Supporting a Shared Dialog on Healthcare Policy between Researchers, Practitioners, and the Lay Public: Creating the SpeakHealth Online Community

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Abstract. The U.S. spends more on health care than any other nation. Despite these expenditures, health outcomes in the U.S. rank surprisingly low among industrialized countries. While access to care and socioeconomic status are strong indicators of health, individual and collective notions of health are the most powerful health improvement assets; no treatment compares. This paper explores the decisions underlying the sociotechnical design of the SpeakHealth online community—a project jointly undertaken by medical professionals, media designers, and information scientists to encourage healthy, mindful behaviors, and to enlist support for structural changes in national healthcare policies and practice. Here we report on the multidisciplinary challenges faced, and decisions made, in crafting its social media strategy and related online community design. The project outcomes made clear that the dynamics between the stakeholders and the professional cultures of these domains was a powerful factor influencing the design of online community.

Keywords: Online Communities, Sociotechnical Systems, Moderation, Design, Social Media, Health, Healthcare Policy.

1 Introduction

More and more, American life involves online interactions. Nearly 80% of the U.S. population is connected to the Internet, the majority of which find themselves online

C. Stephanidis (Ed.): Universal Access in HCI, Part I, HCII 2011, LNCS 6765, pp. 463–472, 2011.

on a daily basis [1, 2]. Highlighting the importance of social support provided within this venue, Raine, Purcell & Smith (2011) found that four in five Internet users (fully 62% of the U.S. population) report active ties to one or more online groups. Healthcare ranked among the more prevalent topics, with 61% of adults looking online for health information [3]. Yet, while many of these users have read the related commentary and experiences left by others in health-related blogs, social networking sites, and other online social media, few have actively contributed their own stories and content to these outlets [3]. Fewer still have contributed their voice to the broader challenges shaping healthcare in the U.S. – how it is viewed, how it is furnished, and how to address the varied cultural and environmental factors that are involved. This dialog is urgently needed; medical science is seeing more and more connections between how we live and our collective health. At the same time, despite spending more on healthcare per capita than other industrialized nation, the U.S. is lagging behind in health outcomes such as access to healthcare, preventable mortality, life expectancy, and increased rates of chronic disease and comorbidity [4].

The SpeakHealth online community originated from the idea that an interactive social site, that foregrounds the distinct challenges—many of them cultural, facing U.S. healthcare, could instantiate discussion among the many stakeholders of healthcare, medical experts and the lay public alike. In doing so, a broad constituency could be guided to leverage collective knowledge and diverse cultural expertise to craft a new shared vision of healthcare – one that could guide policymakers and jumpstart progress towards better health and well-being.[1]

This paper chronicles the initial decisions that impacted the design of the SpeakHealth online community. Connecting these decisions is an underlying narrative on the differing views among those involved in developing the main online community website, principally a collective of medical and health professionals and policy makers (hereafter referred to as the healthcare professionals) and a team of designers of prosocial media (subsequently denoted as the media designers). Hidden conflicts between the visions the two groups had for the project came to light only after the initial site was built. Given the extensive efforts to illuminate just such conflicts early on, the project stands as a lesson about the difficulty different disciplines and institutions have imagining the full implications of what each other have in mind. Despite the best of intentions and significant communications expertise, fundamental misunderstandings will still occur.

For reasons related to the above, the described design of the SpeakHealth community was only operational for a short period of time. Therefore, measures of the effectiveness of the design overall, and of reaction to particular design elements, may never be fully assessed. Instead, this case study focuses on the conversations between the sponsoring organization and media designers and the questions that led to the initial design. Exploring this discourse yields insight into the differing aims of each group and on means of resolution. The value of this article is its potential to inform future multidisciplinary efforts between medical professionals and media designers to create online health communities.

[1] Multivariate measures, recorded from 2008-2010 in the Gallup Healthways Well-Being Index (http://www.well-beingindex.com/) reflect a flat trend in American's self-reported health and well-being.

2 Designing the SpeakHealth Online Community

An online community's design is embodied in the collection of strategies used to develop and maintain it. These strategies run the gamut from those with a social nature (e.g., recruitment strategies, moderation guidelines) to those with a more technical orientation (e.g., the navigational layout, the selection and configuration of tools for community communication). Though numerous guidelines exist that recommend a choice of strategies for particular situations [5-7], these guidelines are often of a general nature, recognizing the contemporary character of design strategies in an evolving world of online technology.

Advances in social media, a term that collectively refers to those web technologies that facilitate interaction based on the co-creation and curation of online content, and a related societal move towards increased levels computer-mediated participation [8], are poised to reshape best practices for online community design strategies. As organizations seek to position their online communities to take advantage of social media, they will have to consider what media will best advance the purpose of their communities and how they can effectively support the member interaction the media engenders. Woven into these considerations are inculcated organizational beliefs on the most effective ways to interact with members and on how the organization itself should be represented by the social media. Strategies, therefore, must account for this duality of concerns, balancing efforts to attract and promote engagement while navigating longstanding concerns of impression management and knowledge representation unique to each discipline.

In the following sections we describe the debate and rationale behind key design choices made in: (1) the presentation of health topics, (2) the moderation of the site, and (3) on methods for stimulating and sustaining social discourse around health care online. In doing so, we note the less obvious challenges with collaboration between healthcare professionals and media designers and how the dynamics of these professional cultures influenced the outcome of the project. The paper concludes with a set of recommendations for the design of online health communities.

2.1 The Presentation of Health Topics

The SpeakHealth online community was envisioned as a place to explore an integrative approach to the many facets that affect ones' health, from lifestyle and environmental factors, to holistic and mainstream medical treatments, to our cultures' approach to healthcare overall. Extending from this vision, the initial design work was undertaken with the goal of promoting the interrelatedness of these topics in a manner that would foreground their holistic, connected nature.

To determine the topics, an extensive period of fact-finding and "story finding" took place. This included weekly meetings over the course of six months. In these meetings the media designers probed the healthcare professionals about the meaning of integrative medicine, who might care about it, and how such content might intersect culturally-held attitudes and beliefs. From this dialog, a number of topics were established as associated to health and well-being and relationships were drawn between them. This map of topics and relationships was simplified to a set of 25 high-level, connected topics visualized as nodes. Using the interconnected map of topics

and relationships as inspiration, the media designers developed a navigational design to facilitate a user in moving between the 25 nodes. This design strategy was chosen to reflect the novelty and effectiveness of the integrative approach to health. It would also suggest, on first sight, that this was an inviting yet unfamiliar health-related site. The map of topics and relationships and the resultant navigational structure are shown in Figure 1.

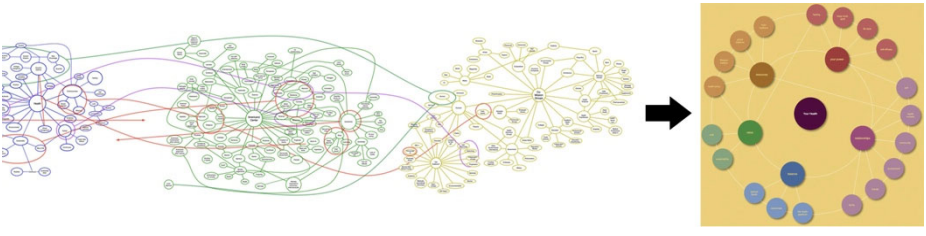

Fig. 1. This figure depicts the progression from brainstorming on the interconnected nature of health and well-being topics (left image above) to a simplified structure of 25 thematic nodes that served as the basis for the site navigation

The node and diagram navigational structure provided a nonlinear exploration of interconnected topics, and was the core framework for a website organized to host a range of directed conversations across a diverse set of healthcare themes. On arrival to the website, a visitor would be shown a small introductory video on the aims of the community and methods of interaction with the site. After viewing the introduction, visitors were allowed to navigate to different nodes, each of which hosted a topic aligned with an integrative health theme (e.g. health policy, "folk" traditions, body-mind-spirit, awareness). At each node the visitor was presented with a media prompt – a short movie or piece of multimedia intended to promote reflection on the given topic. A link to a discussion board provided a forum for focused conversations related to the node's topic. Figure 2 shows a trio of screenshots from the SpeakHealth community website, depicting the introductory video, navigation, and media-prompt.

Fig. 2. This figure shows three screenshots of the initial design of the SpeakHealth online community website. Upon arrival, a user is presented with an introductory video describing the site and its navigation (left image above). The user is then allowed to navigate between connected health topics (center image above). Each health topic includes a media prompt and links to a moderated discussion forum (right image above).

The site was unveiled at a major conference for those in the field of Integrative Health (the Complementary and Alternative Medicine conference in 2008). It was clear from the initial reactions that the project and its design were highly controversial among attendees, with supporters and detractors voicing passionate opinions. The project designers were optimistic that they had found a responsible way to create enough controversy to generate traffic to the site and build an active discourse. What they were not prepared for was that the medical professionals on the project team were uncomfortable with the controversy itself. They were concerned that funders and other colleagues were put off by the novelty of the design and the short films that described topics on the site. The medical professionals distanced themselves from the project and chose not to promote it among their colleagues.

In an attempt to salvage both the original intention of the project, and the level of multidisciplinary collaboration established earlier, the site was transitioned to a more commonplace blog-style format. In this iteration, the topics and media prompts were debuted at staged intervals. To support the sense that the community encouraged collaboration amongst professionals and the public, the media and topics were introduced by one of four main contributors to the redesigned site, representing a media designer, medical specialist, academic researcher, and public citizen.

2.2 The Moderation of the Site

In the initial design of the SpeakHealth online community website, each of the 25 health nodes would link to its own discussion forum. There, members of the community would be able to discuss the issue at hand, perhaps in response to the associated media prompt. Many health-related online communities support anonymous interaction, given the often sensitive nature of the information shared [9]. Rather than following this convention, however, a strategy was developed that required individuals to create an account at SpeakHealth prior to their being allowed to leave comments. Necessitating registration before allowing commenting is a common pattern online; innumerable websites limit posting to registered members to reduce spam and ease the effort of moderation [10]. Yet, whereas most registration programs have users create pseudonyms or "screen names" to denote who made each comment, for SpeakHealth the healthcare professionals proposed a strategy to print the real name, occupation, employer, and contact information as a signature to the end of each posted comment. They backed this recommendation by noting that with full disclosure comes greater transparency; visitors to the community would be able to quickly ascertain the types of individuals engaged in a discussion and users commenting under their real names would be less likely to post inflammatory or inappropriate remarks. As with medical authorship, credentials would help readers assess the validity of points made by commenters and would instill a sense of accountability to comments made.

Responding to this design strategy, the information scientists and media specialists indicated that full disclosure would unnecessarily restrict the amount of individuals contributing to the site. With information that includes their name, profession, location, and employer affixed to their posts, members would be hesitant about providing comments that run counter to accepted norms or might be reluctant to post personal views in comments listing their employer's name.

Resolution came with the decision to allow the user to select their signature from a set of predefined formats, each revealing more information. Users would still be required to provide their contact information but would be informed during registration that the amount of personal information disclosed on the site would be under their control (and modifiable by the user at a later point if so chosen). Table 1 shows the different types of information included in the signature formats with examples of how each signature would appear at the end of a comment.

Table 1. Signature formats and examples

Signature Type	Example
Title First_Name Last_Name, Credential	Dr. David Gurzick, Ph.D.
Employer	Hood College
Profession/Job_Title	Educator
City, State, Country	Frederick, MD USA
Website	http://www.hood.edu
Title First_Name Last_Name, Credential	Dr. David Gurzick, Ph.D.
Profession/Job_Title	Educator
City, State, Country	Frederick, MD USA
Website	http://www.hood.edu
Profession/Job_Title	Educator
City, State, Country	Frederick, MD USA

Registered members and unregistered visitors represented two of the four user roles available in the community, the remaining being moderators and mavens. To ensure that a high level of discourse was maintained in the discussions forums, the role of moderator was established. Aside from keeping the discourse civil and ongoing in the forums they were assigned, moderators were tasked with encouraging commentary from a diversity of different members, professional and public and finding "common threads" of discussion. Using these common threads, the moderators were asked to periodically summarize and post on the state of conversation across the topics for which they were in charge. These summaries were proposed by the healthcare professionals to provide a current snapshot of discussion occurring in the community, much like the abstract of research paper. To make these snapshots more noticeable, the media designers placed these on the main screen of each node below the media prompt and above the discussion board. The combined strategy enabled a visitor to the site to quickly gain a sense of the current state of conversation across the entire community by skimming the abstracts of nodes.

If moderators were more focused more internally, keeping track of the discussion forums, then mavens were focused more externally. Conceived as emeritus scholars or top leaders in their fields by the healthcare professionals, mavens were handpicked to start new discussions and promote the community based on their expertise/and passion in a given area. The media designers would use feedback from the mavens to guide the creation and refinement of media prompts for topics. The various roles in the community are represented in Figure 3.

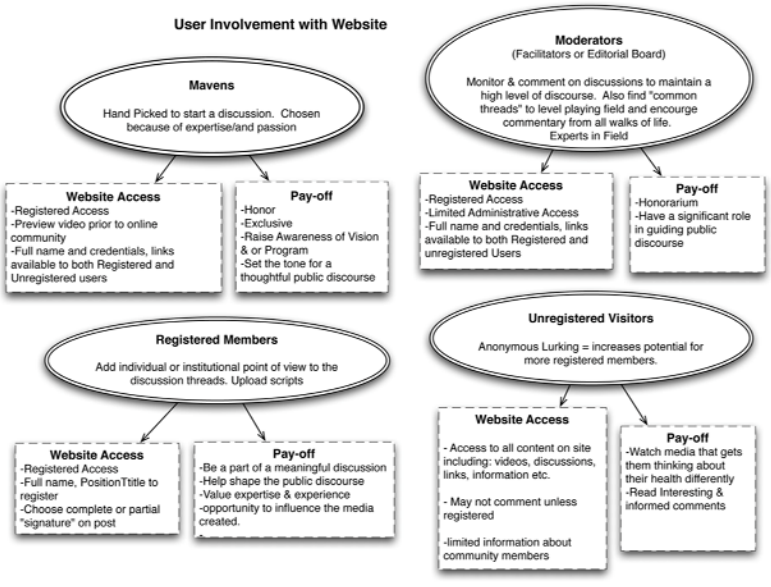

Fig. 3. This diagram represents the planning guide created by the healthcare professionals and media designers to describe the four roles in the SpeakHealth online community: mavens, moderators, registered members, and unregistered visitors.

2.3 Methods for Stimulating and Sustaining Social Discourse around Health Care Online

Central to the aims of the SpeakHealth online community was the desire to stimulate and sustain a social discourse on the nature of personal health and the challenges confronting healthcare overall. This discourse would be directed to craft new insights into how people in the U.S. view their health and healthcare, and to jointly develop new ideas for policymakers and the broader public that reflects a cultural perspective for improving healthcare.

The media designers approached this challenge with the design strategy of developing stories and images that could engage the wider culture at a grassroots level in reflection and conversation on varied health topics. As such, they designed the media prompts to use metaphor and fiction to create individual stories would potentially disrupt users' commonly-held beliefs about health, and yet be supported with research; thereby enacting a social media strategy of taking well-established, unmistakable truths and providing the space for them to interact with the common wisdom. In doing so, the media prompted conflict in the minds of the viewers – a known condition of good stories [11]. For example, one video began with a story describing the connection between social, communal ties and reduced incidence of heart disease[2] read over moving images of modern day suburbia. The video transitioned to show an animated heart flying through space then crash landing in a

[2] The Framingham studies [12].

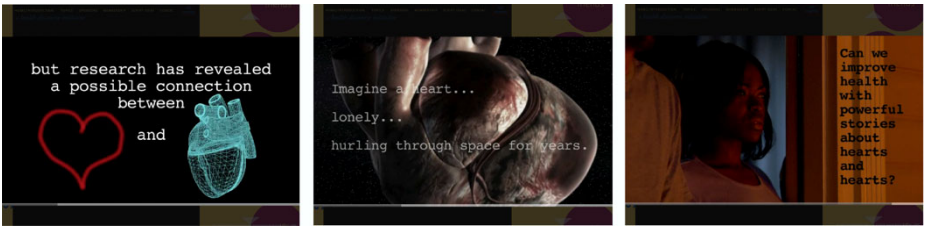

Fig. 4. This figure includes stills from one of the films showcased on the SpeakHealth website. The film showed a flying heart landing in a residential cul-de-sac, emphasizing the often unexpected nature of health events and community response to health crises.

residential neighborhood – reminiscent of the opening suburbia and inviting the viewer to consider their own social and communal ties. Stills from this video are provided in Figure 4.

Again, a tension arose between the media designers and healthcare professionals. In contrast to the media designers, who embraced the use of story to engage users in the topics at hand, the healthcare professionals desired an approach of vetted dissemination that was more traditional and established in their domain. In addition, they desired material that was not polemic, dour, or indicting of current healthcare approaches and practices. These desires culminated in a social media strategy of culling formal media streams and academic journals for informative posts and providing these to members interspersed with more direct calls for comment. Functionally, this used the Twitter micro-blogging service to broadcast these messages to members of the online community. The following posts are examples of the messages the medical professionals broadcast:

> *TIME magazine explores why #yoga works: http://bit.ly/aJUYFA*
>
> *#Teachers - have you taught in an educational #garden? would love to hear about your experiences: http://bit.ly/aFS7Zi*
>
> *Neat Study: Can meditation slow rate of cellular aging? Cognitive stress, mindfulness, and telomeres http://bit.ly/bi6ozq (PubMed)*

Unlike the before mentioned design concerns on the presentation of health topics and the moderation of the site, there was little resolution in the divergent design strategies for stimulating and sustaining an online discourse around health. When the community was first debuted it followed the design strategy created by the media designers. This met with a moderate success when examined by visits to the community, posts per visit, and general inquiries about the community. This debut was limited however, and soon after launch the design strategy shifted from the engagement model of the media designers to the dissemination model of the healthcare professionals (a move that coincided with a departure from the interconnected node navigation to the blog-style format). Interaction in the community diminished.

3 Discussion

The SpeakHealth project represented a unique convergence of professionals from the media and health disciplines, partnered together on equal footing with the joint intent of beginning a new conversation about U.S. health and healthcare. Though it represents a single case with a limited number of actors, the lessons learned in the project shed light on the larger challenges inherent in dealing with disciplines and institutions with different worldviews and entrenched expectations. Viewed from the perspective of design, these challenges afford a set of lessons learned and key questions to ask, for future designers of online health communities.

Assess the willingness to accept innovative approaches. With SpeakHealth, the design, though functional and novel, was considered to unusual professional risky for the healthcare professionals involved. This limited its eventual viability because aspects of the design, the social media strategy in particular, required working through medical professional peer groups to gain traction with the a critical component of the community. Instead, consider designs that achieve parity between traditional and novel approaches only when it serves the purpose of better engaging the community. A measure of comfort can be taken in the design based on how willing a partner is to take it to their constituents and peers.

Plan for engagement over dissemination. The healthcare professionals believed that simple dissemination—a journalistic and academic approach to presenting content, would be more effective at attracting those who might have an interest in the SpeakHealth. While this may have been true of their own constituents, this strategy yielded minimal returns when applied to the larger set of community stakeholders. Unlike dissemination, which projects information from the community, a strategy based on engagement brings directs individuals to become involved and in turn, develop a relationship to the community.

Consider the origins and outcomes of the collaboration. Among the lessons learned, media designers must be sure healthcare professionals fully understand, and have guarded themselves against the risk, of entrenched expectations. The real world of media and gaining public attention around an issue is a challenging proposition not always for the faint of heart. Designers should consider undergoing such projects with themselves as the initiators and as the principal investigators—enlisting input from medical professionals as needed. The key questions that are likely to arise when working with other domains are: (1) What does success look like? (Is the goal really the goal?), (2) How can the professional and institutional reputations survive the world of effective public media?, and (3) How can all involved best organize the collaboration to maximize the effectiveness of the final product?

Acknowledgments. Support for this project was provided by the Imaging Research Center at UMBC. Thanks to all those who participated in the design, discussion, and development of the SpeakHealth online community.

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