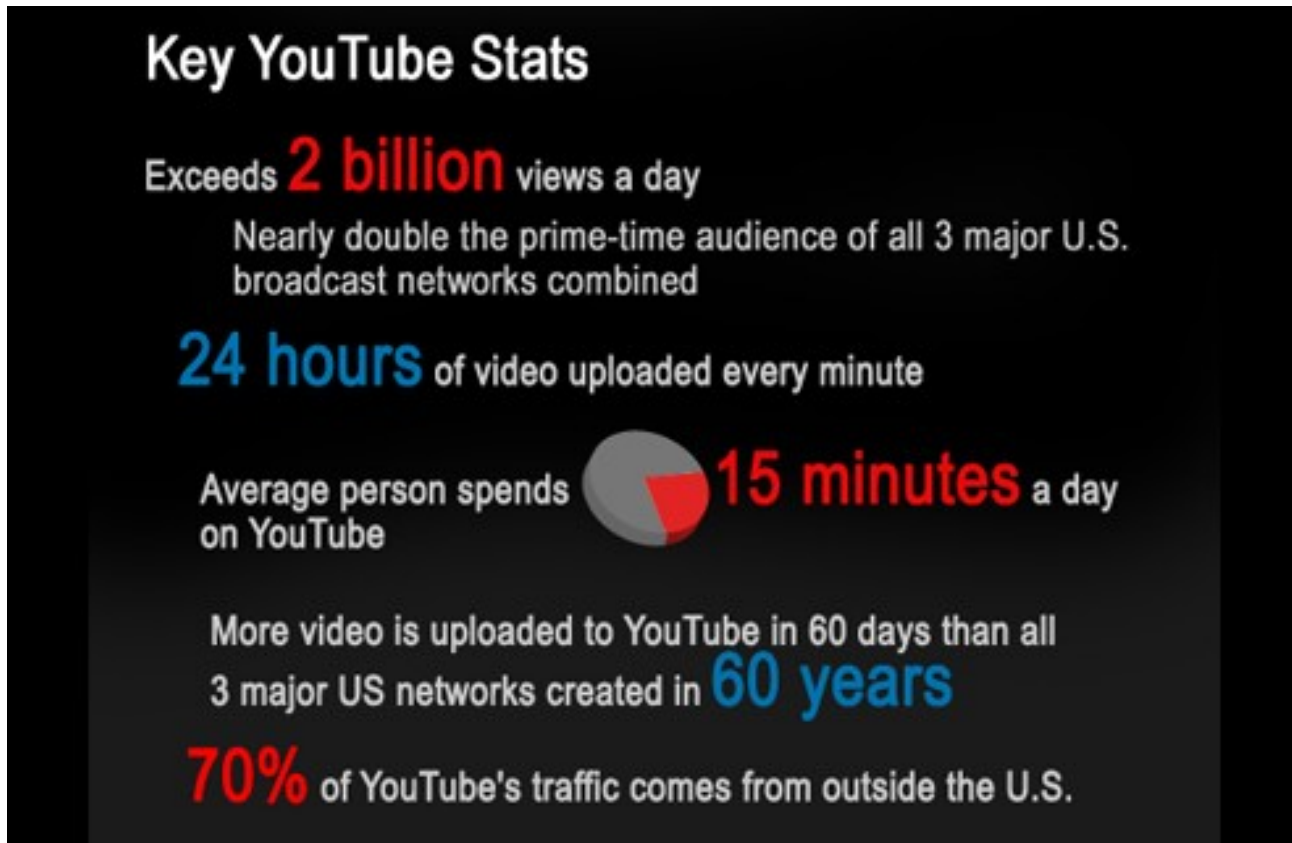
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Introduction

Chad Hurley and Steve Chen wanted to share some videos with a half a dozen friends in a dinner party in San Francisco in the year 2006, this is when Youtube was born. Now Youtube is the most downloaded & uploaded video resources on Internet.

Every day thousands of videos are uploaded by people all around the world:

Youtube statitics sample source. [1]

We can find a lot of hospials, journals & magazines, TV programs offering their multimedia products on the different channels of Youtube.

We are interested on that kind of multimedia products in order to help patients on their diseases. Our challenge will be to collect that information from the sources mentioned above.

Description

Rare disease Video Portal will facilitate solutions for patients´ needs, using the experience of social network achivements.

The European Commission of Public Health defines Rare disease as "life-threating or chronical debilitating diseases which are of such low prevalence that special combined efforts are needed to address them" [2].

In other way the National Organization for Rare Disorders was established in 1983 by individuals and families with rare disease. We should take into account, not only the

patients, but all the people around that suffers the consecuences of their disease.

We can find more information:

- List of rare disease [3].
- Orphan drugs [4].
- Rare Disease Day [5].
- Genetic Alliance UK [6].

Needs

Rare disease ambient person will be involved on a daily work: find a better wellness for them. One of this purpose will consist to give tools, toolkits and applications using new thecnologies for a better kindness way of life.

We consider to take one main objetive: Videos on this topics. We will join all possibles videos in a portal calling it "Rare Disease Video Portal". We must consider the following challenge including the following characteristics as needs for the platform:

- Must contains a pure line of videos avoiding all possible spam.
- Must take into account the accesibility.
- Must recollect all videos from youtube platform and integrate into our platform.
- Must give an easy way to find videos and good filters.
- Must take values for a correct video choice integration.
- Must be easy on it navigation.

We could find some difficulties on this challenges:

- Avoid spam: really will be treating like a quality process, it´s very difficult to find 100% spam, but we will try to avoid a great percent of it. In this way it could be a good choice to select only health channels and filters videos in its.
- Accesibility: It is easy to find derive other diffculties from the rare disease patients, for example, Lowe sindrome will have difficulties of vision.
- Framework to choose: select a good framework where they will receive good results on and rationality time.
- Search engine: give a good engine for filter by tags.
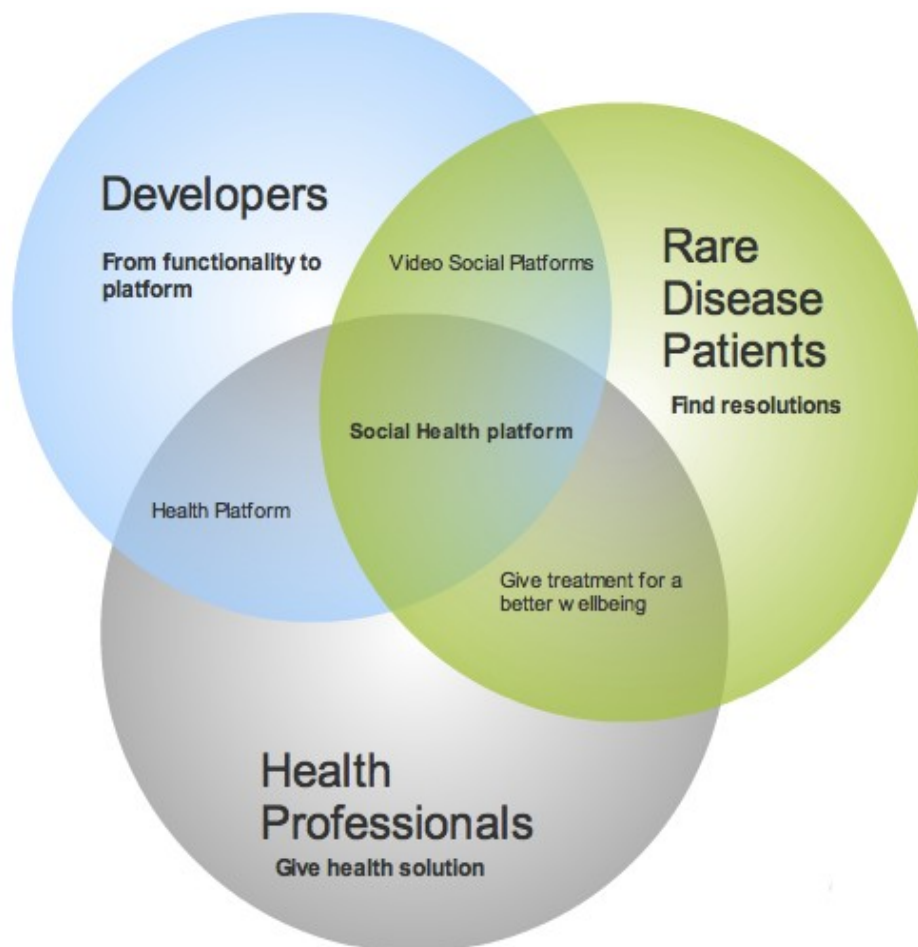- Usability: easy to use and nice navigation.

Proceedings

This project is focusing on two ways:

- **Video Crawler**: where we will recolect a good video choice for youtube channels.
- **Portal show up**: where we will introduce and present all multimedia integrated channels.

We must consider the license and terms of use on each video: in this way it is important to avoid videos where author does not give a Creative Commons licence for playing in the platform.

Functionality

Entities

Objetives

1º) Crawl videos.

- **Youtube API study.**

  We need to connect with Youtube API and search all metadata include in it. A bot will dive into any channels of Youtube.

- **Select recognized channels of Youtube.**

  Norut has been choose those relevant channels where we need to introduce in our platform, in this case there are a thousands of channels where we will find any videos about Rare Disease.

- **Get videos from Youtube.**

  Here we will get metadata from Youtube and introduce it into our platform, we will check licenses and copyright of that videos.

- **Select correct metadata on platform.**

  Norut has been take in consideration metadata of Youtube, specially for avoiding

spam contents. In this case we know that all metadata will not include on our platform.

It´s very possible to select other variables, but it isn´t clearing for this moment. We will include on next analysis document what metadata will be select.

2º) Video Portal display.

- **Choose the platform.**

We need to select the platform where it will show theirs contents.

- **Study data integration.**

In this way, we try to study the metadata integration on this platform.

- **Show elements on each views**

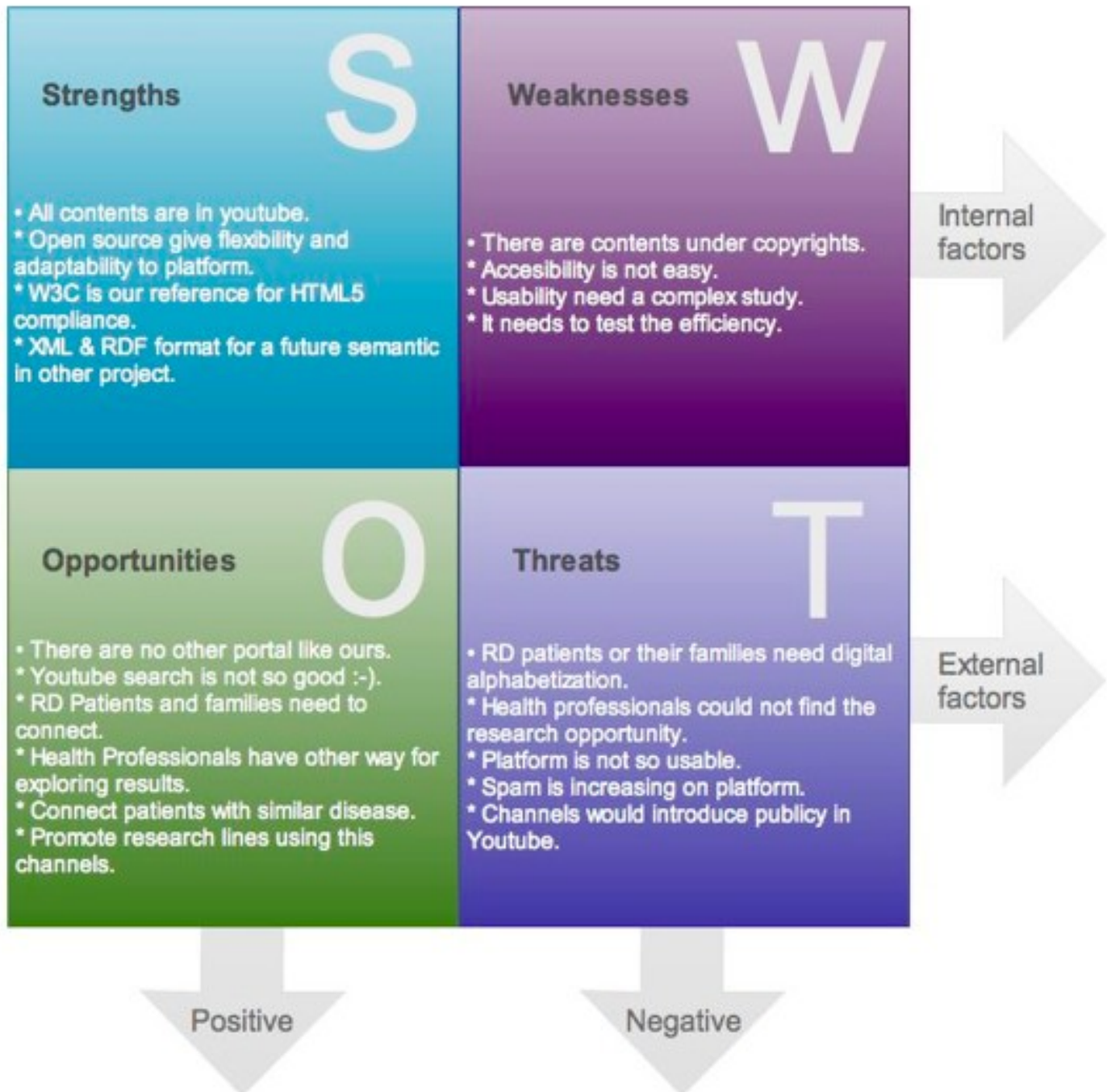Each other views will resolve a way from video access: panel grid, one video.

We are interested for presenting it in HTML5 [7] compliance format. For this reason we choose only Youtube: this give a HTML5 format API for display it player program [8].

We have to find the accesibility of the theme portal, we will include Open Standards [9] in our platform.
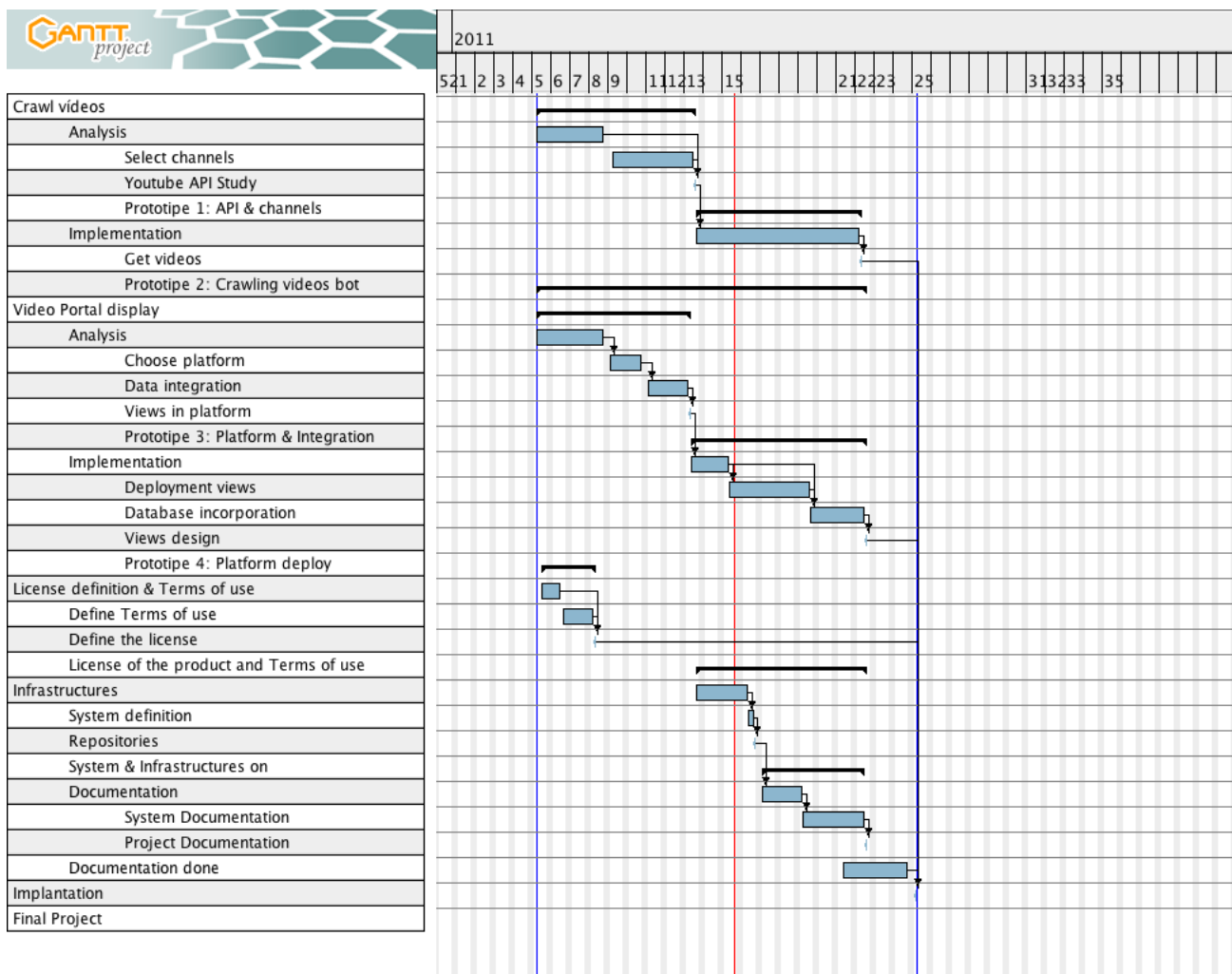
SWOT

SWOT Analysis - RD Video Portal

Strengths **S**	Weaknesses **W**	
• All contents are in youtube. * Open source give flexibility and adaptability to platform. * W3C is our reference for HTML5 compliance. * XML & RDF format for a future semantic in other project.	• There are contents under copyrights. * Accesibility is not easy. * Usability need a complex study. * It needs to test the efficiency.	Internal factors →
Opportunities **O**	Threats **T**	
• There are no other portal like ours. * Youtube search is not so good :-). * RD Patients and families need to connect. * Health Professionals have other way for exploring results. * Connect patients with similar disease. * Promote research lines using this channels.	• RD patients or their families need digital alphabetization. * Health professionals could not find the research opportunity. * Platform is not so usable. * Spam is increasing on platform. * Channels would introduce publicy in Youtube.	External factors →
↓ Positive	↓ Negative	

SWOT Analisis [10]

Task Effort

Feasibility

We need to measure although it is really hard to do it. We will ask for the questión "How is the project going on?" in this case feasibility give us one aproximation for calculating bad/good things [11].

Economic feasibility

Economic analysis is focusing for evaluating the effectiveness of RD Video Portal. It determines the benefits and savings that are expected from our platform and compare with the costs. If benefits outweigh costs, then the decision is made to design and implement the system.

We determinate the cost and benefit factors, following this categories:

- ⚔ Development cost: This will be determinate on gantt project where select time working to design the framework and portal.
- ⚔ Learning cost: This is orienting for a better use of the platform.
- ⚔ Social cost: This is getting facilities for the contents.

In RD Video Portal we need to consider the social cost-based like one of the most important feasibility. We remember that Rare disease need solutions, needs orientation

and connecting for each patients. So, in this case RD Video Portal pass Economical feasibility for social cost, the power of connecting give hopes and grow up on the evolution of each disease.

Legal feasibility

Determines whether the proposed system conflicts with legal requirements like Data Protection Acts. In RD video portal check personal data recovering for Youtube, in this case we are not treating high level personal data, but we need to tell our data how is treating and comunicate to Protection Data Agency.

Operational feasibility

How well a proposed system solves the problems and takes advantage of the opportunities identified during scope definition? And, how it satisfies the requirements identified in the requirements analysis phase of system development? [12].

There are many studies about the wellbeing of connecting patients with similar disease, even more, on rare disease where we could find less patients on a local place.

Schedule feasibility

How long the system will take to develop, and if it can be completed in a given time period using some methods like payback period?. Schedule feasibility is a measure of how reasonable the project timetable is.

On Analysis phase we will define a gantt project where will stablish the schedule on RD video portal.

References

[1] http://www.viralblog.com/research/youtube-statistics/

[2] http://ec.europa.eu/health/ph_information/documents/ev20040705_rd05_en.pdf

[3] List of rare disease webcitation: http://www.webcitation.org/5xwqgaE6D

[4] Orphan drugs webcitation: http://www.webcitation.org/5xwqllC5d

[5] Rare Disease Day : http://www.webcitation.org/5xwqpHePs

[6] Genetic Alliance UK: http://www.webcitation.org/5xwqslDs4

[7]] HTML5 Drafts http://www.w3.org/News/2011.html#entry-9056

[8] http://www.w3.org/News/2011.html#entry-9056.

[9] Open Standars: http://www.webcitation.org/5xwqxE1vh

[10] SWOT Analysis http://en.wikipedia.org/wiki/SWOT_analysis

[11] Feasibility http://www.ihealthbeat.org/perspectives/2011/transforming-health-care-through-improved-clinician-workflows.aspx.

[12] User needs analysis and evaluation of portals.

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