Digital Partnerships for Health: Steps to develop a community-specific health portal aimed at promoting health and well-being

Rita Kukafka, DrPH, MA¹,²,³ Sharib A. Khan MBBS, MA¹ Carly Hutchinson¹ Delano J. McFarlane¹ MEng, Jianhua Li, MA¹ Jessica S. Ancker, MPH¹ Alwyn Cohall, MD²,³
¹Department of Biomedical Informatics, ²Department of Sociomedical Sciences, ³Harlem Health Promotion Center, Columbia University, New York, NY

ABSTRACT
We describe the steps taken by the Harlem Health Promotion Center to develop a community-specific health web portal aimed at promoting health and well-being in Harlem. Methods and results that begin with data collection and move onto elucidating requirements for the web portal are discussed. Sentiments of distrust in medical institutions, and the desire for community specific content and resources were among the needs emanating from our data analysis. These findings guided our decision to customize social software designed to foster connections, collaborations, flexibility, and interactivity; an “architecture of participation”. While we maintain that the leveraging of social software may indeed be the way to build healthy communities and support learning and engagement in underserved communities, our conclusion calls for careful thinking, testing and evaluation research to establish best practice models for leveraging these emerging technologies to support health improvements in the community.

INTRODUCTION
Located in Manhattan New York, the Harlem neighborhood is a community with longstanding health and economic disparities. The Harlem Health Promotion Center (HHPC) one of 33 Prevention Research Centers overseen and funded by the Centers for Disease Control has been working with community partners for over 10 years to address health issues affecting local residents. Beginning in 2004, the HHPC began studying technology use in Harlem with the goal of developing a health-focused web portal that would provide consumers with low literacy, culturally-relevant health information and decision-support products through its Digital Partners in Health Project.

Although national and regional data exist that describes technology use for people of color, specific community level data was unavailable to guide the development of the web portal. A body of studies are emerging that explore the extent to which people of color have access to, or interest in, using the Internet for health-related activities, but few are studies that emulate the Harlem community. Through focus groups and a random digit dial phone survey, the HHPC sought to learn more about Harlem residents’ attitudes and behaviors towards the use of the Internet and the various factors that hinder or promote Internet utilization for information, social support and health promotion.

With this rich set of community level data, the next step for the HHPC research team was to translate the results from the phone survey and focus groups into requirements for the community-specific health website portal. We developed and implemented a method to translate the data into requirements for the portal. Since our findings established a strong desire for content and resources that were community specific, we utilized Drupal¹, a content management platform to enable community residents to publish the content that was most relevant to their community.

Drupal is just one example of social software that has recently emerged as a potential enabler in health promotion and education fields, particularly for disadvantaged groups. According to social constructivist theory² participation and dialogue in social settings offers participants the opportunity to construct and organize knowledge. Social networking software such as Drupal provides a new platform for social constructivist activities. Online learners become active knowledge generators (as compared to consumers) who assume responsibility for constructing and managing their own learning experience. It is anticipated that in coming years, social software tools such as wikis, blogs, social tagging collaborative writing, aggregate content management, RSS (Really Simple Syndication) feeds, and podcasting in health care contexts will become increasingly utilized to produce knowledge, leverage collective intelligence, and build social capital.³ While certain risks are evoked, the HHPC research team is seeking to capitalize on the potential benefits to be received by the Harlem Community when provided with access to the tools enabled by this emerging technology.

Each step in the web development process, from collecting and analyzing the data, to translating data into the web portal functions, and then specifying the specific Drupal tasks and functions required novel implementation of more traditional software
development practices. When compared to more traditional software engineering methods, our methods capitalized on strategies to elucidate multidisciplinary perspectives ranging from software developers, social scientists, community health workers, and community participants. Our overarching goal is also less traditional than most software engineering tasks. Specifically, it is to utilize emerging social enabling technologies to foster a climate of collaboration, flexibility and architecture of participation aimed at promoting and enabling health to the Harlem community at large.

The purpose of this paper is to describe the steps taken by the HHPC to develop a community-specific health web portal aimed at promoting health and well-being in Harlem. Rather than a detailed report, we provide a rather high level analysis of each task. With more questions than answers, our goal is to bring to the forefront discussions that surround best practice models. We maintain that the leveraging of social software may indeed be the way to build healthy communities and support learning and engagement in underserved communities. In the following sections, we describe methods and results that begin with data collection and move onto elucidating requirements for the web portal.

METHODS

Phone survey methodology

A random digit dial landline phone survey was developed, field tested, and administered in 2006 to English and Spanish speaking community members age 18 or older. In an attempt to include more males and younger participants, callers were screened for gender and age after the first few weeks of the survey. Multiple topics were covered, including:

Demographics: Zip, gender, age, race/ethnicity, educational attainment, household income, number of people living in home, and employment and health insurance status

General Health: Self-described health status; presence of existing disability; family health issues; length of time since blood pressure last taken; past medical issues; where are health care services accessed

Health Information Seeking Behaviors: Frequency, location and impact (i.e. changes in behavior) of health information seeking; ease of locating info; clarity and understanding of information; confidence in ability to find info; trust in various sources; trust of and attitudes toward Internet as source of health information

Access to Technology: Forms of technology used; friend and family use of technology; computers and Internet availability in home; children’s use of Internet; availability of Internet in neighborhood; ease of use; length, frequency and location of Internet use; frustrations with Internet use; perceived access barriers; future intentions for computer use through Internet and e-mail.

Focus group methodology

Six focus groups were conducted with English- and Spanish-speaking Harlem residents. Each participant self-selected into a “web user” or “non-web user” category. Three focus groups were held per category with 6-8 participants in each group.

After focus groups were conducted, data was transcribed and then analyzed using Atlas-Ti software. Focus group analysis was conducted using the grounded theory method. Grounded theory provides a systematic method of interpreting empirically collected data, by providing a means of discovering categories and relationships in the data. The researcher can then draw on these categories and relationships to build emergent themes that are “grounded in the data”. Initially coding was of a sample set of transcripts used to draft the codebook. Iterative refinement of the initial codes occurred until a core set of codes was developed. Given the iterative nature of grounded theory, coders always had the option to refine and/or add additional codes if they discovered new themes as they transcribed. Following this process, four coders conducted the analysis of the entire set of focus group data. The four coders were then divided into two teams based on their background; two coders with technology and/or informatics backgrounds formed the first team, while the second team consisted of two coders from public health. The coders were first tasked with coding the transcripts individually. They later returned to their teams to generate a consolidated team code for each of the transcripts. Arriving at team level agreement for the consolidated team code evoked a modified Delphi methodology. The result of this coding strategy yielded each transcript having six different sets of code, one set for each of the four coders, and one for each of the two coder groups. This strategy enabled analysis to be performed both within teams, and between teams.

Web Portal Requirements

As a qualitative research method, grounded theory has, for a long time, been used as a method of inquiry in the field of information systems research and has more recently been adopted in empirical software engineering research. In the latter field it has been used to build descriptive theories of a substantive domain, such as software architecture, or as a method to analyze the data collected using a variety of techniques for system requirement elicitation. Requirements elicitation is the means by which
analysts determine the needs of customers, so that system developers can construct a system that actually addresses those needs. However, in our work we introduced a strategy to articulate the needs identified from focus group and phone survey data analysis in terms of communication objectives and strategies. Each member of the research team, including the developers was instructed to review the data and complete a template with fields that included a communication goal, communication objectives, tailoring variables, requirements, and sample excerpts from the original data to support their statements.

RESULTS
Phone Survey
A total of 646 consumers completed the phone survey. In terms of demographics, the overwhelming majority of respondents were black or Hispanic (89%) and female (68%), while over 40% were over the age of 44. The majority of respondents reported having used computers (77%) and the Internet (65%). Thirty-two percent reported that they had used the Internet in the past to access information about medical problems or treatments, and 31% reported having used the Internet to look for information about diet, nutrition, fitness or exercise. Thirty-two percent reported that they had used the Internet in the past to access information about medical problems or treatments, and 31% reported having used the Internet to look for information about diet, nutrition, fitness or exercise. In general, respondents report interest in utilizing technology to access health information, advice and support. Among Internet users, the Internet appears to be a trusted source of information, with 71% reporting that they trust the Internet for health related information.

Specifically, Internet users reported that the type of information found on the Internet…
“…affected the way I eat or exercise.” (86%)
“…improved my understanding of symptoms, conditions or treatments in which I was interested.” (85%)
“…improved my ability to manage my health care needs without visiting a doctor or other health care provider.” (37%)
“…led me to seek care from different doctors or health care providers than I otherwise would have.” (34%)

Older individuals and those from a lower SES status for whom technology is not a staple do not appear to use or trust the Internet to the same degree. For example, only 29% of non-web users reported trusting the Internet for health-related information. These individuals appear to seek advice primarily from doctors or other health care providers, television, or from family and friends.

Focus Groups

Both qualitative and quantitative analysis was performed on the focus group transcripts. One quantitative analysis was performed to assess the extent intercoder agreement might significantly differ by informatics versus public health professional training and is reported elsewhere. Our analysis revealed that for the most part, Web users and non-users both considered the Internet to be a legitimate source of health information. This attitude prevailed even among those for whom the Internet was not the preferred source of health information. Users were likely to use the Internet as a source of health information because of its convenience. They reported being able to access information pertinent to them whenever they desired, and liked not being confined to a particular day or time, as illustrated by the excerpts below.

“First, I would look [on the Internet] for things that can help my asthma…. Then I would look for all the side effects and what I would have to do if I had to take this [medication].”

“Lucky for me I am very resourceful and I don’t think doctors are gods, so I take that information [that they give me] and I go to the Internet.”

“I think the biggest health issue, as far as I’m concerned, is finding a doctor that works after working hours…That’s the big problem I have…. Because most of them have like, job hours, you know 9-5, and it makes it hard for me to be able to schedule anything…”

Although, respondents reported enjoying the freedom that the Internet allowed, slightly more than half (51%) also expressed difficulty understanding the information they found and expressed a need for assistance in interpreting the health information. Analysis also revealed an overall mistrust of the medical establishment. This establishment was often viewed as a whole entity e.g., pharmaceutical companies, hospitals, doctors and insurance companies, and discussed in that manner. Particularly, providers were often times seen as unresponsive and dismissive. Respondents from the web-user group mentioned that they would like to be able to talk to their physicians about the information they received over the internet, but were reluctant to do so due to lack of communication between patients and providers.

Translating Findings into Web Portal Requirements
Templates were completed for the themes that emerged from the focus groups and phone survey analysis. Figure 1 is an example of the template that was completed for use/misuse of herbal and
homeopathic remedies, an important theme that emerged from the focus group data.

Figure 1: Template for Herbal/Homeopathic Remedies

| Theme (Description of a theme from the transcripts): Herbal/Homeopathic remedies | Seems like people turn to these first before conventional medicine (ginger, vitamin E, goats milk, pomegranate juice) May be seen as safer – distrust of medicine |
| Communication Goal: To increase understanding about conventional medicines and homeopathic remedies |
| Proposed Objectives (How do we propose addressing the theme): 1) To educate patients regarding evidence-based herbal information. 2) To encourage patients to communicate their herbal use to their physicians/pharmacists. |
| Tailoring Variables (Characteristics of the population that the communication objective applies to): If the focus group data is insufficient to elucidate the tailoring variables, a search of the literature will need to be performed. For example, how do behaviors and perceptions of women differ from men? The result will inform that messages should be provided to each group. Sample citations: Use of complementary and alternative medical therapies among racial and ethnic minority adults: results from the 2002 National Health Interview Survey. J Natl Med Assoc. 2005 Apr; 97(4):535-45. The acceptability of treatment for depression among African-American, Hispanic, and white primary care patients. Med Care. 2003 Apr;41(4):479-89. Factors associated with herbal use among urban multiracial primary care patients: a cross-sectional survey. BMC Complementary and Alternative Medicine 2004, 4:18 |
| Functional Requirements (Either for content or channel be as specific as possible): Testimonials from neighborhood providers that emphasize the reason why patients should communicate their herbal use to their physicians. Testimonies from patients on their experiences with using alternative medicines. A drug – drug interaction tool that includes alternative and herbal remedies. |

In a similar fashion, templates were completed for 1) confusion over organic vs. “real” food; 2) eating healthy food – access to healthy foods; 3) attitudes towards doctors, some really trust their doctor and others feel they are not up on latest trends; 4) expressions of poor communication when it came to discussing drug side effects with doctors. Other themes centered not on a specific health issue but on mistrust, mainly of what is viewed of as a multifaceted complex entity- the medical establishment.

Figure 1 is exemplary of the numerous templates that were developed, resulting in a rich list of communication goals, objectives, tailoring variables with supporting citations, and functional specifications. It was at this high level of functional specification that the research team concluded that the Web Portal platform would have to do more than deliver health information, even if it were at a lower health literacy level than the average health content currently available on the Web. Rather, the platform would have to encourage a level of trust and cultural relevance as its foundation. For this, we turned to an architecture of participation – Drupal as the content management platform designed to foster connections, collaborations, flexibility and interactivity. Drupal is considered one of many new types of applications to support the “social web” because it enables content to be easily generated and published by users, and the collective intelligence of users encourages more democratic use.

DISCUSSION

Our observations are consistent with national studies showing that the experiences of African Americans lead to negative views of medicine and the health care system contributing significantly to the sentiments of distrust in medicine and medical institutions. Participatory Action Research (PAR), the research method employed by the HHPC since the center’s creation aims to establish trust between researchers and the community. PAR is based on the principals of participation and collaboration, integrative knowledge, and co-learning. New social software platforms such as Drupal are very much an extension of this method, but with a capacity unforeseen in the non-technological world.

The “architecture of participation” offered by Drupal and other types of social software emphasize the pre-eminence of content creation over content consumerism. Information is liberated from the control of experts (often the source of mistrust) allowing members of the community to create, assemble, organize (tag), locate and share content to meet their own needs or the needs of their community. As an illustration, content developed by an expert can tell a member of the community that it is important to eat more fruits and vegetables. The expert may also provide actionable tools so the individual community member can track caloric intake or calculate a personalized risk score for heart
disease due to lifestyle factors. However, community members may respond to this direction with comments such as: [excerpt from focus group] "it is hard getting healthy foods. Stores make it difficult by putting the unhealthy foods at eye level and the healthy foods are harder to find. It is here that most health promoting interventions will end. However, a social networking platform, such as the one we are creating with Drupal, will enable yet other community member to respond. Available to the rest of the web portal community, this community member may provide information listing stores that do stock fresh foods and vegetables at reasonable prices. Dialogue of this sort is critical not only to learning e.g., that fruits and vegetables are important to maintain good health, but also to facilitate action that is trusted and grounded in the social milieu of everyday living.

The Drupal modules we are including will enable the Web portal to provide community residents with the ability to participate actively in health promotion by connecting virtually with community members through online "talk" and sharing in blogs, groups, forums and other wiki-based modalities.

Preparing for the launch

One of the ways the portal will be marketed is through a community technology forum scheduled for May 2007. HHPC’s Community Advisory Board is playing a vital role in preparations for the forum and portal launch. To pilot test the Web Portal, HHPC is collaborating with the Harlem YMCA in its efforts to fight obesity and improve members’ overall health and wellness. Following the initial launch, HHPC will work with community stakeholders to identify and implement strategies for wider dissemination.

CONCLUSION

The purpose of this paper is to describe the steps taken by the HHPC to develop a community-specific health web portal aimed at promoting health and well-being in Harlem. Although the platform and tools presented in this discussion have a clear fit to the goals of HHPC and the population it works with, we call for careful thinking, testing and evaluation research to establish best practice models for leveraging these emerging technologies to support health improvements in the community.

Acknowledgments

We are grateful for our partners at the Harlem Health Promotion Center’s Community Advisory Board, the Digital Partners for Health Working Group, and the Harlem YMCA. This project was supported with funding from the Centers for Disease Control (Project U48-DP000030).

REFERENCES