Using the Internet to disseminate the knowledge generated by an FP project

The GenoMEL experience

Project LSHC-CT-2006-018702
Genetic and environmental determinants of melanoma: translation into behavioural change

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PRIORITY 1
Life sciences, genomics and biotechnology for health

Introduction
In the 21st Century many Europeans first turn to the Internet when they need information. To be taken seriously an organisation therefore needs an online presence. The GenoMEL website www.genomel.eu was created in 2004 to promote the Melanoma Genetics Consortium. It carried descriptions of the consortium partners, lists of their scientific papers, and an overview of existing/proposed studies. Under an FP6 Network of Excellence (NoE), it has under gone two major reorganisations, numerous minor revisions and switched its focus to disseminating the outputs of the project. It has now received over 125,000 visitors.

Original features of the website
The website began with two sections. A public section and a password protected members' section. The public section contained descriptions of the individual groups, a description of the overall project and specific pages aimed at patients and clinicians. However, the group descriptions provided most of the content.

The members' section contained: a directory of members; a slideshow; a notice board; a meeting minutes area; a members' messaging service; a who's who area; a calendar; GenoMEL policy statements and a resources area. Many of these facilities were under utilised by members who generally preferred to communicate by email. However, the resources area proved popular, with folders containing presentations from previous meetings and a wide range of other documents. By mid 2011 the resources area contained over 200 presentations and other files.

Expansion of the website
Gradually the clinician pages and patient information pages were revised and expanded. In 2008 the GenoMEL patient information web page was commended in the British Medical Association (BMA) Book Competition Awards.

A major output of the project was a series of Content Management Systems (CMSs). Two of these were placed on the patient information page and were specifically aimed at melanoma patients with a diagnosis of melanoma. A major component of both these packages were interviews with actual patients, talking about their experiences and how they have dealt with melanoma. Subsequently, the dealing with the diagnosis CMS was highly commended in the 2010 BMA Patient Information Awards.

Three CMSs were created for healthcare professionals. The first was a tutorial aimed at encouraging clinicians to diagnose melanomas at an early stage improving outcomes for melanoma patients. This CMS contains many clinical photographs, video, animations, diagrams, a series of case studies and assessment exercises. The early diagnosis tutorial was well received by the medical community. In 2009 the Royal College of General Practitioners reviewed the tutorial and gave us positive feedback, "... an excellent educational tool for all doctors training or established in general practice... pictures are of excellent quality and the variety of examples used the best our commentator has come across." The early diagnosis of melanoma tutorial was extensively revised in February 2011.

A second tutorial was added to the physician page in 2009. This CMS promoted the use of dermoscopy in the early diagnosis of melanoma. It was subsequently released as an 'app' on the iTunes store. The third tutorial concerned genetic counseling for melanoma and was launched in late 2010. This CMS also contained photographs, video, animations, diagrams and assessment exercises. Promotion of this CMS continues.

Health psychology questionnaires
As part of the NoE, GenoMEL launched a series of online questionnaires on the website. The first was available in ten different languages and garnered over 10,000 responses. This questionnaire was aimed at the general public and examined behavior in the sun. The second and third questionnaires were aimed at people who were already participating in GenoMEL's melanoma studies. As a result of these questionnaires two scientific papers have been published, a third has been accepted for publication and more are likely to follow.

News and meetings
The website home page has a news section; this is updated on a monthly basis via a blog. A list of relevant national and international meetings was also maintained during the project but this has now been discontinued to reduce the amount of updating that the website requires.

Languages
The original intention was to have the website available in four or five languages to increase its appeal to a European audience. Many of the web pages were translated and were available in Dutch, Swedish, Spanish, Latvian and Russian. However, every new page, and every revision of an existing page, required translation and the amount of work required quickly mushroomed. The possibility of computer-assisted translation was investigated but would still have required specialist input. Rather than have a patchwork of translations of varying dates it was decided to concentrate on a single language, English, but to strive to make the text as clear as possible. This also enabled the consortium to concentrate on translation of the online questionnaires.

Visitor numbers and locations
Since the NoE began the website has achieved over 125,000 visitors.

Year	Unique Visitors
2005	952
2006	14,823
2007	33,154
2008	30,763
2009	32,989
2010	9,741
2011	2,583 (so far)

Map overlay, visitors to the website since the major revision in September 2009
There were 24,186 visits from 2,877 cities

Conclusions
The Internet provides an excellent opportunity to publicise your project and disseminate your research findings. In particular, it can reach large segments of the European population, enabling your project to establish a public profile. However, creating an effective project website is a major undertaking. Many researchers underestimate the work required, especially

in terms of maintenance. Out of date information can be worse than no information at all because it reflects badly on the commitment of the project partners. Proper resourcing and planning can avoid these problems.

Key questions for project websites

Before creating your site

- Is the domain name short, relevant and memorable? (Preferably a .eu name.)
- What is the consortium's key message?
- How is that message going to be communicated?
- Who will build the site? What sites have they previously created?
- What colours, fonts, pictures, etc. are needed for a unified look?
- How much effort will be required to maintain the site?
- Who will be maintaining the site?
- Are other languages necessary?
- Is a secure, members' only area required?

When creating your site

- Is the site clear and simple to look at?
- Who will proof read the text?
- Is the text as easy to read as the subject allows?
- Is a tracking tool, such as Google Analytics or Statcounter, necessary to monitor usage of the site?
- What links to other sites are needed?
- Have the funders been acknowledged with appropriate text, logos and web links?
- Has a privacy policy been included?
- Have terms and conditions of use been included?
- Are there creation dates on the individual web pages?

When maintaining your site

- Is the site disseminating the consortium's latest findings (if appropriate)?
- What other sites should link to this one?
- Are the existing links up to date?
- Is the original 'message' still relevant after one year?
- Has the whole website been formally reviewed in the last two years?
- Are there revision dates on the web pages?
- What will happen to the site when the funding period ends?