Cultures of Participation - @myHealthImpact: For Students, By Students

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Abstract

Culturally relevant health information is said to benefit diverse populations and is critical for health dissemination and user experience creation. Social media and online content provide mechanisms to engage specific populations while helping to reduce barriers that can often hinder participation and engagement. Using action research and informed by co-creation theory, the MyHealthImpactNetwork.org initiative seeks to provide a user experience targeting Black female college students. Data were collected from females at a large university located in the Southeast United States. Through focus group participants’ feedback, co-creation with students as design delegates and reviews of social media resentments, MyHealthImpactNetwork.org evolved to include user-driven content. Results indicate that Black females are interested in HIV prevention information that uses simple, non-technical health jargon. The information should be, however, socially engaging to enable their voices to be heard, absent of cultural assumptions and biases about Black women, and embody an ownership ethos relative to social content. Informed by principals of canonical action research and the co-creation that results between the researcher and potential user, these findings suggest that the hedonic dimension underpins the key design lessons. This research helps to fill a void in the literature regarding the creation of user experiences for health-related messages, particularly those regarding stigmatized conditions, such as HIV, while designing for cultures of participation among under-represented groups.

Keywords: Co-Creation, Canonical Action Research, User Experience, Participatory Design, Social Media, Black Women, Healthcare, HIV

Introduction
The estimated rate of new U.S. HIV infections for black women is more than 15 times as high as the rate for white women, and more than three times as high as that of Latina women (CDC, 2011, 2012). Nationally, Black women account for 66% of new cases of HIV among women. Roughly, 60% of HIV-infected 13 to 24 year-olds is unaware of their status (CDC, 2011, 2012). The MyHealthImpactNetwork.org experience was developed in an effort to address these pressing issues by disseminating HIV prevention information to college students, in general, and Black college students, in particular, with an initial focus on women. Though digitally connected and significant users of social networking, Black women are more likely to be excluded from or misrepresented by the mainstream health services discourse and information (Payton and Kiwanuka-Tondo, 2009; Warren et al., 2010; Brock et al., 2010). Limiting their access to health services or dampening voices in the discourse offers an opportunity to provide targeted health education. Further, with the lack of culturally relevant information and platforms, there is an opportunity for dialogue to promote grassroots change to address health issues – particularly those that are associated with stigma and often associated with those from underrepresented populations.

Though a myriad of challenges are associated with the above context, opportunities lie in the ability to connect with the population of interest and hear their voices, perceptions and realities related to HIV and health information. This requires two actions: hearing and listening to the voices. The former requires use of human sensory while the later is depicted by active engagement to understand and gather meaning. This process is analogous to co-creation between designers and consumers of health information.
creation can foster engagement and empowerment for the design of user experiences (Kohler et al., 2011), and can be useful among those removed and/or underrepresented in the discourse. As noted in Kohler et al. (2011), the resultant user experience can be a source of co-creation, creativity and connections.

To address the previously cited barriers and implement co-creation principles, leading health care organizations have espoused the use of participatory design for health information dissemination principally for vulnerable populations. The Centers for Disease Control and Prevention defines vulnerable populations by race/ethnicity, socio-economic status, geography, gender, age, disability status, etc. and those chiefly affected by health disparities. Hence, Black women and those of color are included in this definition. Given the presence of health disparities, such as HIV, among Black women, their views are critical to the co-creation and design of any user experience intended to serve this demographic. Participatory design will play an integral role in identifying problems, addressing these issues and designing creative solutions intended for diverse populations.

To provide clarity of what participatory design means, research scholars offer the following:

“Participatory Design is about the direct involvement of people in the co-design of the technologies they use. Its central concern is how collaborative design processes can be driven by the participation of the people affected by the technology designed. It brings together a multidisciplinary and international group of software developers, researchers, social scientists, managers, designers, practitioners, users, cultural workers, activists, and citizens who both advocate and adopt distinctively participatory approaches in the development of information and communication artefacts, systems, services, and technology.” (http://pdcproceedings.org/about_pdc.html)
Participatory design has been implemented by the U.S. Department of Health and Human Services to create health literacy materials ranging from guidebooks and videos, and guidelines offered by its Healthy People 2020 initiative. More importantly, this design technique is critical to gaining credibility among the population in question (U.S. Department of Health and Human Services, 2011, 2013). In the co-creation effort, however, this integrity is informed by the plurality of action research methods (Baskerville and Wood-Harper, 1998) which can foster trust, and a sense of value and ownership among users (Sen et al., 2011).

In this paper, I describe the co-creation efforts used to launch an HIV prevention and awareness user experience, myHealthImpactNetwork.org. This platform is intended to address the health information and health needs of Black female college students. I discuss the co-creation framework as presented in Kohler et al. (2011) and canonical action research (Davison et al., 2004; Davison et al., 2012) that guided this research. I contend that context is relevant and define four key findings based on the data gathered from the population of interest.

This manuscript proceeds as follows. In the next section, I discuss participation relative to user experiences via social networks. Next, I overview user participation and participatory design but justify the use of the co-creation framework in this study. I, then, describe the method used for the study that is informed by canonical action research.
This is followed by design lessons as offered by the MyHealthImpactNetwork.org user experience. The manuscript concludes with a discussion of the findings, theoretical contributions and implications.

**Literature Review**

**Defining User Participation**

Online social networks are facilitating digital queries and dialogue among people as they rely increasingly on family, acquaintances and coworkers. These social networks provide the vehicle for information seeking, sourcing and content integration. This behavior demonstrates the social capital of users to probe their personal networks rather than conducting Web searches (Morris, Teevan and Panovich, 2010). Social network inquiries have been shown to include opinions, recommendations, factual knowledge, rhetorical comments and invitations. In a survey of 624 Twitter and Facebook users, Morris et al (2010) concluded that social networks, however, were inappropriate for questions on personal matters including health.

Communication and disclosure within social networks are challenged by the need for users to balance their individual impressions or self-presentations and sharing personal health information within the network (Newman et al., 2011). Impression management is influenced by user-established trust and personal assessment of the content and topics provided by the artifact (Sillence et al., 2007) as well as socially accepted norms. Communication via social networks offers the ability to provide online emotional and social support, health information, patient status, topics on living with a particular
medical condition, and prevention and intervention information. Despite these benefits, users do not necessarily feel compelled to openly disclose their personal conditions and are often confronted with tension between impression management and information seeking. Beyond these concerns, stigmatized health conditions often spur biases due to online or offline association with a topic or content even in cases where people do not have a disease, such as HIV.

In the case of FaceSpace, a sexual health promotion intervention platform, Gold et al. (2012) address the issues of social participation among young people between 16 and 29, and men who have sex with men (MSM). These researchers initially used “imaginary characters to post video content and interact on various social networking sites, with a focus on sexual health promotion messages” (p 2). Later evolutions of the project targeting gay men (“Queer as F**k”) have resulted in a more user-centric, user-driven sexual health dialogue among the target population. Participation, however, involves more than information blasts to target groups, but is facilitated by interactive tools, polls, questions and comment solicitations. This, in turn, lures others to the artifact to read, experience, hangout, browse, assess and return to content (Ito et al., 2010; Preece and Shneiderman, 2009). Lurking, often considered legitimate peripheral participation (Lave and Wenger, 1991), occurs among trusted socially connected people, when positive word-of-mouth endorsements, and where perceived benefits of the “for us by us”, or “pro am” ethos is reflected in user-generated content. The term “pro am” is defined as an “indicator of how creative production at the consumer layer is increasingly seen as a generative site of culture and knowledge” (Lange and Ito, 2009, p 246).
Participation is also influenced by the content offered by the artifact and helps to create a stimulating user experience. In the case of young people, content creation is now common practice, and digital media production has proliferated in the age of Web 2.0 by using and integrating social tools, such as YouTube, Instagram, Twitter, Facebook and Flickr. This media production redefines social norms, amplifies voices that traditionally have been dampened and yet, embodies creativity (Ito et al., 2009). Hence, young people are embedding their likeness, consciousness and images into the content, and this contemporary approach is termed “user-generated content”, “pro-am”, and “remix culture” (Lange and Ito, 2009).

**Participatory Design**

Participatory design is the direct involvement of people in the co-design of artifacts, processes and environments that shape (and influence) their lives (Robertson and Simonsen, 2012, p 3). In addition, as participation provides users legitimate access to and participation in the design process, a “co-design arrangement leading to acceptance of users’ power and influence for a community or social cause result” (Robertson and Simonsen, 2012, p 10). DiSalvo (2012) offers that community-based participatory design has emerged given the proliferation of social media tools. Enabled by Web 2.0 applications, these communities offer the field opportunities to better understand the issues that affect social causes, political nuisances and new modalities of participation relative to context.
Mainsah and Morrison (2012) led the delTA design team that sought to promote civic engagement among youth via social media. Few studies on civic participation have focused on the relevance and active voices of young people and how they shape the discourse of participatory public cultures. Mainsah and Morrison argue that “while designing for participation suggests planning for access in a near remediation manner” (p 1), the inclusion of young people, popular culture and their participation provides the field with opportunities for social media participation, personal and group identity, and empowerment. Participation with design and design by participation includes crafting room for delegates (young people or youth, in their study) to and in the design processes.

Nicholas et al. (2012) examined the use of participatory design techniques to engage young people in the use and design of mental health services. Notwithstanding ten years of investment by government and non-government Australian agencies, young people failed to engage in health information seeking behaviors to identify appropriate care and services. Via a series of workshops focused on designing online content and awareness campaigns, the group developed ReachOut.com which uses youth delegates (Mainsah and Morrison, 2012). These delegates develop and/or refine their identities (or personas) using Facebook, create physical and digital collaborative content, and strengthen shared goals among the youth participants and design scholars.

Specifically, in the Mainsah and Morrison (2012) study, the delegates engaged in a number of co-creation activities to inform, update and improve the ReachOut.com user experience. These activities included feedback to user experience developers, serving as
users of the social media content created and more importantly, producing social media content. According to these authors, few studies had examined “looping” young users into the co-creation design process, but this inclusion of young users enrich user participation and participatory design efforts. This is important in an effort create both value and benefits to the population in question as well as continued engagement by users.

**Theoretical Framework: Designing User Experiences via Co-creation Principles**

Co-creation is the “process during which consumers take an active role and co-create value together with the company” (Prahalad and Ramaswamy 2004; Kohler et al., 2011, p 773). Co-creation provides a theoretical underpinning to better integrate the concepts espoused in the user participation and participatory design literature. To connect user participation and participatory design as noted above, Kohler’s co-creation research (2011) serves as a foundation – given its foci on interaction experiences and virtual environments as provided in the work of marketing scholars (Nambisan and Baron 2007; Nambisan and Nambisan 2008). Critical to this co-creation theoretical framework is the notion that virtual environments enable customer/user interactions that can be a source of value. As noted by Kohler et al. (2011, p, 774-775),

“Nambisan and Nambisan (2008) propose an analytical framework suggesting that virtual co-creation systems have to consider four experience dimensions—pragmatic, sociability, usability, and hedonic—in order to serve participants’ needs. The first aspect relates to the customer’s experience in realizing product-related informational goals in a virtual customer environment, while the underlying social and relational aspects of such interactions form the sociability component. The usability dimension is defined by the quality of the human–computer interactions. Finally, interactions in virtual environments can be mentally stimulating or entertaining, referring to the hedonic component.”
These four factors along with collaboration serve as the basic underlying framework for this research. Yet, there is opportunity to augment the framework based on the context, such as, health (HIV focus), technology enabled (online social networks) and target user population (Black females). Though the research of Kohler et al. (2011) is situated in the context of a for-profit business environment, the framework rests on creating innovation to generate value. Given this study’s focus on creating a valuable user experience, this is equally important relative to the context noted above.

**Methods and Findings**

*Method - Action Research*

Often questioned on validity and scholarly journal fit, action research in the information systems field has been met with opportunity and challenge. Baskerville and Wood-Harper (1998) described and analyzed the multi-dimensional aspects, such as frameworks, assumptions and goals, of action research methods. Accordingly, these researchers defined action research as a “cognitive process that depends on the social interaction between the observers and those in their surroundings” (p 91).

Action research forms vary to include canonical action research, prototyping, soft systems methodology, participant observation, action learning and others. One distinction noted by Baskerville and Wood-Harper (1998) is the iterative nature of a few of the forms – namely, canonical action research, soft systems and prototyping. Specific to this research study, canonical action research provides iterative, rigorous and collaborative nature for both the organization (or potential users) and the researcher. The
iterative process fosters mutual learning among the organization and researcher, increases understanding of context and improves opportunity for intervention in cases where corrective actions or adjustments are needed. As offered by Susman (1983) and noted in Baskerville and Wood-Harper (1998), the five steps to this cyclical process include Diagnosing, Action Planning, Action Taking, Evaluating and Specifying Learning.

Subsequent research (Davison et al., 2004) provided guiding principles of canonical action research and addressed the issues of questionable methodological rigor and overemphasis on consulting. Highlighting both the rigor and relevance of canonical action research, these IS researchers offer the field five principles (in part based on extensive years of experience and findings in the social sciences literature) as noted below (p. 69):

1) The Principle of Researcher-Client Agreement
2) The Principle of the Cyclical Process Model
3) The Principle of Theory
4) The Principle of Change Through Action; and
5) The Principle of Learning Through Reflection

Each of the above principles provides stated criteria to guide the action researcher as well as capture the rigor and relevance of scholarly publication. Davison et al. (2004) provided 31 criteria that reflect the five canonical action research principles. In a more recent study, Davison et al. (2012) extend beyond the criteria to the how in explaining both what the research should do and the importance linkages to theory and the
challenges associated with canonical action research. Studying two Chinese public 
relations organizations, these scholars demonstrated how to overcome the challenges 
associated with the research method in Diagnosing the Current Situation; Planning 
Interventions and Organizational Changes; Evaluating the Impact of an Intervention; and 
The Nature and Role of Theory in Canonical Action Research.

Given the rigorous, iterative, context-specific and reflective foci of canonical action 
research, the method is appropriate for this study. To study the co-creation experience of 
HIV and health dissemination among Black, college-aged females from a Southeast US 
institution, canonical action research principles guided this study. These principles 
guided an iterative design effort, involve mutual learning and embody collaboration. I 
reviewed the process over an 18-month period from the initial to final launch design. 
Adhering to Susman’s (1983) five steps and following the 5 guiding principles of 
Davison et al. (2012), I offer the findings via the phases below.

**Findings**

*Initial Design Cycle*

*Phase 1 - Pre-work – Planning and Team Development*

The author formed an interdisciplinary team of information, social scientists, health care 
IS and diversity researchers as well as a creative design organization in response, in part, 
to earlier published work on designing HIV prevention and awareness online experiences 
targeting Black female college students (Payton and Kiwanuka-Tondo, 2009; Warren et 
el., 2010). College students in the demographic group served as design delegates and are
members of the target population of Black, college-aged students, in general. The use of design delegates fosters trust among established peer social networks and offers social participation as prescribed by the reader-to-leader framework (Preece and Shneiderman, 2009). While the design delegates played dual roles as readers and contributors (by blogging, creating content and gaining recognition for their roles and association with the initiative), they accelerated readership among their peers and provided legitimate peripheral participation prior to the actual project’s online launch.

Undergraduate students served as design delegates and were compensated for their work. Delegates assisted the author by identifying focus group participants from student-led organizational meetings on a Southeast university campus. Three student delegates also assisted in the initial design and implementation of the myHealthImpactNetwork platform.

I met with the design delegates three times weekly: one virtual and two face-to-face. The student delegates indicated that their peers give minimal attention to old-style bulletin boards and flyers, and a more direct peer-to-peer invitation would be more effective. Consequently, I coordinated with the diversity expert to identify members of the target audience with delegates’ feedback and weekly input. Tables 1 and 2 capture how the delegates influenced the design process as well outcomes of team meetings.

Table 1 – Design Delegates’ Influence
Design Delegates’ Influence

| **• Revised initial plan to target population by shifting from paper flyers to personal contact** |
| **• Provided insight into social networks currently available** |
| **• Confirmed the need to include social media and finding from research studies** |
| **• Assessed useful and usable features of existing websites with similar target population** |
| **• Created content with inclusion of arts theme with music genres (e.g., hip-hop, jazz), blogs, digital content, etc.** |
| **• Implemented a health-tainment appropriate to both design and content; content will have a mix of health messaging with some entertainment aspects to connect or “hook” the target population** |

Table 2 - Team Meetings’ Outcomes

| **Team Meetings’ Outcomes** |
| **• Communication plan was developed to reach the target population** |
| **• Outline and direct contact with team’s diversity coordinator on existing social networks** |
| **• Social media and user experience design reviews, presentations & research principles** |
| **• Detailed listing of best practices and key features from existing websites with similar target population** |
| **• Detailed list of marketing plan with color scheme, logos, initial text for website pages** |
| **• Meeting notes to ensure there was roadmap to guide both design, tasks and responsibilities** |

Phase 2 - Focus Groups, Exploration and Formative Research

Design absent of race, gender, and identity will encapsulate the assumptions, controls and potential barriers associated with that of designers. (Payton and Kiwanuka-Tondo, 2009; Warren et al., 2010). Hence, the focus group sessions involved discussions on healthcare seeking along with racial and gender identity to establish the context for a desired “pro am” experience (DiSalvo, 2012). Focus groups are an effective method for rich discussion and interaction between research participants that facilitates the exploration of
under-researched topics like HIV prevention. Focus groups and other qualitative methods have been said to explain the how/why inquiries while providing a holistic view of social phenomena (Ulin et al, 2005). Three focus groups were conducted to assess 40 Black female college students’ perceptions and attitudes regarding HIV prevention and awareness websites as discussed in Payton and Kiwanuka-Tondo (2009).

Focus group sessions were conducted between October 2011 and November 2012 at a large U.S. Southeast university, and design delegates attended each focus group session. “The focus groups were guided by two research questions: What are Black female college students’ perceptions of current messages present on websites about HIV/AIDS awareness and prevention? And what messages do Black female college students find culturally relevant to them? During the focus group sessions, the participants were shown the National Institutes of Health website as it was deemed the leader in the field based on HealthRatings.org (2007), and this strategy extends the prior work of Payton and Kiwanuka-Tondo (2009)” (Payton et al., 2014, p 527).

These sessions lasted between 60 and 90 minutes and took place at a large U.S. Southeast university. Participants ranged in age between 18 and 24. Each participant was provided informed content forms that were approved by the university’s institutional review board (IRB) and given a gift card at the conclusion of each focus group session. A graduate student prepared each session’s data transcript within 48 hours, and the author and design delegates met within one week to discuss the transcripts. Design delegates also attended each focus group. In addition, independent coders examined the themes that emerged
from the discussions. Independent coders conducted thematic analysis to identify recurring themes in the data. In this research paper, I focus on those themes central to the design process though others related to stigmatized health conditions (i.e., HIV) as noted in Payton et al. (2014). The themes that influenced the design of the user experience included: 1) Website content/layout, 2) Cultural resonance, 3) Use of layman’s terms, 4) Stereotype deflation, 5) Ease of information, and 6) Image identification.

These themes influenced the design process, and both improved and informed the communication among the research team members. Though the author and members of the team would revisit with a smaller sub-set of focus group participants, the design delegates who are members of the target population served as surrogates to voicing their input into how the findings influenced design. To this extend, the co-creation of the MyHealthImpactNetwork informed the team of the more detailed issues as described by focus group participants. These details are listed in Table 3.

<p>| Table 3 - Thematic Analyses Themes and Influence on Design |</p>
<table>
<thead>
<tr>
<th>Theme</th>
<th>Design Influence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Website Content/Layout</td>
<td>- Avoid too much information</td>
</tr>
<tr>
<td></td>
<td>- Need for aesthetic appeal</td>
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<tr>
<td></td>
<td>- Simple layout to avoid cluster</td>
</tr>
<tr>
<td></td>
<td>- Include digital and social media content along with “hooks” to both inform and engage users</td>
</tr>
<tr>
<td>Cultural Resonance</td>
<td>- Use succinct messaging via web &amp; social media</td>
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<tr>
<td></td>
<td>- Include cultural messages void of stereotypes or assumptions about health behaviors</td>
</tr>
<tr>
<td>Layman’s Terms</td>
<td>- Use simple language</td>
</tr>
<tr>
<td></td>
<td>- Reduce use of medial/clinical jargon</td>
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<tr>
<td>Stereotype Deflation</td>
<td>- Avoid imposition of designers’ assumptions regarding culture of population, health &amp; HIV</td>
</tr>
<tr>
<td></td>
<td>- Avoid negative images of &amp; content on Black women</td>
</tr>
<tr>
<td>Information Ease</td>
<td>- Make information easy to location</td>
</tr>
<tr>
<td></td>
<td>- Avoid overly complicated search features</td>
</tr>
<tr>
<td>Image Identification</td>
<td>- Include personal stories, blogs or digital content</td>
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<tr>
<td></td>
<td>- Focus on awareness &amp; prevention information</td>
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</tbody>
</table>

Figure 1 is a screenshot of the original interface. The co-creation effort was influenced by the outcomes listed in Table 1 (design delegates) and those in Table 3 (focus group themes).
Figure 1: Initial MyHealthImpactNetwork.org Landing Page

**Final Launch Design**

*Phase 3 – Social Interactions Discovery*

Additional data collection included participant observation by the design delegates who were naturally embedded in college life, have established personal social networks and can provide feedback from the target population based on daily interactions and existing social networks. The author held brainstorming and debriefing sessions with the student design delegates following each focus group. During which time, the group discussed and mapped user design requirements derived from these sessions. The team compared their observations, discussed design direction and compared notes as captured in Tables 1, 2 and 3.
Further, two post-focus group sessions were held with fifteen (15) returning participants. Data collection included laboratory experiments for participants and the author to engage in co-creation. This provided users with a sense of empowerment to know that their initial responses and voices were valued in the user experience design process. One session was held in August 2012 with six (6) participants and served as a pre-launch before going live. During this session and as shown in Figure 1, these participants critiqued an initial prototype of MyHealthImpactNetwork.org via a whiteboard. Table 3 guided the discussion to capture participants’ responses. Responses were coded as green, blue or yellow to indicate, design features to keep, add or revise, respectively. To guide the session, design delegates reviewed the initial design with each participant via laptops, tablets and multiple web browsers. The themes in Table 3 guided these reviews to permit the delegates with validation and cross-reference of participants’ responses to capture user design needs.

Qualitative data offer insight into participants’ comments on the initial design:

*Purple is a powerful color. It makes you comfortable.*

*Too much text is shown on the landing page. Use more pictures that we can relate to.*

*Panels are good for organizing the layout.*

*Show the alternative content...blogs, Tweeter. We are social, but use large font to emphasize the facts/stats.*

*Site is helpful. I would recommend it.*
Participants were also administered the USE survey (Lund, 2001) shown in Table 4. USE stands for Usefulness, Satisfaction and Ease of Use and has been validated by the Usability and User Experience group of the Society for Technical Communication (STC) Community. The items are on a 7-point Likert scale. The item results ranged from 5.1 to 6.4. Though a small sample size (6) was used, these data offered additional insight how the initial design captured the spirit of co-creation and how the target population perceived the system’s value.

### Table 4: USE Survey Items

<table>
<thead>
<tr>
<th>Survey Items</th>
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</thead>
<tbody>
<tr>
<td>1. It helps me be more effective.</td>
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<tr>
<td>2. It helps me be more productive.</td>
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<tr>
<td>3. It is useful.</td>
</tr>
<tr>
<td>4. It gives me more control over the activities in my life.</td>
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<tr>
<td>5. It makes the things I want to accomplish easier to get done.</td>
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<tr>
<td>6. It saves me time when I use it.</td>
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<tr>
<td>7. It meets my needs.</td>
</tr>
<tr>
<td>8. It does everything I would expect it to do.</td>
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<tr>
<td>9. It is easy to use.</td>
</tr>
<tr>
<td>10. It is simple to use.</td>
</tr>
<tr>
<td>11. It is user friendly.</td>
</tr>
<tr>
<td>12. It requires the fewest steps possible to accomplish what I want to do.</td>
</tr>
<tr>
<td>13. It is flexible.</td>
</tr>
<tr>
<td>14. Using it is effortless.</td>
</tr>
<tr>
<td>15. I can use it without written instructions.</td>
</tr>
<tr>
<td>16. I don't notice any inconsistencies as I use it.</td>
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<tr>
<td>17. Both occasional and regular users would like it.</td>
</tr>
<tr>
<td>18. I can recover from mistakes quickly and easily.</td>
</tr>
<tr>
<td>19. I can use it successfully every time.</td>
</tr>
<tr>
<td>20. I easily remember how to use it.</td>
</tr>
<tr>
<td>21. It is easy to learn to use it.</td>
</tr>
<tr>
<td>22. I quickly became skillful with it.</td>
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<tr>
<td>23. I am satisfied with it.</td>
</tr>
<tr>
<td>24. I would recommend it to a friend.</td>
</tr>
<tr>
<td>25. It is fun to use.</td>
</tr>
<tr>
<td>26. It works the way I want it to work.</td>
</tr>
<tr>
<td>27. It is wonderful.</td>
</tr>
<tr>
<td>28. I feel I need to have it.</td>
</tr>
<tr>
<td>29. It is pleasant to use.</td>
</tr>
</tbody>
</table>
The second post-focus group session of nine (9) participants was held in September 2012. For this session, the above process was repeated. A few comments from the September session included:

“Y’all really did it.”

“I feel like by input mattered and matters for creating some for us”.

“Now, that you have done this, when will myHealthImpactNetwork have a mobile app?”

“I like the positive approach to the HIV problem in our community. So much focuses on the negative and stereotypes”.

The USE survey produced similar simple statistics [5.1 to 6.4].

**Design Rationale and Influences**

While the “Net” enables an increased delivery for health care information dissemination and can encourage behavioral change (Kalichman, Benotsch, Weinhardt, Austin, and Luke, 2002; Pew Internet & American Life Project, 2006), it also offers the opportunity for individuals to learn about themselves and engage those in their social networks. These enabling online features can empower users, mold information and dampen the content divide by tailoring individual messages for specific audiences. Such engagement and participation provides a connected state for delegate persons - as the artifact, idea or process becomes an extension of one’s personal identity (Dick et al., 2012). Earlier research (Pierce, 2003) called this association psychological ownership that embodies solving a problem or building “something” – thereby resulting in increasing value (Kohler et al., 2011) for activities involved as delegates invest personal time and effort.
Hence, the “my” in myHealthImpactNetwork.org prescribes to “pro am” (Ito, et al., 2010) while empowering the platform’s delegates with psychological ownership to invest, (re)shape and engage in the experience.

Twitter is the most popular social media site among digitally connected African-Americans, and Black women are highly engaged in activities associated with social media, including blogging, following and liking (Neilson, 2012). Twitter has become the largest micro-blogging site on the Internet. More than one quarter of online African-Americans (28%) and one quarter (26%) of Internet users ages 18 to 29 use Twitter while 15% of social network site users engage in health information seeking activities on the web (Smith and Brenner, 2012). Based on these and previously mentioned findings, Twitter (@myhealthimpact) was selected as the initial social media tool for the platform. With current trends in social media participation and engagement, the target population of Black female, college students was appropriate. The premise is to engage users based on legitimate peripheral participation (Lave and Wenger, 1991), or reading/lurking (Preece and Shneiderman, 2009) and to engage in the myHealthImpactNetwork experience based on the trusted involvement by agent users and design delegates.

*Phase 4 – Initial Social Media Evaluation & Learning*

Additional evaluation included site usage and following statistics as well as any indications of knowledge change among the demographic. To measure the myHealthImpactNetwork reach, data from September 1, 2012 to May 1, 2013 were evaluated. The Twitter handle had 415 followers by May 1, 2013. Figure 2 shows the
gender distribution of the 415 followers with 249 females (60%), and 166 males representing 40 percent. Most followers were between 18 and 24 years old which aligns with the target population of college-aged students. The data confirm that women are the primary users.

![Follower Demographics Chart]

**Figure 2:** @myhealthimpact Twitter Follower Demographics Between September 1, 2012 and May 1, 2013

Figure 3 shows the daily Twitter interaction among followers with a total of 698 mentions and 441 retweets. Retweets help to gauge what content resonates with users while mentions help to gain additional followers and increase online influence. Figure 3 shows three peak mention times: December 2012, February 2013 and May 2013. Retweets show an upward trend between January 2013 and March 2013. This activity in the virtual space can be attributed, in part, to social media interactions and engagement in the physical space with events of interest, such as World HIV Day, national politics and
debates, news topics (i.e., CNN’s Black in America documentary) project research dissemination and presentations, attendance at local health and HIV events, and college commencements. There were a total number of 1,139 interactions with users during this nine (9) month horizon.

![DAILY INTERACTIONS](image)

Figure 3: @myhealthimpact Twitter Daily Interactions Between September 1, 2012 and May 1, 2013

Table 5 lists the major Twitter topics based on tweets during the time horizon, which captures the rhetoric used the social network (Choudhary, et al., 2012).

<table>
<thead>
<tr>
<th>Topic</th>
<th>Message Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Celebrities</td>
<td>HIV activists - Bono, Alicia Keys, Magic Johnson</td>
</tr>
<tr>
<td>Music, Media &amp; Pop Culture</td>
<td>BET Black Girls Rock, Kayne West, CNN Black in America</td>
</tr>
<tr>
<td>HIV Awareness</td>
<td>HIV statistics on the U.S. Southern states, AIDS Free Generation, role of gender equity, and getting tested</td>
</tr>
<tr>
<td>Politics</td>
<td>U.S. Presidential Election, race in America</td>
</tr>
</tbody>
</table>

Table 5: Major Twitter Topics of @myhealthimpact Between September 1, 2012 and May 1, 2013
Design Lessons

The theoretical framework underpinning this research is co-creation. Co-creation is anchored in users/consumers actively participating in the formation of a system while simultaneously creating value. Four experience dimensions along with collaboration situate co-creation: pragmatic, sociability, usability, and hedonic (Nambisan and Nambisan, 2008). These dimensions define the myHealthImpactNetwork experience, in part. I offer design lessons in the context of healthcare education, in general, and those focused on under-represented populations, in particular.

Design Finding 1 – Use Simple Language and Information Integration

The social network allows interaction with the target audience and opportunity to learn what types of health information and user experience the population desires. HIV and other health updates occurred daily and include news findings, medical facts, awareness events and prevention information. Adopted from a myriad of reputable health sources, such as the CDC and NIH, myHealthImpactNetwork.org serves as an information integrator, but used simple less clinical language. Weekly and monthly themes guided the social media activities and informed users of the intended direction(s). For example, during the initial weeks of the academic year, there was a focus on HIV statistics dissemination, and during the first week in December, the focus was World AIDS Day. While users inquired about other conditions, such as mental and sexual health, and technology topics, such as mobile apps to disseminate health information, the experience has evolved to address these users’ needs and interests.
Design Finding 2 – Tell A Compelling Story

The blog space permitted storytelling on critical topics, such as HIV testing, the male perspective, current events, social justice action and features from guest bloggers. This reinforced the “for student, by student” ethos where the design delegates demonstrate psychological ownership (Pierce, 2003; Dick et al., 2012) with vented time, thought and effort in co-creation. Further, this demonstrated how these participation roles communicated the relevance of young people sharing and contributing to the discourse. For instance, the Can Music Increase AIDS Awareness? blog by a former design delegates challenged readers to think about how hip-hop musicians have raised HIV awareness. One blog reader stated ‘I’ve always wondered how Magic was living healthy…I got mad at Magic…until I continued to read’. This comment was in reference to Kanye West’s song Roses where he says ‘If Magic Johnson has a cure for AIDS/and all the broke people pass away/you tellin’ me if my grandma was in the NBA/right now she would be okay?’ To which the blogger responded, “it is interesting to see how an artist was able to use a song about his grandmother to paint a picture about the economic hardship that buying medicine for HIV/AIDS can cause”.

Compelling stories from the user’s point of view include cultural relevance, images that create group affinity or personal connection, appropriate context and a balance of information/facts and entertainment. The entertainment is defined as digital media, open voices based on personal experiences and the inclusion of music. In the case of myHealthImpactNetwork, hip-hop was the most likely mentioned genre that is nuisance in life experiences, cultural meaning and a vibe (or atmosphere) of carefully crafted lyrics.
that draws (or hooks) in its audience. These stories offer hooks that speak to the type of online experiences users seek while incorporating how they currently use and adopt technology. Further, the stories and experiences leverage online places and spaces where the users have established digital and social presence (i.e., personal capital).

Design Finding 3 – Choose Topics Based on the Network’s Needs and Perceptions
The social network communicated and responded to a number of tweets indicating mishaps in the messaging. For example, in an effort to connect youth culture and music, the design delegates tweeted during the 2013 Super Bowl. Early into the event, a number of followers responded by stating:

“Why are you tweeting about the Super Bowl? You focus on health & HIV”

“Is this the myhealthimpact focus?”

“Looking 4 health information & not football stuff from u!”

Social media demonstrated affordance by enabling users to provide meaningful feedback while communicating users’ expectations of context and appropriate cultural territories associated with the user experience (Mainsah and Morrison, 2012). In this instance and though a mainstream event, Super Bowl tweets were deemed inappropriate by the followers and reinforced the type of experience valued via co-creation. On a practical level, the tweets were removed from the Twitter feed, and the users were acknowledged for their feedback.

Design Finding 4 – Determine and Implement Appropriate Hooks
Interactive and visual appealing features, such as videos, heat maps, word clouds, and
mobile, strengthen young people’s ability to relate to the health care content. This facilitates decision-making while conveying health messages to users. Though interactive, the content is part entertainment with an educational foundation that creates a user experience (health-tainment). This approach is inclusive of hip-hop music, social and political concerns of young adults, but void of debasing images of Black people. Figures 4 and 5 show the most recent myHealthImpactNetwork landing page designs.

Table 6 outlines how these findings relate to the four experience dimensions along with collaboration of the co-creation theoretical framework.

**Table 6 – Key Lessons from the Action Research**

<table>
<thead>
<tr>
<th>Co-Creation Dimensions</th>
<th>Key Lessons</th>
</tr>
</thead>
</table>
| **Pragmatic**          | • Use simple health message  
                          • Simplify layout to better improve the experience  
                          • Design simple search features & easier information searches |
| **Sociability**        | • Leverage offline & online social networks  
                          • Encourage dialogue in topic within the social network |
| **Usability**          | • Create a simple, clean interface  
                          • Design for aesthetics |
| **Hedonic**            | • Foster user engagement  
                          • Create health-tainment  
                          • Create a cultural spirit absent of negative imagery  
                          • Capture personal stories via digital content, blogs, music, & social user concerns as “hooks” to increase participation, engagement & contributions |
| **Collaborative**      | • Co-create the co-creation system, MyHealthImpactNetwork |
Figures 4 and 5: myHealthImpactNetwork.org Landing Page with Infographics, Active Tweeter Feed, Video Content, Word Clouds, Photo Gallery, Blog Space, & Mapping for Visualization
Conclusion

Theoretical Contribution

This research is situated in the co-creation work similar to Kohler et al. (2011) and informed by the Nambisan’s virtual customer environment experience framework (Nambisan and Barron, 2007; Nambisan and Namnisan, 2008). Canonical action research (Baskerville and Wood-Harper; Davison et al., 2004; Davison et al., 2012)) guided the iterative, reflective and collaborative approach to uncovering the co-creation for the myHealthImpactNetwork experience. This research on MyHealthImpactNetwork, however, has some distinctions from those noted above. The MyHealthImpactNetwork experience focuses on health education not a corporate setting. The co-creation uses both design delegates and those in the target population to understand and create value. The design experience intends to focus on a demographic often under-represented (college-aged Black women and college matriculating) in community health education initiatives (U.S. Department of Health and Human Services, 2010; Gold et al, 2012). In addition, cultural appropriations are often absence or have minimal levels of representation (Brock, et al., 2010), and fail to create cultural resonance, image identification or stereotype demystification.

The iterative action process created a greater sense of ownership, time invested and participation in the co-creation. This was particularly the case among the design delegates and focus group participants who re-participated in the follow-on sessions for the initial design. By leveraging existing online and offline social networks, greater participation via social media resulted as illustrated in the Phase 4 description.
The health-tainment, cultural appropriations and digital, yet, personal content emphasizes the “hooks” valued by the target population. These “hooks” highlight the hedonic experience dimension. If a health education experience can meet the hedonic needs of its intended audience, the co-creation process can be seen as an opportunity to engage community and amplify often unheard voices. This hedonic effect is becoming more significant among health literacy initiatives to address and reduce health disparities, such as HIV (Ulin et al., 2005; US Department of Health and Human Services, 2011, 2013).

**Implications**

A critical aspect of the myHealthImpact experience is consumer health literacy and advocacy. This broadens the HIV topic to include less “shocking” information associated with stigmatized conditions and social network where individual impression management is important. As several young women offered: “I do not need people to make assumptions among me”. While the Internet has shown technology affordances, such as, freedom of speak, empowerment and liberation, there are the counter unintended outcomes (Lee, 2010). Despite the ubiquitous nature of the Internet access in homes, workplaces and schools and its associated supposed technology affordances, image control is critical even among young people who are seeking to manage their digital personas. The reach of myHealthImpact spun additional student activism, including on-campus HIV testing by a Black male student organization and the local health department, in-person meet-ups that focused on mental health by Black student female groups and overall health engagement among those participating in the myHealthImpact experience. The network has attracted students from other institutions as bloggers and
others who served as social media delegates by engaging in online and offline HIV and other health messaging forums. Here is where the online has influenced the offline, but the question of change behavior must be assessed to determine additional impact on the users.

The development of myHealthImpact experience continues to be iterative in nature and find its theoretical underpinning in co-creation. During the co-creation, a sense of participation occurs among those involved. Rather this participation is viewed as tedious or engaging work is to be determined by users. As offered by Fischer (2011), the cultures of participation engenders a mechanism (or artifact, process, environment) for human connection, particularly among those disconnected persons, while bringing them together as a collective with a clearly defined purpose. Through cultures of participation, individuals can influence, (re)define and develop social norms via tools for sharing information and heightening awareness.

Beyond the participation discourse, scholars (Kvasny and Payton, 2007) have articulated the need to address the content divide when designing artifacts, particularly for populations traditionally absent from the social participation in Health 2.0. This content divide work is intended to add to our body of knowledge on experience design and “pro-am” ethos notions of participation. Issues of technology affordances, unintended consequences associated with cultures of design, identity and stigmatized health conditions, such as HIV, can benefit from further investigation.
Though the initial efforts of myHealthImpact show promise, implications for its growth and sustainability are practical issues. Social media, while perceived “free” by some, does not happen effectively without costs and infrastructure. Effectively and efficiently identifying design delegates and other members of the project initiative comes with challenges associated with project continuity, and an understanding of context.
References


