

**Contemplating Public Policy in HIV/AIDS Online Content, Then  
Where is the Technology Spirit?**

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**Abstract**

Adaptive structuration theory (AST) has long been an accepted framework for investigating structures within technological artifacts and work environments. Information systems, organization science and communication scholars have prefaced AST context in terms of collaborative, group decision support systems. The social structures, however, can be characterized by features of rules, resources and capabilities along with a communicative *spirit*. Spirit is said to enable the user to better understand and interpret the meaning of a technology. Our research varies from the traditional focus of AST studies given that our context is not in single, for-profit organization with a common corporate mission or objective. Rather, we concentrate on the HIV/AIDS pandemic among Black women and the spirit communicated to this population by a principal government healthcare website. By interacting with a group of healthcare experts and practitioners during a 14-month period, we sought to understand the site's meaning and indications as its mission is to disseminate HIV/AIDS and other pertinent medical information. Further, our findings suggest that AST is a research framework that functions as a source for the notion of spirit. The (un)intended spirit inscribed on ICT may be (ex)inclusive with regard to the population or society it intends to serve. Hence, grassroots approaches and audiences can, in fact, offer effective insight into user-centered designs focused on educational and prevention content among those most affected and infected by chronic diseases, such as HIV.

Keywords: Adaptative Structuration Theory, Black Women, HIV/AIDS, Cultural Competency, Public Policy

## **Introduction**

Underserved populations are experiencing amplified incidences of HIV/AIDS (Center for Disease Control and Prevention, 2006). For several years where men have dominated the estimates of new infections, women are now significantly affected and infected. While much public attention (Kiwanuka-Tondo and Payton, 2009) has focused on sub-Saharan Africa, Black Americans, in general, and Black women, in particular, have become what some consider an ignored, under-funded health epidemic. An even more astounding statistic shows that Black women accounted for 72 percent of all new diagnosed HIV/AIDS cases in America (Center for Disease Control and Prevention, 2006; LaVeist, 2005). The AIDS diagnosis rate for Black men was nearly eleven times greater than their white male peers, and this rate is twenty-three times greater for Black women in comparison to white women (Center for Disease Control and Prevention, 2005; LaVeist, 2005).

Technology is seen as a key contributor to improving healthcare delivery, service capability, and prevention and education dissemination. *The New York Times* (August 21, 2006 as reported by the Kaiser Family Foundation) reported that EMR technology would reduce medical errors and costs, lead to personalized medicine and strengthen the infrastructure to enable health information networks. The anticipated outcomes would enable hospitals, providers, insurers and employers to track patients' encounters and data (Payton and Ginzberg, 2000; Kovak, 2005). One universal driver in

healthcare is the premise to lower costs via implementation of technology innovations (Medical Records Institute, 2006; Henry Kaiser Family Foundation, 2006). This should, likewise, be the case for the HIV/AIDS care where much of the treatment is administered in smaller clinical settings.

Healthcare industry trends point to the use of IT in a patient-centered communication and services by physicians, nurses and other providers of care (Madden and Fox, 2006). Yet, notwithstanding the much anticipated hopes of IT's impact on the healthcare system, the US Department of Health and Human Services (November 2000) *Healthy People 2010* directive concluded:

*Often people with the greatest health burdens have the least access to information, communication technologies, healthcare, and supporting social services. Even the most carefully designed health communication programs will have limited impact if underserved communities lack access to crucial health professionals, services, and communication channels that are part of a health improvement project.*

Drawing on AST and its definition of spirit, we examine a government healthcare website by engaging in action research with healthcare educators and practitioners over a 14-month timeframe. Such an assessment can strengthen the educational content as healthcare providers and researchers attempt to effectively reach a population that is currently experiencing distressing incidences of the disease. Hence, we sought to address the following research question:

- How does a Web-based technology's spirit translate in the community of Black women affected by and infected with HIV/AIDS?

Our literature review is summarized in the following section. Next, we describe our research methodology, and present our results. Our conclusion, then, assesses our findings and interpretations. We conclude with limitations and a call for future research.

## **Literature Review**

### **The AST Concept of Spirit**

AST is a blend of decision-making and institutional schools of thought. The result produced the social technology perspective which demonstrates that mutual influence and social processes are not mutually exclusive. In fact, DeSanctis and Poole's (1994) work heightened the IS field's awareness that in the presence of advanced technologies (e.g., web-based applications, e-portals, collaboration applications), social interactions unfold and result in unanticipated appropriation moves, users' appropriation and levels of appropriation of analyses. Likewise, this work can lend its findings to the healthcare and health informatics disciplines. Much of their work examined these phenomena in the context of group decision support systems (GDSS). These scholars offered dimensions to characterize the "spirit" of an advanced information technology's social structure. For GDSS, these dimensions were

inclusive of decision processes, leadership, efficiency, conflict management and atmosphere. However, this schema can prove to be rather dissimilar and/or require augmentation in the presence of not-for-profit ICT motives, health disparities and chronic diseases, such as HIV/AIDS among Black populations. Such augmentation to AST warrants the inclusion of a number of health policy dimensions, namely (LaVeist, 2005; Isaac, 2004; Shi and Stevens, 2005; Aday, 1994):

- Race/Ethnicity of intended audience (Black women)
- Socio-economic status (SES)
- Vulnerability to chronic diseases
- Cultural factors
- Biases in care delivery and treatment (Cultural Competency)

This is particularly the case under the conditions of advanced technologies' designs where ICT designers and sponsors are not void of predefined notions of structuration. AST (DeSanctis and Poole, 1994) defines the social structures provided by an advanced information technology as a combination of structural features and spirit. Structural features are the specific types of rules and resources, or capabilities offered by the application or technology. Spirit is the general intent with regard to values and goals underlying a given set of structural features. We contend that technology designers convey both spirit and cultural competency in their designs of advanced ICT.

Thus, the spirit in question is not that of the users. Rather, we focus on the designers (and/or organizations) who sponsor healthcare websites and the associated portal content. To understand spirit, or the general intent of ICT, one cannot ignore cultural competency, as this discourse calls for the inclusion of a targeted population's cultural values. To ignore cultural relevance would be the equivalent of user-centered design devoid of the user (Klein and Hirschheim, 2001). Others (Nakumara, 2002) go further and describe this phenomenon as the architecture of belief to signify how designers, through their choice of keywords, images, and use of language, create interfaces which represent the identities of some idealized user population(s). Thus, the interface reflects the cultural imagination of the designer, and performs familiar versions of race, gender, and class.

Accordingly, DeSanctis and Poole (1994, p 126) expanded the notion of spirit and offered that this discourse defines "how people act when using the system, how to interpret its features...". Moreover, spirit is a function of signification as it enables users to interpret meaning from the technology. Spirit also contributes to processes of domination as it can result in advantages and/or privilege by some over others. It is best articulated by the perceptions of users, rather than intentions of designers. DeSanctis and Poole (1994) concluded that the researcher is the best person to explore the

spirit embodied within and by ICT. To do so, multiple resources of evidence are warranted to assess values and goals of a technology.

While ICT were thought to be the magic bullet to healthcare information education and dissemination, adaptive structuration theory (AST) suggests that unintended community structures and human action can and often do emerge. That is, technological artifacts are social systems that can be and are often designed with a specific objective(s), yet, they are socially shaped as opposed to being clearly delineated products (Hutchby, 2001). Hutchby (2001) goes further to propose that technologies can be viewed in terms of affordances. Similar to AST, affordances posits that the unintended is less deterministic, and technology can be both shaped by and shaping of the practices humans uses in interaction with, around and through them (p. 444). When affordances is taken in conjunction with technologies as text as offered by Grint and Woolgar (1997) as noted in Hutchby (2001), ICT are configured (or written) by designers, developers and producers who impose meaning and objectives. Subsequently, these texts are deciphered by users who can have disconnected interpretations from that of designers. In the context of this study, websites intended to disseminate HIV/AIDS information targeting Black women involve socially negotiated processes of deliberate messages and decoded meanings.

### **ICT and the HIV Prevention Movement**

Recent press releases by the Obama Administration have indicated future directives to invest billions in information technology to support healthcare delivery and initiatives. Government and private studies have found that much of the \$2.5 trillion spent on healthcare each year is wasted on the duplication of tests and unneeded procedures (O'Harrow, 2009). A nationwide network of electronic health records is said to be one starting point for the current administration. We contend, however, that critical to this network model are data and change management (Payton and Ginzberg, 2001) as well as patients in this age of global connectivity which impacts evolving notions of work-life-play.

According to Kvasny, Chong and Payton (2006), patients are becoming more empowered and educated via the Internet as health information sources proliferate (Ryer, 1997; Payton and Brennan, 1999; Payton, 2003). The number of Americans going online for medical advice on a typical day has already exceeded the number who actually visits health professionals (Fox and Rainie, 2002). HIV/AIDS patients are among the healthcare consumers with chronic and stigmatized medical conditions who increasingly use the Internet as a major source of information (Kalichman, Weinhardt, Benotsch & Cherry, 2002). Though Pew Internet and American Life Project (2006) data shows proliferations in Internet use for health information and utilization among all demographic groups, access is greatest among those

most educated with higher incomes. This access and use, however, is least significant among Blacks and Latino who continue to trail whites and Asian Americans (National Science Board, 2006). While Blacks are 11 percent of the overall U.S. population, 14 percent of non-Internet users are Black. Socially inclusive eHealth applications can, therefore, play an important role in reducing health disparities. Moreover, web content draws heavily on the myopic norms, ideologies and power structures which are often translated into daily social interactions (Brock, 2005). Others assert that there is minimal web content that reflects cultural competency (Lazarus and Lipper, 2000).

The lack of cultural competencies in the communication of HIV/AIDS prevention information between Blacks, in general, and the provider/research community plays a significant role in the high infection rates, according to healthcare research organizations, such as Healthy People 2006, and health scholars (U.S. Department of Health and Human Services, 2005; The Howard University National Minority AIDS Education and Training Center, 2002; Prather, Fuller, King, Brown, Moering, Little, and Phillips, 2006; Scott, Gilliam and Braxton, 2005). Cultural competency is defined as the demonstrated awareness and integration of three population-specific issues: health-related and cultural values, disease incidence and prevalence and treatment efficacy. Although online health information is

available from multiple sources, evidence shows that racial and ethnic disparities and lack of cultural competency exist (LaVeist, 2005). In fact, *Healthy People 2010* defines a health disparity as: “racial and ethnic minorities experience multiple barriers to accessing healthcare, including not having health insurance, not having a usual source of care, location of providers, lack of transportation, lack of child care, and other factors. A growing body of evidence shows that racial and ethnic disparities in health outcomes, healthcare access, and quality of care exist even when insurance, income, and other access-related factors are controlled” (US Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health*, 2000).

Similar to the AST discourse, the healthcare body of knowledge advocates the presence of government rules, resources and policies to translate and interpret spirit. While DeSanctis and Poole (1994) conjecture AST in a for-profit organization context, our work converges on governance in a public policy, not-for-profit context. This is analogous to Payton and Ginzberg (2001) and Payton and Brennan (1999) findings on diverse models of health information networks intended to address and embrace focused medical content, scope and organizational objectives. The healthcare policy dimensions offered by LaVeist (2005), Isaac (2004), Shi and Stevens (2005) and Aday (1994) not only capture process, as noted by AST, they are what

we term the total healthcare experience. The total healthcare experience encapsulates the social and psychological experiences of race and ethnicity in the healthcare system (Harvard School of Public Health, Health Disparities and the Body Politics, 2005).

As certain communities are impacted by the digital inequity, which goes beyond the often conceptualized digital divide, to effectively access, use and benefit from information and communication technologies (ICT), we contend that the discourse of systems design in the absence of social norms can be applicable to a plethora of healthcare contexts. This can include Latino women with breast cancer, obesity among socio-economically disadvantaged adults, and Asians combating diabetes. We, however, have focused our research on U.S. Black women affected by and infected with HIV/AIDS given the distressing rates of the disease among this population. To this end, the Black AIDS Institute (2008) reported that U.S. Blacks with HIV, at least 500,000, are more numerous than seven of the fifteen target nations in the former President Bush's global AIDS initiative, which roughly allocated \$19 billion internationally over the last five years. Taking in conjunction with the alarming HIV/AIDS rates among U.S. Black women and the attention to the disease as a global epidemic, there appears to be an acute disconnect with the report calling the Black population a neglected epidemic. Hence, we converge on Black women for this study.

To this end, while Black women may be engaged in online health seeking behaviors using not-for-profit models, the web content can draw heavily on the conventional media content (Brock, 2005) and therefore reproduce and disseminate a spirit characterized by the absence of cultural competency, societal rules, expectations and power. The need for gender-specific HIV/AIDS interventions has proven effective among Black women as self-efficacy increased with timely health education follow-up (Mize, Robinson, Bockting, Scheltema, 2002). Hence, there is a need to uncover the inscribed spirit of well regarded and intended information and communications technologies (web portals) aimed at targeting Black women.

Moreover, to effectively reach the population, we contend that differences between access and use are noteworthy and have been articulated in Payton (2008) and Kvasny and Payton (2007). That is, effective reach of a population conveys the inclusion of social, economic, and technology-use attributes—which can capture the notion of digital equity. This concept rests on critical issues of how individuals can use information provided by these technologies and what strategic skills are desirable to prosper in the global economy. Accordingly, Gurstein (2003) asserts that effective use of the Web occurs when people are able to manipulate this technology purposefully and

independently to improve their life chances in culturally relevant domains such as economics, education and even health.

Our work seeks to use AST as a framework and source for the notion of spirit espoused among the top government healthcare information portals as defined by Consumer Health WebWatch, a joint project of the Health Improvement Institute, WebWatch and Consumer Reports. The results can uncover unanticipated appropriation from designers with unexpected moves by (un)intended users in the potential use of online HIV/AIDS information among Black women. Given the above, we reiterate our research question:

- How does a Web-based technology's spirit translate in the community of Black women affected by and infected with HIV/AIDS?

### **Methodology**

IS researchers (Klecun and Cornfod, 2005) have advocated critical approaches to evaluation in the context of healthcare. These critical approaches focus on a societal/organization level while uncovering unintended consequences and assesses the macro context. Thus, our research uses action research to determine the spirit communicated by top governmental Websites with a focus on Black women. Action research is inclusive of a myriad of qualitative methodologies that are well-regarded by the public health community. For example, Ulin, Robinson and Tolley (2005)

recapitulated the use of participant observation, documentary research, interviews, focus groups and field notes in the context of HIV/AIDS in Kenya and the US, health promotion in the Mississippi Delta and HIV surveillance and sexual behavior. David Satcher, former US Surgeon General, in a foreword published in Israel, Eng, Schulz and Parker (2005), underscored the criticality of community-based participatory research by concluding:

*...For research aimed at understanding and closing these gaps (access to quality healthcare, practice of healthy lifestyles, quality of physical and social environments and policies), (this) research is a viable approach.*

Our choice of action research rests on the need to combine a theoretical and methodological focus on complex relations among 1) personal and social meanings, 2) individual and cultural practices and 3) context (Ulin, Robinson and Tolley, 2005). While quantitative methods result in the analyses of surveys yielding hard facts, these techniques lack contextual detail. In the context of this research, we assess a public health issue which is embedded in cultural contexts. The lives, challenges and working conditions of the actors involved in this study enable us to best capture, hear and listen to data through lenses typically left untapped by quantitative approaches. As Ulin, Robinson and Tolley, 2005) indicated, qualitative research is characteristic of the how/why inquiry, in-depth understanding, holistic view of social phenomena, inclusive of respondents as active participants and is iterative (p. 6) and is critical to shaping public health policy.

Starting in January 2005, we engaged in participant observation with five HIV/AIDS social/medical service agencies located in the Southeast. We interacted with 10 directors or outreach coordinators to inform this discourse. Among these directors were a physician director of a rural HIV/AIDS outreach clinic, one care coordinator, three local government HIV/STD education and outreach communications experts, two directors of non-profit women’s transitional living program, one HIV/AIDS outreach coordinator, and two public policy specialists working on federally funded HIV/AIDS outreach initiatives. Table 1 below describes the characteristics of the informants.

Our research uses action research to investigate the spirit of the social structures espoused by ICT (e.g., government-sponsored Web portals intended to disseminate health-related and HIV/AIDS information). We converge on *spirit* to inform the social structures imparted in this discourse. Based on recent findings in the healthcare community, our question is undoubtedly critical.

Table 1: Informants’ Characteristics

<b>Informant</b>	<b>Demographics</b>	<b>HIV/AIDS Service Population</b>	<b>Organization</b>
Physician	Black Female	Rural, low-income residents	HIV Clinic (A)
Care Coordinator	White Female	Rural, low-income residents	HIV Clinic (A)

Health Communication Expert #1	Latino Female	Urban & rural residents; income varies; largely un or underemployed segment	Local Government (B)
Health Communication Expert #2	Latino Male	Urban & rural residents; income varies; largely un or underemployed segment	Local Government (B)
Health Communication Expert #3	White Female	Urban & rural residents; income varies; largely un or underemployed segment	Local Government (B)
Director	Black Female	Urban residents; income varies; largely un or underemployed segment	Transitional Women's Program (C)
Director	Black Female	Urban residents; income varies; largely underemployed segment	Transitional Women's Facility (D)
Program Coordinator	Black Female	Urban residents; income varies; largely underemployed segment	Transitional Women's Facility (D)
Public Policy Specialist	Black Female	Urban & rural residents; incomes varies	Advocacy Group (E)
Public Policy Specialist	Black Male	Urban & rural residents; incomes varies	Advocacy Group (E)

The US Department of Health and Human *Services Healthy People 2010*

report summed it best by concluding:

*Research indicates that even after targeted health communication interventions, low-education and low-income groups remain less knowledgeable and less likely to change behavior than higher education and income groups, which creates a knowledge gap and leaves some people chronically uninformed. With communication technologies, the disparity in*

*access to electronic information resources is commonly referred to as the digital divide. The digital divide becomes more critical as the amount and variety of health resources available over the Internet increase and as people need more sophisticated skills to use electronic resources. Equitably distributed health communication resources and skills, and a robust communication infrastructure can contribute to the closing of the digital divide and the overarching goal of Healthy People 2010 to eliminate health disparities.*

While action research (Baskerville and Wood-Harper, 1998; Israel, Eng, Schulz and Parker, 2005; Ulin, Robinson and Tolley, 2005) varies in form, we used participant observation, unstructured interviews and archival information for our research. Since January 2005, we interacted with a combination of these five organizations on a bi-weekly basis. Our participant observations enabled us to be directly involved in organizational meetings, conference calls, facility tours and health needs assessment sessions. However, due to the stigma associated with the disease and client confidentiality concerns, we did not interact with persons infected and/or affected with HIV/AIDS. Rather, our informants provided insight to aid us in understanding and capturing the notion of spirit of a government website's social structures.

We narrowed our effort to concentrate on the National Institutes of Health which houses both women's health and minority health pathways to HIV/AIDS information, and the National Institutes of Health, as a part of the Department of Health and Human Services. Its primary objective is to

support and conduct medical research to improve people's health. In 2005, the NIH site is ranked number two on the [HealthRatings.org](http://HealthRatings.org) initiative and is the only government site listed on the top 20 list. By 2007, the NIH site ranked number one on the health ratings list.

Figure 1 (for 2005) shows the lists of top health websites with ratings ranging from poor to excellent. Ratings are based on extensive evaluations by health and medical experts which benchmark content reliability, data quality and information currency. Figure 2 shows the listings based on 2007 ratings.



Figure 1 – Top Websites by HealthRatings.org in 2005  
Permission Obtained??

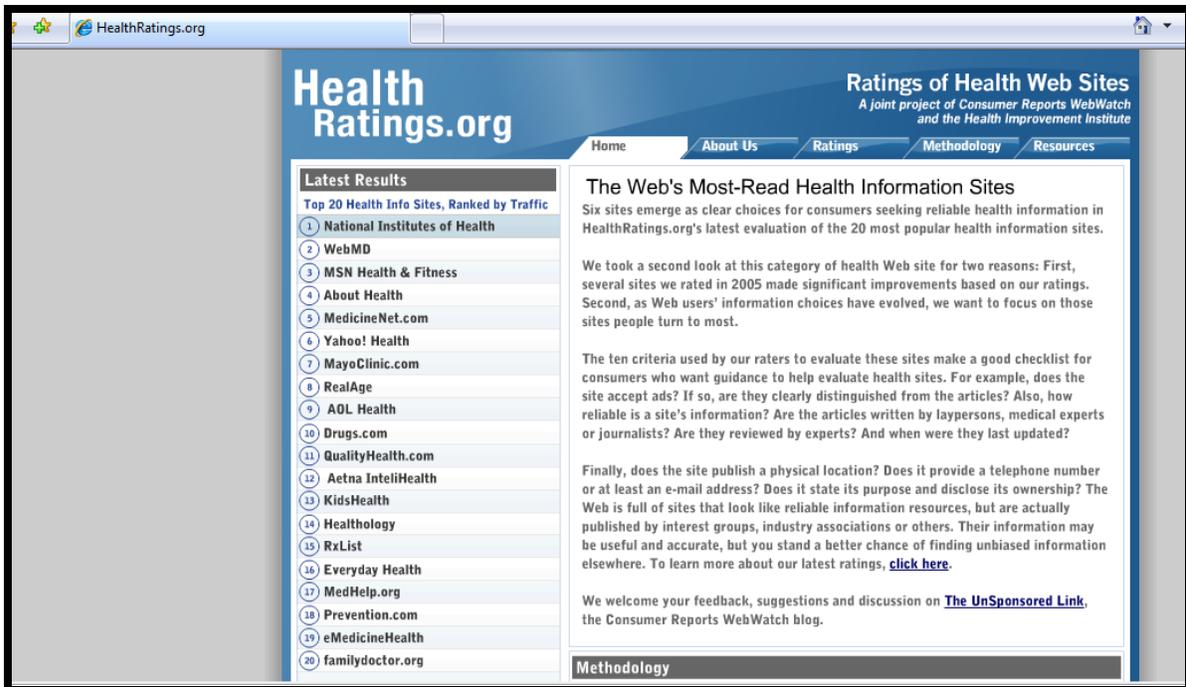


Figure 2 - Top Websites by HealthRatings.org in 2007  
 Permission Obtained??

Figure 3 shows the NIH Website. The portal houses information on health, grants, news, research, institutes within the organization and background on the NIH. Users can further seek information on the President Obama's Recovery and Reinvestment Act, swine flu pandemic, clinical trials and even access to Medline Plus, a service of the U.S. National Library of Medicine, just to name a few.



Figure 3 – National Institutes of Health Site  
 Permission Obtained from NIH, May 20, 2009

In terms of archival information, we gained access to organizational documents, health communication outreach initiatives and service channels to provide HIV/AIDS educational outreach to Black women. We also sought to determine how a few of the Black female participants would navigate the NIH site for HIV/AIDS prevention information. In addition, we attended departmental meetings, community outreach events, used documentary sources (e.g., epidemiological public health research reports) and collected field notes (Ulin, Robinson and Tolley, 2005).

## Data Analysis

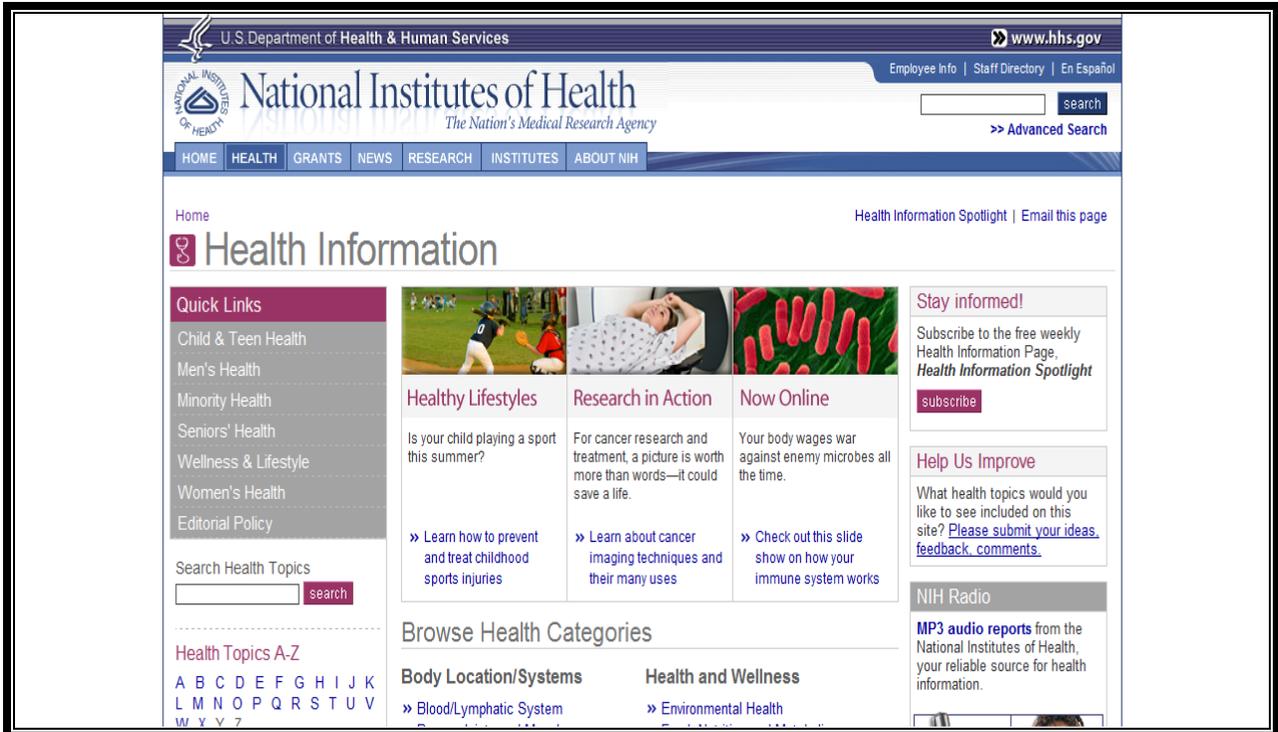
We used techniques for analyzing qualitative data by finding illustrative themes which emerged among each of our data collection points/interactions. While we sought to establish common themes in the data, our analyses followed a community participatory research framework which is widely accepted in the healthcare policy literature (Miles and Huberman, 1994; Israel, Eng, Schulz and Parker, 2005; Ulin, Robinson and Tolley, 2005). Hence, we engaged our team of healthcare experts on an iterative, often bi-weekly basis to ensure that we were correct in our interpretation of the data from organizational documents, focus groups, participatory observation, etc. Once we established codes relative to spirit of the NIH Website, we synthesized and refined our data prior to subsequent interactions. We followed this process over the 14-month timeframe to support our results. During this time, we also investigated communal perceptions and established consensus where there was incongruence. It was important that we accurately capture norms and beliefs of Black women through the perceptions of the research informants.

### **Results: Findings Relative to AST Spirit and Public Policy Dimensions**

The mission and purpose of the NIH Website is to provide comprehensive health information from government sources to healthcarehealthcare professionals and consumers. The research informants and other data sources suggest that the spirit of the technology lacks cultural identification

for Black and other under-represented minority women, imposes what appears to be a scientific, often an exclusionary, spirit and is best designed without regard to social norms of the group in question. According to the health professionals in this study, their clientele would describe the NIH portal as *too technical in terms of medical jargon, difficult to navigate by even those of us who are highly educated and is void of simple language to enable receptivity.*

To assess the above thinking of the NIH portal, we asked three Black women to navigate the NIH website for HIV/AIDS prevention information, we received distinct differences in our observations. Subject 1 is between 20 and 30 years old, college educated and completed the task by saying “this is confusing; I am not sure that I would read through all of this information. Should I click Minority Health or Women Health first?” Her click streams are as follows: 1) A to Z Health Topics, 2) Minority Health, 3) African American Health and 4) NIAID: African Americans Answers on HIV Vaccine Research (PDF). These screen grabs are below.



**Figure 4: Screen Grab 1 from Subject 1**  
 Permission Obtained from NIH, May 20, 2009

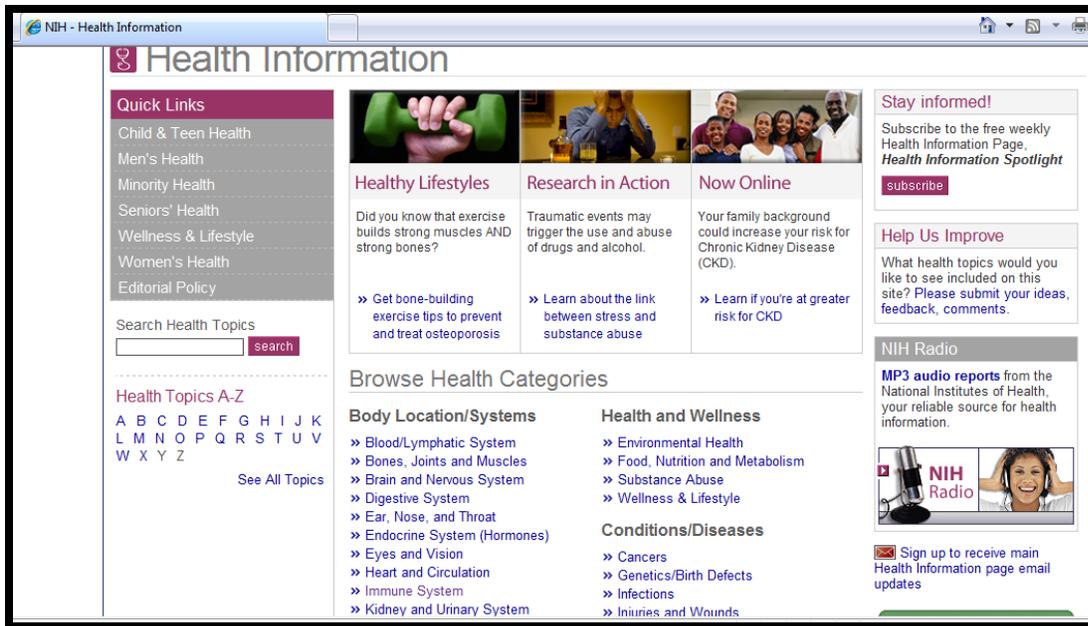


**Figure 5: Screen Grab 2 from Subject 1**  
 Permission Obtained from NIH, May 20, 2009

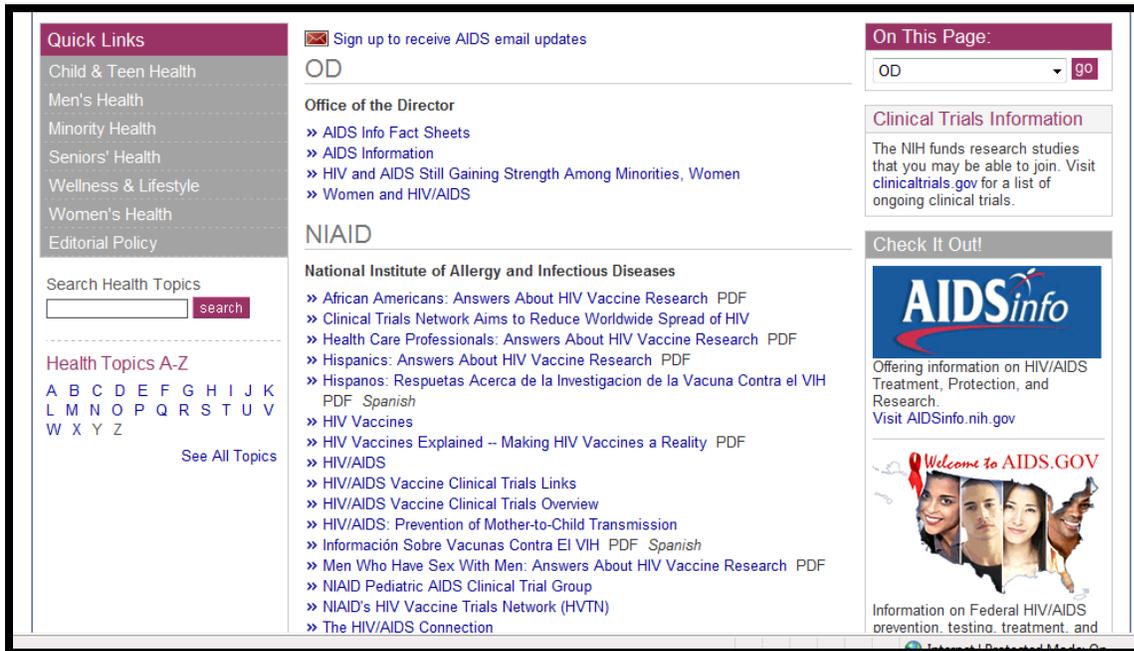


**Figure 6: Screen Grab 3 from Subject 1**  
Permission Obtained from NIH, May 20, 2009

Subject 2 is between 40 and 50 years old, college educated and concluded that the exercise “assumes that people know much of the medical jargon”. Her click steams are as follows: 1) A to Z Health Topics, 2) Body Location/Systems, 3) Immune System and 4) Human Immunodeficiency Virus (see AIDS). These screen grabs are below.



**Figure 7: Screen Grab 1 from Subject 2**  
 Permission Obtained from NIH, May 20, 2009



**Figure 8: Screen Grab 2 from Subject 1**  
 Permission Obtained from NIH, May 20, 2009

Subject 3 is between 30 and 40 years old, college educated and offered that “the site is not user-friendly. The information is not on the homepage. I would read through the first five links, then look for the LiveChat or email someone at NIH”. Her click steams are as follows: 1) Types “HIV African American women” in the search box; 2) She reads the first five hyperlinks of the 2, 790 hits for specific information; and concludes by resorting to emailing NIH though her preference is a LiveChat function. This screen grab is below.



**Figure 9: Screen Grab 1 from Subject 3**  
Permission Obtained from NIH, May 20, 2009

AST's notion of spirit center about decision processes, healthcare informative technologies should account for broader policy themes that influence the population (herein, Black women). According to one informant,

*The NIH has very, very smart people working in there. The agency produces excellent information for you or me, but for the people that I work with, the site is far-reaching. For those of us beating the streets, technology is not of concern to my client. What is of concern are living conditions (which most could not fathom), earning a living and simply surviving. My demographic of sistas do not see themselves when they look at the information.*

Others spoke of the lack of Internet access due to absence of indispensable necessities. This was particularly the case of those participants serving a low-income population and those in rural southern areas. Several participants offered:

*My people need basic telephone service, transportation and need to be (re)educated. Internet access presents a divide along racial and economic boundaries. Literacy rates where we are....Let me explain....we create literature for second and third grades reading levels. Otherwise, the information will not get through. We have found that peer counselors communicate effectively with those infected and affected.*

*But...then, there are some, internal and external, to the medical community that do not value Black life. And...there are Black folks that still do not trust the medical community.*

*People with idle time...no community-based infrastructure and no jobs are plagued. Illegal drugs, prostitution and physical proximity to major interstates only serve to create more risk for exposure.*

Stigma associated with the disease continues to challenge Black women and is noted as too often negatively impacting decisions to seek or evade

HIV/AIDS services. Moreover, societal judgments regarding morally accepted norms and behaviors dampen the reach of even the most effective outreach services. The following notes from community outreach events and meeting notes substantiate these observations.

*There are places in the state that I simply cannot talk to about HIV/AIDS surveillance, education, protection, etc. This happens frequently in rural areas where the knowledge is critical. People are scared. When they are scared, they do not listen or permit others to listen. It is a power struggle.*

*I was told by the church preacher that my soul is going to hell for the information that I am giving out. He said that HIV/AIDS was not a priority. Can you believe this? In a community that is high-risk with a 45% to 60% infection rate.*

With regard to Internet access as a mechanism to enhance HIV/AIDS, clearly a significant barrier is access. ICT access goes beyond a physical space. Rather, access raises issues of digital equity while shifting the notion to one of social justice and is inclusive of geographic, race, gender, educational resources and age disparities (Payton, 2008). If we are to presume that a significant percentage of the clientele, herein, are economically disadvantaged, then stigma can be an obstacle to electronic access, principally in context of public forums (e.g., libraries, community centers, churches). Hence, patients must engage in a perceived safe, or nonjudgmental environment, and this would enable a broader reach for information dissemination.

Several informants offered additional input and pointed out that diversity in communication modalities is critical, given the complexity of the HIV/AIDS pandemic in the Black community. Thus, a number of the organizations suggested the following:

*Prevention messages should not be limited to the Internet. In fact, we have seen that radio, television and print media are effective among our service area. Though these are simple forms of media and less complicated than websites, they work. We can reduce the spread...but the messages have to be tailored for the population's culture...and there has to be an awareness that all Black folks are not the same!*

*Simply put, these women do not see themselves and cannot relate to the website in question. Image matters. My transitional clients need to be heard and by not including what looks like them, they assume that their voices do not matter. Here, we give them voice through our programs.*

Each informant spoke to the significance that peer educators have on HIV/AIDS prevention and intervention information. Simply summed, peer educators are often community-based, affected and/or infected by the disease question and culturally attuned. They often function in team scenarios with physicians, care coordinators, program directors and health communicators. Moreover, peer educators are said to influence health behaviors particularly in outreach environments. In this context, the intended spirit inscribed on ICT can be more inclusive with regard to the population in need by including complementary human (grassroots) actors.

To address the research questions, our findings suggest propose that the inscribed spirit of HIV/AIDS educational portals conveys one of nonparticipation due to a number of factors. While AST exposes power moves and absence of user engagement in the ICT design process, identity biases and dominant culture language norms implemented by designers, public policy underlies the rationale explaining these outcomes. With the intention to propagate health education, broader health policy issues, such as cultural competency and health disparities, should be integrated into the design processes. To this end, the intended and perceived inscribed spirits are incongruent, thereby resulting in exclusion of a needed segment of society.

Black women are much more likely than Black men to seek health information online (Spooner and Rainie, 2000; Payton, 2009). This suggests that Black women are increasingly able to gain access to online health resources. Despite this finding, Lazarus and Lipper (2000) determined that there is little Internet content which reflects cultural diversity of low-income **and** minority users (including Black women independent of income and educational status). Hence, ICT applications with an inscribed spirit of inclusion and cultural relevance could, therefore, play a central role in reducing health disparities.

## **Implications and Conclusion**

When IT designers and sponsors engage predefined notions of structuration void of user-centered culture and norms, receptivity and the anticipated spirit can be limited. By recognizing these pitfalls, healthcare professionals and policymakers can better design the dissemination of medical education used by ICT, in general, and to target, highly vulnerable populations, in particular. The IS field has long advocated for user-centered design approaches to user interfaces and software application development (Klein and Hirschheim, 2001). Yet, to completely embrace these methodologies, designers should implement a spirit of inclusion and should embrace public policy as technology continues to broaden in scope, focus and ubiquity (Cushman and Klecun, 2006). Consequently, ICT hold implications of empowerment, power structures, governance and social (dis)order that will affect populations (e.g., gender, race, socio-economic, literacy rates, geographical locales, religion, cultural practices, just to name a few) differently, and often with unanticipated consequences. A coupling of informative medical content and cultural dimensions (without imposition of what is the norm) could heighten HIV/AIDS awareness by informing behaviors among Black women, thereby increasing receptivity.

Further justification for investigating this and other health pandemics revealed the following:

- 1) The continued proliferation of health information networks;
- 2) Research shows that racial disparities impact health outcomes, healthcare access and quality of care; and
- 3) Black women have a 64% to 70% HIV/AIDS infection rate (Center of Disease Control, , 2005, 2007)

Health policy researchers (Schulz, Freudenberg and Daniels, 2006) document the voluminous new evidence of racial, socio-economic and gender inequalities and disparities in the U.S. and global healthcare systems. The triangulation of race, class, and gender exacerbates the complexities of service delivery, in general, and HIV/AIDS care, in particular. The epidemic is too often met with societal stigma and the antiquated moral debate. Despite these and other tribulations, an awareness and inclusion of social, cultural and political context is critical. By (un)consciously neglecting these social constructions and merely bounding our focus strictly to organizational entities, we reduce our understanding to IT artifacts while omitting substantive impacts (Galliers, 2003). Further, web designers, government agencies and other entities must not preface our results by concluding that nonuse of the ICT described, herein, as *abnormal*. People, however, can have carefully crafted rationale as to why they do not engage with a technology, and the

social context often facilitates our knowledge leading to these outcomes (Cushman and Klecun, 2006).

While health information portals/networks are prevalent, the above facts suggest that the inscribed ICT spirit and anticipated social interactions are, at best, incongruent. Hence, the notions of inscribed and perceived spirit can be useful in the evaluation of healthcare information networks intended to reach diverse populations. Such an assessment can drive public policy and continue to strengthen the work of health agencies, such as the NIH, CDC and others. Further, multidisciplinary problems, whereby no single field has the overarching solution(s), warrant broader assessments from a myriad of fields. When the issues investigated by this research are unattended and health disparities are unaddressed, the ripple effect is the economic impact of rising healthcare costs for all members of society (Harvard School of Public Health, 2006).

Our work illustrates that ICT through its spirit, rather intended or unintended, can be exclusive and, yet, offer the necessity to be inclusive of social and psychological dimensions of individual experiences. Issues in the public policy debate, such as patient-centered communication, health literacy and workforce diversity, are impacted by the proliferation of IT use in this discourse. Madon (2005) provided an overview of how a health

mapping project in India made use of epidemiology, IS, engineering and statistics experts. Likewise, to address the issues, herein, user-centered design methodologies and action research approaches can be implemented to better reflect an inclusive spirit among ICT, particularly those directed toward vulnerable populations facing chronic diseases.

Hence, if IS will further shape the healthcare and health disparities landscape, then the field must open itself to public policy issues of health, education, target populations, designs and effectiveness. These issues offer the IS field rich opportunities to explore global health issues ranging from obesity, diabetes, mental health, malaria, substance abuse, just to name a few, among diverse world populations.

Lastly, this research is not without its limitations. We limited our scope to a single government portal. Future investigations should include analyses on additional, yet targeted HIV/AIDS portals, such as [womenshealth.gov](http://womenshealth.gov), and those created by grassroots organizations, such as the Black AIDS Alliance and Black AIDS Institute. Direct contact with women using these healthcare services would also augment our understanding of how the direct users view ICT. By using both quantitative and qualitative analyses, the inclusion of Black women from all socioeconomic backgrounds would, likewise, benefit those in healthcare to gain a broader cross-section of the community.

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