Healthy Harlem: empowering health consumers through social networking, tailoring and web 2.0 technologies

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Abstract
Consumer health informatics has emerged as a strategy to inform and empower patients for self-management of their health. The emergence of and explosion in use of user-generated online media (e.g., blogs) has created new opportunities to inform and educate people about healthy living. Under a prevention research project, we are developing a website that utilizes social content collaboration mediums in conjunction with open-source technologies to create a community-driven resource that provides users with tailored health information.

Background
Knowledge about disease, health, lifestyle choices and ways to self-manage health are influenced by socio-cultural perceptions and attitudes. Adoption and social support of healthy living practices such as eating a healthy diet or exercising can significantly reduce the risks for developing chronic illness or suffering from advanced stages of such illness if one is already afflicted. However, most healthcare providers are either hard pressed for time to educate their patients about important health promoting information or their recommendations have several limitations. Their advice could be generic (e.g. “lose weight” for obese patients), goal-oriented (“exercise more”) while failing to specify how a person could reach that goal, or may be expressed in a vocabulary that patients cannot comprehend.

Solution
The core project of the Harlem Health Promotion Center (a Prevention Research Center sponsored by the CDC) has focused on the creation of a community health website that can overcome the limitations mentioned above. Our approach differs from the traditional top-down and provider-driven health education and counseling efforts in that we are enabling the Harlem community (which has higher than national rates of mortality and morbidity) to create self-management and other health information resources using online media and social collaborative technologies. These technologies include blogs (an online personal diary), wikis (a webpage that can be edited by any user of the website), and pod or vodcasts (audio or video files that can be played on mobile devices). Such technologies (labeled as part of the Web 2.0) enable people to create resources built from shared or collective intelligence; the poster child of such social knowledge creation on the web is the wikipedia (www.wikipedia.org). Efforts are being made to use them for healthcare purposes too.

Website and Technology Features
Employing the community-based participatory model adopted by the Prevention centers, we have formed an advisory committee consisting of community stakeholders to guide our web development efforts. We have customized an open-source content management system, Drupal, (www.drupal.org) to create a community-driven website to promote healthy living. The website content can be viewed by anyone but users must register to post or comment on the site’s content. Registered users can submit their own blog (e.g., “how I quit smoking after ten failed attempts”) or create special interest groups and social networks, each with their own discussion forums. They can also post events of interest, links to useful health resources, or participate in several special programs, such as the Harlem YMCA sponsored “Fitness Challenge”. Registered users can also rate posts made by other users or flag posts as inappropriate (community policing and appraisal). An overall moderating team consisting of our experts as well as users will provide editorial control to ensure content quality. We also intend to embed research studies within the information resources of the site and recruit users to participate in them. One such study would be to assess participants for behavioral risk factors that may be linked to chronic diseases (smoking, sedentary lifestyle, etc.) and based on the evaluation, provide them with tailored recommendations.

References