

Ten lessons for developing a health information website

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Abstract

This paper outlines ten lessons derived from the development of a palliative care website, www.pallcarevic.asn.au. The following program elements contributed to the success of the project: (1) peer and stakeholder participation; (2) response to a significant need; (3) networking skills; (4) administrative skills; (5) mediation of conflicts; (6) project management skills; (7) sourcing of good evidence; (8) iterative evaluation involving users and stakeholders; (9) iterative expert evaluation; and (10) a well thought through sustainability strategy.

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GENERAL PRACTITIONERS and community nurses rely on easily accessible, evidence-based online information to guide practice. A recent survey focusing on the Internet use of 2200 US-based family physicians indicates that 59% of respondents regularly search the Internet for clinical information¹ Although the growing demand for appropriate user health information on the Internet has been persuasively argued,^{1,2} there is little guidance available concerning the development of online health information resources. The lessons outlined in this paper were designed to provide doctors and other health professionals with a practical guide for the development of a health information website.

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What is known about the topic?

More people are using the Internet to source health information.

What does this paper add?

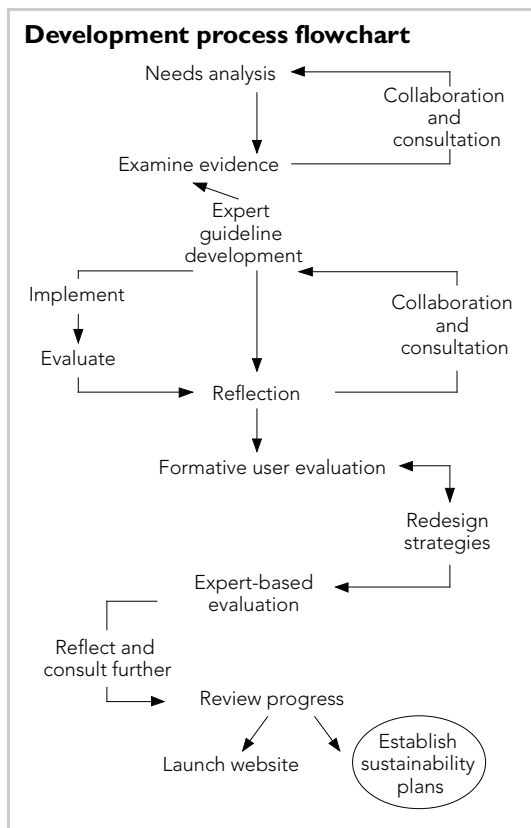
Based on the authors' website experience, this paper outlines 10 suggestions for the development of a meaningful website.

What are the implications for practitioners?

This suggests the website development plan needs to ensure a well managed iterative process with appropriate participation to respond to an identified need. Sourcing good evidence and ensuring a sustainability strategy are also essential.

We derived the following ten lessons from a study conducted between June 2003 and May 2006. The study gave rise to a palliative care information website (www.pallcarevic.asn.au) currently hosted by Palliative Care Victoria (PCV). A detailed description of this government-funded project has been published elsewhere.³ Because of the limited scope of this paper only a very cursory summary of the project is given.

The project was constructed in four main stages. The pre-development stage involved the identification of the needs of the target audiences through a literature review, a pre-development online survey, and (1) a gap analysis undertaken by user working groups (consumers and health professionals) under the oversight of a project reference group of key stakeholders. After a lengthy consultation and development process, (2) a test website (beta site) was developed by the Centre for Online Media and Educational Technology (COMET) for eventual transfer to the PCV website. The beta test site development was undertaken with input from external experts and the user working groups. (3) The beta site was then assessed by key stakeholders, including consumers. Finally, as last modifications were made to the site, (4) a



sustainability plan was implemented in conjunction with PCV. The figure provides an overview of the participatory methodology (see Box).

Developing a health information website

Existing health information websites have an uneven track record, and a growing body of literature identifies the often questionable quality of content, language, site maintenance, and accessibility provided by such sites.⁴⁻⁷ Summarising this literature, it appears that for online health information resources to be efficient, four basic conditions have to be met: their content needs to be clinically authoritative, accessible, sustainable, and has to respond to the information needs of potential user groups. Although websites developed by doctors may vouch for the evidence level of the clinical material

reported, they are less likely to involve site users in the development of material. Yet user engagement is increasingly necessary to meet patient and community needs. The following ten points address these requirements.

1 Good evidence ensures effectiveness

The most important function of a health information site is to provide accurate and authoritative information. Hence the drafting of comprehensive editorial guidelines operationalising the notion of evidence-based medicine (EBM) is of enormous importance. "Decisions that affect the care of patients should be taken with *due weight* accorded to *all* valid, relevant information".⁸ Bearing this in mind, it makes common sense to include evidence from randomised controlled trials with consensually formed clinical guidelines as well as systematically evaluated qualitative studies and expert opinions. Although not the result of controlled trials, such studies represent expert knowledge and best practice. The material needs to be reduced and simplified to be effective.

2 Peer and stakeholder participation (multiple data sources) can generate a more authoritative site

Health information needs are diverse and complex. In the field of palliative care, site users required medical, clinical, legal, and psychosocial information in order to make informed choices. Generating targeted user participation that represents all potential user groups ensures that the content of online health information resources corresponds to user needs, is relevant, uses appropriate language, and is easily accessible.

3 Need for website generates user commitment and participation

Health information providers should consider whether peers, stakeholders, and members of the wider community share their view regarding the salience of the problem the website is designed to address. Our study relied on the participation of a large number of doctors,

nurses, patients, family and community members who, over the course of 3 years, generously donated their time and energy to meet an identified deficiency. The need for a particular health website is likely to influence the commitment and support of participants.

4 Effective networking skills contribute to increased participation

Involving key representatives from all relevant stakeholder groups in website working groups requires networking skills. It is unlikely that an individual web developer has access to the multiple networks that need to be accessed during the development process. The initial scoping of beneficiaries and key stakeholder groups can be greatly facilitated by drawing on established medical and health networks.

5 Administrative skills and access to resources facilitates quality outcomes

Any project with considerable involvement of peers and stakeholders is time consuming and requires substantial administrative resources. Clearly, access to cost-effective web and educational design technologies was crucial for the success of the project. A solid administrative structure that clearly defines competencies, tasks, accountabilities, auditing tools, as well as communication and feedback channels is required. Moreover, office support staff and basic administrative infrastructure should be available.

6 Mediation of internal and external conflict of interests promotes collaboration

Working with a range of diverse stakeholder groups, participants and experts is likely to generate tensions. We found that doctors, nurses and consumers had different views on the amount and depth of information needed on the website. Individuals often had strong ideas derived from their own personal interests or professional needs. The wide representation and feedback mechanisms meant that it was important to gain negotiated decisions on content,

format, "look and feel", links and coverage. Such issues need to be carefully negotiated to ensure that the final site remained balanced and representative.

7 Project management skills foster efficiency

Collaborative projects tend to generate a very large volume of information and paperwork. This can severely test the capacity of project officers. The careful design of feedback mechanisms in conjunction with significant data-management skills, a solid audit trail and additional support staff during peak feedback periods are needed to remain in control of an often erratic data flow. Moreover, project officers need a good grasp of research techniques, and solid time management skills, as well as experience with establishing voluminous literature reviews.

8 Iterative evaluation involving users and stakeholders ensures more relevant and useable content

Theoretical contributions to the field of educational multi-media design indicate that issues regarding content, language, and "look and feel" can be resolved through an ongoing consultation with user groups⁹ based on cycles of self-testing, ongoing feedback, and constant adjustments.¹⁰ Our experience clearly confirms that user participation and iterative testing takes care of the scoping of audiences, content, language, and design.

9 Expert evaluation fosters the quality of content and design

To ensure the quality of content and design, various expert groups should be involved in the iterative evaluation process. Experts should have an expertise in:

- relevant health care fields;
- educational health design;
- readability assessments; and
- multi-media web design and online education

In addition, input can be sought from webmasters of other relevant websites to incorporate

relevant material or design techniques and to obtain critical input.

10 A sustainability strategy ensures continuity

Without a well-elaborated sustainability strategy the continuity of a health information website is in doubt. Alongside ongoing stakeholder support, a successful sustainability strategy depends on the availability of sufficient resources. In the absence of such resources, several alternatives are on offer. Our project relies on a voluntary editorial panel that is responsible for the currency and consistency of the content. A feedback structure has been incorporated into the site providing ongoing evaluation data of the site to the editorial panel. Stakeholder groups are involved in assessment and take responsibility for specific sections of the site. However, the employment of a webmaster/researcher for the maintenance of the site would be desirable.

Final considerations

By following these ten lessons, health care practitioners will be likely to produce web content that is clinically authoritative, accessible, sustainable, and responds to the information needs of potential user groups. However, we should add that depending on the complexity of information needs the process can be extremely labour intense and should only be attempted if a team with experience in collaborative and participatory methods is available to ensure the website is properly evaluated.

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Competing interests

The authors declare that they have no competing interests.

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