Improving consumer and health professional access to comprehensive, accessible, evidence-based online information

Final Report

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Part C – Executive Summary

1. Background

Program/project title: Improving consumer and health professional access to comprehensive, accessible, evidence based online information

Time period: June 3rd 2003 to February 28th 2006.
Organisation: School of Nursing & Midwifery La Trobe University
Project Manager: Kathleen Swift.
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Setting:
The setting was primarily the Palliative Care Victoria (PCV) Website. Palliative Care Victoria is a small organisation with excellent support from skilled volunteers. The setting benefited from academic input (La Trobe University) into the website development, clinical input from a range of medical and nursing personnel, plus consumer input via feedback for evaluation of whether consumer needs were met in the material provided by the developing website. The project work was based at the La Trobe University Clinical School of Nursing at Austin Health, Melbourne Australia

Background:
The project was designed to improve community and professional awareness regarding palliative care in supporting the care needs of health professionals, patients, and carers. At the outset of the project there was no co-ordinated approach to the organisation and dissemination of palliative care information and educational material in Victoria. PCV had some excellent leaflets available on their website. However the organisation did not have the capacity to develop a website to provide busy clinicians, interested consumers, or members of the general public with information that could guide practice or empower consumers in their decision making. The previous Director of PCV supported by various government reports had identified the need for better online access to information for consumers and health professionals. A website was needed that provided fact sheets and links to other information for the general public and health professionals, particularly GPs and community nurses in urban and rural contexts.

2. Project Objectives

The overall aim was to improve the current Palliative Care Victoria website so that it provided online access to information for the general public, including those with sight and language difficulties, along with accessible evidence-based pain, symptom and psycho-social information for health professionals, particularly GPs and community nurses.

Specifically the project was designed to:

- Improve the scope, accessibility, content and evidence-base of the web-based information available to members of the general public to enable informed and empowered choices regarding end of life care alternatives and service provision;
- Provide health professionals with highly relevant and accessible web-based evidence based information regarding best practice pain, symptom and psycho-social management of palliative care clients;

- Develop web links to and from appropriate sites and develop website to increase accessibility for consumers with sight and language difficulties

3. Methodology/Description

The project was constructed in four main stages. The pre-development stage involved identification of the needs of the target audiences through the literature review, a pre-development online survey, and a gap analysis undertaken by the expert panels (consumers and health professionals) under the oversight of the Project Reference Group of key stakeholders. After a lengthy consultation and development process, a test website (beta site) was developed at La Trobe University in Victoria for eventual transfer to the Palliative Care Victoria website. The beta (test) site development was undertaken with input from external experts and the expert panels. The beta site was then assessed by key stakeholders, including consumers. Finally, as last modifications were made to the site the sustainability plan was implemented in conjunction with Palliative Care Victoria.

The target audiences for this project were the general public (in particular people with a life-limiting illness, their carers, prospective volunteers and people wanting more information about end of life issues), health professionals who are not specifically involved in palliative care (particularly general practitioners and community nurses), along with members of the palliative care field. These three audiences are looking for different levels of information tailored to meet their needs.

The choice of the evaluation design was governed by the project's scope. As the project was structured to be responsive to feedback from stakeholders a *formative* evaluation (sometimes called process evaluation) was designed. This approach enabled the project staff and researchers to design an iterative process of continuous improvement through trial, analysis, and feedback from key stakeholders in order to adapt and modify the project to meet emergent needs. Formative evaluations account for and are responsive to changes in and unanticipated effects of the implementation progresses. In this way, the study of effects and outcomes of one stage inform the development process of the next stage and provide guidance for the development of the investigative framework that best addresses the evaluation questions.

4. Results

The project was successful in meeting its goals. A beta website www.latrobe.edu.au/pallcarevic was designed through a highly consultative and capacity-building process. The beta website was evaluated by external experts and key stakeholders. This feedback was incorporated into the website, which is currently ready to be handed to the webmaster appointed by Palliative Care Victoria (PCV) and under the guidance of an Editorial subcommittee of the PCV Board. Agreement has been reached that the Special Interest Groups of PCV will undertake to identify relevant sections of the site that need updating and refer them to the editorial subcommittee. The new website www.pallcarevic.asn.au will be officially launched by Palliative Care Victoria on May 22nd 2006 at the commencement of Palliative Care Week. The website has been included in the new Department of Human Services, Victoria (DHS) Communication strategy. Funding from DHS to Palliative Care Victoria will enable the development of podcasting technology to support professional education and training.

There were two unexpected but very welcome outcomes. The first unexpected outcome was the extent to which representatives of the palliative care community became involved in the project and enthusiastically supported it. This level of involvement has created a degree of capacity building that exceeded expectations. The other unanticipated outcome is the extent to which the website has been incorporated into policy through the DHS Communication Strategy and the way its online capacity will be further enhanced with the incorporation of the podcasting technology.

5. Discussion

The major achievement of this project is the creation of a beta tested website based on a wide-ranging collaborative design process incorporating users of palliative care services, key stakeholders in the palliative care community, as well as Divisions of General Practice and the Royal District Nursing Service. The governance structure of a highly dedicated Project Reference Group supported by two panels of experts was instrumental in shaping the website development strategy. Content for the website was provided by experts and the evaluation was largely informed by user feedback. The Centre for Online and Multi-media Educational Technologies provided web design and testing expertise and responded rapidly to continual requests for change. Moreover, a sound sustainability plan was developed in order to ensure the ongoing relevance of the new PCV site.

To have the website 'up and running', as was initially planned, by the end of 2005 would have been only possible if we had limited the scope of the website to the original two portals, one for consumers and one for general practitioners/community nurses. However, the gap analysis and the pre-development user survey suggested to include resources for carers, volunteers, and the palliative care community. In retrospect, this was a wise decision. Moreover, the collaborative project design that we employed allowed us to ensure that the information and resources were thoroughly examined by the target audiences, including all government and palliative care key stakeholders. It also enabled us to devise strategies to ensure sustainability. However, given additional funding, we would have preferred to carry out a thorough sustainability analysis as well as a site assessment based on an online survey and user statistics.

The site has been developed in such a way that the new site owners, Palliative Care Victoria, can finalise a few details related to the upkeep of content and can apply for Health on the Net (HON) accreditation. The United Nations-endorsed HON accreditation is highly regarded as it demonstrates that the website has met the highest standards of health evidence reliability and credibility.

6. Conclusion

The major recommendations arising from the project are:

1 That the PCV website be a prototype for the development of other health related state-wide associations.

- That any website so developed includes definition and explanations of key terms and concepts, evidence-based clinical information, psychological and legal resources, as well as an exhaustive list of agencies and community organisations that provide health care assistances.
- That government support be provided for a web specialist position to support and maintain the PCV website and other websites of similar, health-related co-ordinating bodies.
- That when developing such a web-site, the aim should be that the website will become a central reference point for health practitioners as well as non-professionals searching for information on the internet.

2 That the capacity building process will engage representatives of all potential user-groups of such health-related websites

- That multiple stakeholders be involved in the development and testing process to produce a website of quality and enhance capacity building in the field.
- That the collaborative project design used for this project is productively applied to other online health information/education projects.

3 To ensure sustainability, Palliative Care of Victoria (PCV) requires a continuing plan of responsibility and resources to maintain the newly developed PVC website, including the appointment of an Editorial Panel and ensuring that PCV Special Interest Groups revise site content relevant to each group on a regular basis.

- That PCV continue support for the PCV volunteer webmaster and regularly review user statistics of the site to ensure its ongoing relevance.
- That PCV ensures that ongoing site maintenance is costed into plans for implementing the palliative care communication strategy.
- That PCV ensures that ongoing dissemination of the existence and purpose of the PCV web-site continues.
- That the PCV Board seeks HON accreditation for the site