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Abstract

While advances in highly-targeted therapies and increased use of mammogram services have contributed to the overall decline of breast cancer deaths in the U.S., these benefits have not been equitable for all women. Less educated, poor, rural, non-Hispanic African-American women have poorer access to cancer services and are less likely to have had a mammogram than urban women. Lack of physician recommendations and perceived barriers in accessing diagnostic services are major factors that hinder the uptake of regular mammograms in rural communities. This paper reports results of formative research conducted as part of a larger study focused on the participatory development of an electronic reminder system for breast cancer screening. The paper discusses insights gained from focus groups with rural patients and clinicians about their information needs, breast cancer screening behaviors, barriers to care, and mammography referral practices.

Keywords: system design, participatory approaches, reminder systems, health informatics systems, breast cancer screening
Participatory Design of a Health Informatics System for Rural Health Practitioners and Disadvantaged Women

Breast cancer is the second leading cause of cancer death for women in the United States, with 182,460 newly diagnosed cases in 2008 and 40,460 deaths in 2007 (American Cancer Society, 2008; Ozols et al., 2007). While the development of highly-targeted therapies and increased use of mammogram and adjuvant therapy services have all contributed to the overall decline of breast cancer deaths, these benefits have not been equitably distributed among low-income, non-Hispanic African-American women, especially for those living in rural or inner-city areas (Chlebowski et al., 2005; Gordon, 2003; Masi & Olopade, 2005; Shavers, Harlan, & Stevens, 2003; Smigal et al., 2006). These disadvantaged women have been found to have poorer access to cancer diagnostic and treatment services and are less likely to adhere to breast cancer screening recommendations (Haggstrom, Quale, & Smith-Bindman, 2005; Koil, Everett, Hoechstetter, Ricer, & Huelsman, 2003; Mitchell et al., 2006; Paskett et al., 2006). Non-Hispanic African-American, rural women are two times more likely to be diagnosed with more advanced stages of breast cancer, have larger tumors, and demonstrate longer delays between symptom recognition and medical consultation than their non-Hispanic white counterparts (Chlebowski et al., 2005; Clark et al., 2009; Gorin, Heck, Cheng, & Smith, 2006; Sassi, Luft, & Guadagnoli, 2006; Young & Severson, 2005).

Problem Statement

While the factors contributing to disparities in breast cancer incidence and mortality, especially among disadvantaged populations in the U.S., are numerous and complex, experts have pointed to failures in the healthcare system to deliver adequate and
timely cancer care as a critical issue (Coleman et al., 2003; Corbie-Smith, Flagg, Doyle, & O'Brien, 2002; Gornick, Eggers, & Riley, 2004). These population groups experience significant barriers to seeking diagnosis and treatment, including lack of knowledge about the disease and treatment, logistical problems in accessing cancer-related healthcare (e.g., finances, lack of transportation, family care, communications), lack of social support, and difficulties dealing with multiple and fragmented healthcare facilities and organizations (Ahmad, Stewart, Cameron, & Hyman, 2001; Ashing-Giwa et al., 2004; Hurd, James, & Foster, 2005; Husaini et al., 2005).

Another significant barrier to timely provision of early detection services is the lack of information about screening and cancer care options, especially among health practitioners in rural and remote areas (President's Cancer Panel, 2001). As a key strategy, a panel convened by the National Cancer Institute suggests the need to educate primary care providers about cancer, and to develop and disseminate better tools for conveying information about cancer and cancer care options. In line with this, health informatics or computer-based tools (e.g., decision support systems and automated reminder systems) have improved screening rates and patient adherence to adjuvant therapy appointments, but their use and sustainability especially within rural healthcare settings requires further investigation (Coleman et al., 2003; Engelman et al., 2004; Garg et al., 2005; Jimbo, Nease, Ruffin, & Rana, 2006; Ruffin, Fetters, & Jimbo, 2007).

This paper presents results of formative research in an ongoing three-year project focused on designing a reminder system to improve screening rates and access to breast cancer care resources for rural, largely non-Hispanic African-American and low-SES populations. The project seeks to improve healthcare access among underserved
populations and reduce disparities in the timely delivery of preventive interventions through the development of a comprehensive, extensible, and user-friendly system adapted to rural clinic settings. As such, it is important for intended primary and secondary users (i.e., rural health practitioners and breast health coordinators) to be substantively involved iteratively throughout the design process to ensure that the system could be readily adapted within the users’ work patterns and environments.

The System for Tracking, Empowering, Equipping, and Reminding (STEER) is an electronic reminder and patient management system that: sends regular alerts to physicians to provide timely referrals in accordance with breast cancer screening guidelines; generates screening reminders for their patients that will include information tailored to their specific needs or perceived barriers to care; helps clinic staff collect information from patients; and facilitates tracking of patient adherence to mammogram appointments.

The following section describes issues surrounding breast cancer screening behaviors and interventions particularly for disadvantaged populations. We then present results of focus group interviews with rural women and health care practitioners aimed at answering the following research questions:

1. What are the information needs of disadvantaged women regarding mammograms and other preventive services and resources for cancer in their communities?
2. What factors influence rural women’s breast cancer screening behaviors?
3. What factors influence mammogram referral practices of healthcare providers and clinical staff in rural clinics?
The paper also discusses health informatics solutions, system design challenges and directions for future research. The overall goal of this paper is to enhance our understanding of how to design health informatics systems that might be more readily adapted in rural communities and that consider the main challenges of disadvantaged women and rural healthcare practitioners in relation to their breast cancer screening behaviors and referral practices.

**Cancer Screening Interventions for Vulnerable Populations**

While overall cancer screening rates in the United States have increased dramatically in recent years (from 28.8% in 1987 to 70% in 2000), rural areas have schedule delays due to limited mammography capacity (Coughlin, Thompson, Hall, Logan, & Uhler, 2002; Yabroff et al., 2004). Women who live in rural or inner-city areas, with less than a high school education, without health insurance coverage, or who are non-Hispanic African-American and older, are less likely to have had a recent mammogram (Clark et al., 2009; Cronan et al., 2008; Farmer, Reddick, D'Agostino, & Jackson, 2007; Smigal et al., 2006).

**Patient-based barriers to cancer screening.** Several studies have identified key behavioral barriers (i.e., deficits in knowledge and information including inaccurate estimates of breast cancer risk, inadequate knowledge of cancer treatments and survivability) that have inhibited the uptake of mammograms especially among older minority women (Chen, Diamant, Pourat, & Kagawa-Singer, 2005; Engelman et al., 2002; Young & Severson, 2005). Other studies have linked the health information seeking behavior of women and their use of information to make decisions about preventive care and screenings (Warner & Procaccino, 2004; Yoo & Robbins, 2008).
Lack of access to cancer screening and treatment facilities has been a significant problem in rural areas. For example, in a retrospective study of a cohort of 117,901 65-to 79-year-old female Kansas Medicare beneficiaries, Engelman et al. (2002) found that after adjusting for age, race, and county educational level, the odds of receiving a mammogram was slightly lower for persons residing farther from a permanent facility. Similarly, Cummings, Whetstone, Earp, and Mayne (2002) examined the impact of mammography programs in a population-based sample in four predominantly rural eastern North Carolina communities (N=843). The researchers found that African-American females aged 65 years or older had the lowest reported mammography rates (42%), whereas non-Hispanic white females aged 50 to 64 had the highest rates (58%). They also found that uninsured women and those with less education were less likely to have received a mammogram.

**Physician-based barriers.** Disadvantaged women report two major reasons for not having a recent cancer screening: lack of physician recommendation and perceptions about the prohibitive cost of cancer screening services. Physician recommendations are offered less frequently for more vulnerable populations such as rural and inner-city residents, and older, minority, less educated and lower income women (Ahmad et al., 2001; Breen & Meissner, 2005; Cronan et al., 2008; Husaini et al., 2005; Jones, Caplan, & Davis, 2003; Liff, Chow, & Greenberg, 1991). In Paskett et al.’s (2004) study of 897 women older than 40 years living in a tri-racial rural population in South Carolina, 67% percent reported that a physician had never encouraged them to receive a mammogram, although 75% reported having received a regular checkup in the past 12 months.

In line with this, interventions that have sought to: improve clinicians’ knowledge about and adherence to cancer screening guidelines, implement a reminder system, and
provide routine feedback to physicians, have been found to significantly improve preventive care (Ahmad et al., 2001; Breen & Meissner, 2005; Coughlin et al., 2002; O’Malley, Forrest, & Mandelblatt, 2002; Schueler, Chu, & Smith-Bindman, 2008). In their review, Breen & Meissner (2005) found that physicians who had better general knowledge about prevention and lower patient volume tended to have higher referral rates. The uptake of adult immunization and cancer screening services significantly improves when supported through organizational changes in staffing and clinical procedures that encourage patient self-management through financial incentives and reminders (Chen et al., 2005; Gornick et al., 2004; Stone et al., 2002). In an earlier review of interventions to improve cancer screening, Rimer (1998) found that reminder systems had the potential to double or triple the odds that women would get breast or cervical cancer screening and suggested that this should constitute a minimum practice for all healthcare clinics. Rimer noted that individual screening behaviors were less likely to be sustained without corresponding changes in the practices of providers and healthcare systems. In focus groups, O’Malley, Beaton, Yabroff, Abramson, and Mandelblatt (2004) found that physicians were interested in getting feedback on how their screening practices compared with those of other practitioners in their area and suggested that physician audit with feedback could improve screening referral practices.

**Addressing Health Disparities Using Health IT**

One strategy proposed to improve mammogram rates, especially in hard-to-reach areas, is to develop and disseminate better tools to assist healthcare providers in conveying information about early detection and cancer care options. The STEER project is developing one such health IT solution that can serve as a resource for rural healthcare
providers. The literature is rife with evidence that the implementation of general office systems (be these low-tech sticker reminder systems, postcards or targeted phone reminders) can be effective in boosting cancer screening rates (McPhee & Detmer, 1993). Moreover, advances in computing technologies have enabled automation of these office systems and have also proven efficacious through several studies (Engelman et al., 2004; McPhee & Detmer, 1993; Roetzheim et al., 2004). Computer automation not only systematizes the process of gathering patient data and thus lowers demands on appointment face-to-face time, but it also has the added benefits of facilitating archiving and retrieval of patient information (Jimbo et al., 2006).

**Designing Effective Health IT Systems**

Rapid advances in information and computing technologies increase the number of possible IT solutions that can be applied for healthcare delivery and promotion (Kwon & Kim, 2009; McKemmish, Manaszewicz, Burstein, & Fisher, 2009; Stvilia, Mon, & Yi, 2009; Xie & Bugg, 2009). And yet, the reality is we are still unable to harness the benefits of health IT nor do we fully understand its impact on health outcomes (Bessell et al., 2002; Copeland & Martin, 2004; de Lusignan, 2005; Evers, 2006; Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006; Walther, Pingree, Hawkins, & Buller, 2005). To be most effective, IT-based interventions must be designed, developed, and implemented using a sound conceptual framework that connects factors affecting utilization, the user's experience within the media environment, and post interaction outcomes (Given, Ruecker, Simpson, Sadler, & Ruskin, 2007; Lustria, 2007; Lustria, Cortese, Noar, & Glueckauf, 2009; Orzano, McInerney, Scharf, Tallia, & Crabtree, 2008; Robins, Holmes, & Stansbury, 2010; Street, 2003).
Figure 1 outlines the preliminary dimensions and variables of interest of this study. The main variables of interest are the factors that might influence the design and utilization of STEER by the providers in the rural health clinic and how their use of the system might influence patient uptake of screening behaviors. A number of studies suggest taking a systems approach that considers not only technological and user factors, but also institutional factors in the design and implementation of health IT (Bowler & Large, 2008; Marchionini, 2008; Street, 2003). User factors that may affect the adoption of STEER and shape decisions about its design may include health practitioners' computer literacy skills, attitudes towards IT, knowledge about IT systems, prior exposure to IT systems, and attitudes towards the health issues the IT system is designed to help solve. Characteristics of the technology itself may also affect its use and include such factors as the user interface, perceived usability, ease of navigation, interactive features, availability of different media formats, and compatibility with existing systems. Regardless of the potential benefits of the IT system for improving healthcare, it is doomed to fail if its use is not supported at the institutional level and it is not made a part of usual care (Street, 2003). At the institutional level, influencing factors may include perceived need for the system, administrative support for the use of the clinic-based system, the existing IT infrastructure and attitudes towards computing at the rural clinic, administrative support for personnel training, and concerns about maintenance costs, to name a few (Gustafson, Brennan, & Hawkins, 2007).
Method

Participatory Design of STEER: Rationale for Participatory Approach

Participatory design is an enhanced user-centered approach to designing information systems through the active involvement of users throughout the design process (Irestig, Eriksson, & Timpka, 2004; Muller, 2003; Schuler & Namioka, 1993; Sjoberg & Timpka, 1998). Substantive user involvement in the design process has been found to increase user commitment to system adoption, increase ownership of the system, improve learning and understanding, and improve system quality and user satisfaction (Brandt & Grunnet, 2000; Fowles, 2000; Muller, 2003; Muller et al., 1995; Muller, Wildman, & White, 1994; Pederson & Buur, 2000). In this study, primary and secondary users of the system were consulted iteratively at key points throughout the design process: as the system was conceptualized (user analysis and task/workflow analysis); after a prototype was developed (usability testing); and after initial implementation (process evaluation). User feedback and suggestions on how this system could be integrated within the primary users’ daily work routines within the rural healthcare clinic setting were also solicited.

Formative Research: Needs Analysis

Focus groups with the primary and indirect users at each study site were conducted iteratively throughout the design process, with initial sessions focusing on needs assessment. The discussion protocol for the focus group sessions was developed by an interdisciplinary team with combined expertise in health informatics, telehealth, cancer communication, information seeking, rural and family medicine, and qualitative research methods.
**Study population and sample.** Two rural counties in Florida—Gadsden and Wakulla—with high incidence of breast cancer were chosen as the main study sites for this project. The Tallahassee Memorial Cancer Center of Tallahassee Memorial HealthCare (TMH) based in Tallahassee, FL, and its family outreach clinics, provide most of the healthcare services in this area, and in many cases, are the only centers for miles around where individuals without health insurance can get cancer screening and treatment.

Gadsden County in Quincy, Florida is the largest rural county served by TMH. Most of the jobs available in this area are agriculture-based and low-paying. Historically, Gadsden has been one of the most impoverished counties in the United States, with a per capita income of $14,499 per year—49% below the statewide average of $21,557. About 22.2% of families in Gadsden live below the poverty level. The county has the fourth lowest literacy rate in Florida, with 40% of adults functioning at the lowest level of literacy. About 66.1% of Gadsden’s residents are non-Hispanic African-American. Recently, Gadsden county’s 25-bed critical access hospital was closed and its license was suspended by the Florida Agency for Healthcare Administration. TMH has one outreach clinic based in Quincy, but patients must travel either to Leon County (5 facilities available), Madison County (1 facility), or Taylor County (1 facility for mammograms and other breast cancer treatment services.

The second study site is Wakulla County, the second largest county serviced by TMH. Similar to Gadsden County, the job market is based on agriculture and aquaculture. Recent growth has been rapid, with a 24% increase in population since 2000, while Gadsden County’s growth in the same time period is only 3%. Wakulla residents have a per capita income of $22,842 per year, 1% above the statewide average of $21,557. About 11%
of families in Wakulla live below the poverty level. According to the Florida Adult Literacy Survey, 17% of adults currently function at the lowest level of literacy. About 17% of Wakulla’s residents are non-Hispanic African-American. Wakulla County does not have a hospital, urgent, or emergent care; only paramedic services are available. TMH has one outreach clinic based in Crawfordville, but similar to Gadsden patients, those seeking mammograms and other cancer treatment services must travel either to Leon County (5 facilities available), Madison County (1 facility), or Taylor County (1 facility).

**Outreach clinics sampled.** The Tallahassee Memorial Family Medicine (TMFM) clinics in Quincy (Gadsden County) and Crawfordville (Wakulla County) are the primary healthcare facilities serving the 45,087 residents of Gadsden and 28,213 residents of Wakulla counties. The Gadsden clinic is staffed by 4 medical doctors, 4 registered nurses (RNs), 2 advanced registered nurse practitioners (ARNPs), and 4 nurse assistants. The Wakulla clinic is staffed by 3 medical doctors, 2 RNs, 1 ARNP, and 3 nurse assistants. In 2006, 3876 women over 35 years of age (or at risk for breast cancer) were served by these two clinics—about 38% of these women were non-Hispanic African-Americans.

The Tallahassee Memorial Family Clinic in Quincy has broadband Internet connectivity (T1 connection) and 7 computers (Pentium III). The Tallahassee Memorial Family Clinic in Crawfordville also has broadband Internet connectivity (T1 connection) and 4 computers (Pentium III). Each clinic has a limited patient management system for registering, scheduling and billing patients, but neither clinic has a true electronic patient record management system in place.

**Focus group interviews with primary and secondary users of STEER.** Five focus groups with a total of 28 rural healthcare practitioners (including one breast health
coordinator and one breast cancer patient navigator from TMH) from the two study sites were conducted in Phase 1 of this three-year project. The discussions focused on identifying participants’ experiences dealing with socio-economically disadvantaged women, and getting their insights about the perceived usefulness of an electronic health resource like STEER in their workplace. The clinicians and their staff provided Institutional Review Board (IRB)-approved consent and Health Insurance Portability and Accountability Act (HIPAA) privacy authorization forms. In addition, the clinic staff each received $25 and lunch for their participation in the focus groups. Focus groups with clinic staff were conducted at the TMFM clinics in Gadsden and Wakulla counties.

**Focus group interviews with breast cancer survivors.** We also conducted one focus group each with breast cancer survivors from Wakulla and Gadsden counties. The discussions aimed at helping the research team understand patients’ experiences, challenges and information needs from the time they were diagnosed and during their cancer treatment. Breast cancer patients were identified through the TMH cancer registry and sent invitation letters for the focus groups through their respective oncologists. The breast cancer survivors provided IRB-approved consent and HIPAA privacy authorization forms. In addition, they each received $25 and a light snack for their participation in the focus group interviews. Focus groups with breast cancer survivors were conducted at public libraries in Quincy and Crawfordville.

**Focus group protocol and analysis.** All focus groups were facilitated by the first author. Two other researchers took notes, which were then supported through video-recording and audio-recording of all sessions. The analysis of the focus group data was completed by two researchers and used the focus groups notes and full transcriptions of
audio and video recordings as primary data sources. Open coding methods based on grounded theory (Charmaz, 2006; Strauss & Corbin, 1998) were used to analyze the notes taken during each focus group. An initial codebook was developed through an inductive analysis of the interview transcriptions. The codebook included explicit directions for coding procedures as well as a detailed set of codes to be used to assess the common themes and threads in each interview session. Two coders tested and modified this codebook through an iterative process of coding. Discrepancies in coding were discussed and the codebook was subsequently modified until an acceptable level of inter-coder agreement was reached. The research team also conducted follow-up interviews with the clinicians to help validate the information obtained during the focus groups.

Results and Discussion

The research team conducted three 1-hour focus groups in each county: one for clinicians (physicians and nurse practitioners), another for other clinic support staff, and one for breast cancer survivors. We felt it was important to separate out the two healthcare practitioner groups to enable the participants to voice their opinions freely and provide us with insights into clinician and staff perspectives. Table 1 summarizes the composition of each focus group.

[INSERT TABLE 1]

The data collected via focus groups reflect the perceptions of focus group participants and what they were willing to disclose during the group discussions, so the findings below are framed as "perceived and stated" factors.

Perceived and Stated Factors Influencing Rural Women's Cancer Screening Behaviors
**Transportation issues.** In this mixed rural/urban area, the difficulty in arranging transportation to a mammography facility is prohibitive for many women; as one provider said, "while educational tools or reminders would help it’s still going to boil down to how to get them from point A to point B." From the rural locations, the distance to the nearest mammography facility is perceived to be "far" (regardless of the actual physical distance in miles) and requires a reliable mode of transportation. For these women, gas is an expensive commodity, so even if the woman has a car and can drive, the cost of gas may keep her from making the trip. If the woman cannot drive and/or does not have a car, she must arrange for other transportation. Clinicians, staff, and patients all reiterated this problem, saying: "They don’t drive or they’re too old or they don’t like driving in Tallahassee"; "They don't have a way to get to Tallahassee to get a mammogram"; "I don’t have someone to drive me, I don’t have a vehicle." Public transportation in these areas is limited, extremely time-consuming, and prohibitively expensive, to the extent of being dismissed as an option by many focus group participants: "Even before it [Medicaid funding for transportation via van service] was cut, you had to give them a leave time, and they’d pick you up at like five in the morning because they have to pick up everybody and take them to Tallahassee and take them back at five [or] six in the evening." Transportation provided by family or friends is frequently unreliable and is sometimes expensive. This is exemplified by one patient, who says that women "Can’t depend on everybody to take you places, sometimes they’ll say they’ll take you but then they’ll come up with excuses; some people don’t realize how serious it is." This was echoed by a provider: "A lot of my patients have to pay to get here; even though it’s their family, they got to pay them twenty bucks to get them a ride here." In some cases, women are reluctant to ask family or friends for this
kind of assistance; they may wish not to be a burden or inconvenience, and privacy concerns keep them from talking about health issues even with close family or friends ("I feel shame about having cancer, I keep it hidden even from my family").

**Fear of the procedure.** Fear of the procedure influences women’s willingness to undergo mammography. Some women fear the procedure will be painful based on feedback they have heard from other patients. Other women have not had a pleasant experience with a previous mammogram and are unwilling to repeat it. There is also some fear that the mammography procedure itself can cause breast cancer. The fear of the procedure and its discomfort is demonstrated by several patients and clinic staff, who said: "Well, it's uncomfortable; it’s getting squished"; "There’s a lot of fear about pain!"; and "Fear is a big thing among a lot of my patients, they really have a terrible fear of going and they just don't want to have their breasts squashed flat, and them that does it comes back with horror stories so that doesn’t help any." In contrast, two survivors pointed out that "mammography is less painful than surgery; the benefits of finding something early outweigh the discomfort" and that "So many things are out of our control, but colonoscopy and mammography are things you can choose to do and why wouldn't you get them done? Doesn’t make sense to me, so what if it’s painful or gross?"

**Financial problems.** Financial limitations influence women’s ability and willingness to seek mammography. Uninsured and under-insured women have the most difficulty with screening, but some insured women can have difficulty even with a small co-payment. One clinic staff member exemplified this common concern specifically for uninsured women, saying: "the dollar signs are adding up by the time they’re having to find a ride over there, their time off if they do work and they just don’t have insurance, plus the
payment of the mammogram itself then getting the bill in the mail from the radiologist." A breast cancer patient put the financial issue of preventative care in a larger context, saying, "We are a poor county, people cannot even get treatment for drug addiction and wind up in corrections instead, they just cannot afford [preventive care]." Again, though, just as with the pain of the screening, a breast cancer survivor brought up a contrary view, reminding the group: "Mammograms are cheaper than surgery!"

**Issues with self-care.** There is a tendency, noted across all focus groups, for women to place their own healthcare as a low priority compared with other demands on their time and money resources. Other demands include care for their children, care for other relatives, and their jobs.

I worked 12 hours a day and got paid for 8, and spent the rest of the time taking care of my kids, especially my daughter who has a 13-year-old, a 10-year-old with special needs, and a baby; I stayed with my mother-in-law in Pennsylvania when she was sick; I always took care of other people, I was at the bottom of my list. [patient]

My doctor kept saying I should get one [a mammogram], but I was busy working, and every time a family member had surgery I would fly to wherever they were (I have a son in Wisconsin with Crohn's, and husband with Crohn's). I was on the bottom of the list to take care of. [patient]

They're taking care of other family members who are sick and so their health gets put aside, you know: "Oh I've got my grandfather here who's got one foot in the grave and I've got to take care of uncle Billy too and they're all living here at
my house so for the past two years I haven’t done anything for myself.”

[healthcare practitioner]

And even when the women are able to focus on their own health, other conditions and concerns can take priority over mammography screening:

I went to my doctor and he kept at me, but I’d put him off about getting a mammogram. I had health problems: diabetes, and different things, and I’d take my physical and skip some of the things, but my doctor wouldn’t let me pass getting the mammogram, and to satisfy him I went. [patient]

I have my physical and my mammogram and my colon thing, everything that I have to have, I do it every year. I’d been worried with my knees, nothing felt funny in my breast; it wasn’t hurting. I didn’t do self breast exams. I was going to get my knees done, and something just kept at me to go take my mammogram. [patient]

_Cynicism about preventive care._ The healthcare practitioners noted that in their interactions with patients, they often have to frame a discussion around the patients' non-belief in preventive care (see McKenzie, 2009 for a discussion of informed choice discussions in health settings). Providers report encountering patients who believe that "we all got to die of something, might as well be breast cancer," or "I’ve lived this long and I’ve lived a good life and if I get breast cancer, then okay." In a more pointed description, one provider says, "They sometimes say 'I don’t want any of that. I don’t want any cholesterol checks, I don’t want any mammograms, I don’t want to do pap smears, I don’t want to do any health maintenance, because I don’t believe in that. If I’m sick I’ll come and
see you.' These sentiments echo closely the theoretical work of Chatman (1996, 1999) in that the patients are reluctant to take the risk of seeking or receiving information (screening results) from the healthcare provider, whose worldview differs by holding preventive care as a valued activity. The provider went on to point out that it is not just a matter of willful non-adherence to healthcare guidelines, but that "It's usually some deeper belief behind it; in a 15-minute visit you're not going to be able to change that."

**Language and cultural barriers.** There are language barriers that hinder seeking mammography for populations whose first language is not English. Explaining the procedure itself, and explaining and completing the often complicated administrative steps required to get the procedure scheduled and paid for, can be daunting for women in the target population for STEER, but particularly so when the first language of the patient is not English. This is especially true because in this geographic area (unlike, for example, South Florida) there are comparatively fewer multi-lingual materials available.

Across the focus groups, participants indicated that women who are aware of a family history of cancer, and especially breast cancer, are more likely to be compliant with screening guidelines. Culturally, however, we found (primarily, although not exclusively, through our Gadsden County focus groups), that African-American women especially are less likely to know about a family history of cancer or breast cancer because there is a strong cultural taboo against talking about cancer (see also Case, 2008; Chatman, 1996; Sligo & Jameson, 2000). As one patient pointed out in a statement typical of many, "There was no family history [of cancer] that I knew of, just diabetes and high blood pressure; then last year I found out my niece had had cancer. She is a very secret person." Non-Hispanic African-American focus group participants also said they found it difficult to understand
their personal risk for breast cancer before they were diagnosed. A few, particularly, had difficulty in accessing their complete family medical history because some of them were not raised with their blood families: "I grew up not with my sisters and brother, so I got in touch with them to ask, and I found out my mother had cancer in her feet and an aunt died with cancer; I didn’t grow up with my family so I didn’t know."

Other cultural-family norms among these women also emerged as important to their thoughts about, and adherence to, breast cancer screening. First, childcare, or lack thereof, was not identified by any group as being a barrier to breast cancer screening when the researchers asked about it. Second, religion and its influence on women's approach to health and healing must be examined, considered, and incorporated into an intervention when it is appropriate for the target population. One idea several women expressed during our focus groups in both counties was that God worked with and through their healthcare providers to heal them. As one woman said, "The grace of God is the reason I'm here, and I'm thankful for my doctors and the radiation people"; another said, "I thank God every day. God does the healing but He works though doctors and nurses too." The women looked to their faith for healing and emotional support: "When I looked in the mirror and saw my bald head, my one breast, and my wrinkled body, and I could laugh, I knew He had healed me."

The above findings must be contextualized in what this study has considered the "target population." The "target population" even across two different counties in North Florida does not have identical needs when it comes to supporting breast cancer screening adherence, so any system must be tailorable across many variables. For example, in Gadsden County, clinicians indicated a significant difference in screening adherence
between older women (55+, who had higher adherence) and younger women (40-55). Clinicians in Gadsden indicated that educational materials tailored for younger women would be helpful. The clinicians in Wakulla, on the other hand, indicated that there was no observable difference across age groups and that the market for educational materials was saturated. Most women were sufficiently educated about screening and that other factors were influencing their adherence or lack thereof. So, even a basic decision about providing access to enhanced educational materials has to produce an adaptable result in the system implementation.

**Perceived and Stated Factors Influencing the Activities of Healthcare Providers and Clinical Staff**

**Compliance reporting and verification.** The focus groups with healthcare providers and clinical staff underscored a lack of closure in the "feedback loop" of compliance reporting for most patients (this is true not only for breast cancer screening but also extends to colorectal cancer and diabetes screening). The "unclosed feedback loop" occurs when patients are reminded to get a mammogram, and even when the provider actually schedules the mammogram for the patient. If the patient is compliant and gets the mammogram, the results come back to the provider, so the loop is closed for compliant patients. However, if the patient does not get the mammogram, there is no notification of non-compliance. The lack of a mammogram will only be noticed the next time the patient happens to visit the provider for a routine (i.e., physical) or non-routine (i.e., injury or illness) visit, and even then it is usually more a matter of a clinical staff member or nurse spotting the discrepancy in the patient’s chart rather than a systematic flag. There is generally no built-in explicit notification that a patient was NOT screened, so follow-up
reminders for patients who may need them most (patients who did not receive their screening) do not occur in a systematic way. One provider explained:

If they say they've had [the mammogram] and it’s not in the chart then we call and get it, and that’s easy enough to do, but there’s no way to know once we’ve sent the letter or once we've given them the prescription, to know if they've actually gotten it.

And another provider shared that identifying women who have not been screened is difficult because their clinic still uses a paper-based medical records system:

We don’t have any system for identifying all women over the age of 40. We’re not on computerized records yet so we don’t really have a way to tap into all the women who are over 40 or all the women who are over 50 that need a mammogram that are in our practice. We do look at that when they come in; we have a flow sheet on the chart to see when they’ve had it if they’ve had it. If it’s time to have it, then they get an order form.

On the other hand, women who are insured and whose insurance is provided by specific carriers receive regular screening reminders from their rural clinics since the latter receive incentives from the insurance companies to increase screening compliance. Additionally, providers themselves systematically receive data about non-compliance (reminders) and have reason to encourage screening for those women (incentives). One provider explained, "We do get a list [from one HMO] of women that had not had mammograms, but unless they're a certain insurance we have no idea who those women
are." As well, women who receive regular health care tend to be more compliant with breast self-exams and mammography, further exacerbating these findings.

**Varying clinic procedures.** The breast cancer screening tracking systems examined in these clinical practices: (a) use multiple media but primarily a combination of paper materials (formal letters and informal internal notekeeping) and telephonic support; (b) are tied to existing practices of patient tracking; and (c) depend on the provider, staff, and insurer and so may vary widely even within a clinic. Despite their low-tech nature, the systems the providers had in place to improve breast cancer screening compliance were surprisingly effective, as are many ad hoc systems.

Each clinic had unique practices for tracking adherence and following up on mammograms with patients who had different insurers. One clinic staff explains, "We actually have a flow sheet. A lot of the other providers don’t use that flow sheet so I’m not sure how they capture all that on theirs." Another staff member noted the use of routine and acute care visits for tracking screening adherence: "It’s usually whenever they come in for a full checkup. I mean I ask them even if they come in for a cold, when their last [mammogram] was, but it’s usually addressed when people came in for a full entire checkup."

**Guidelines and insurance.** The existence of multiple screening guidelines, combined with the varying levels of coverage by different insurance companies (and how those affect patients' out-of-pocket costs), shapes the way the clinicians recommend and prescribe screening and diagnostic mammography for their patients. Two different clinicians explained these effects:
There’s tons of guidelines out there. Most of the family physicians try to follow the Family Physicians’ but there are the various health plans’ guidelines also, Medicare guidelines, so with that in mind we try to tailor it so that the patient’s mammogram will be paid for, you know, so that they won’t be stuck with the bill.

And

If they have insurance that covers yearly [mammograms], then that’s what I recommend, but if they have less than that ... sometimes they’ll actually come out and say ‘you know I can only have every other year’ then I’ll ask ‘Do you have a strong family history?’ and then I try to recommend maybe we should do it every year? Especially if they’ve palpated a lump or something, then definitely I’ll recommend that they have a yearly. And I’ll even try to get it pushed through if I can get a diagnostic and not just the screening.

**A new system must fit existing workflow.** Providers and staff vary widely in their opinions about whether a reminder system like STEER will influence patient behavior. They expressed that the idea of learning a new system that does not interact closely with their existing systems (or incoming systems, such as electronic medical records), or that requires additional work by the staff, holds little appeal. One staff member responded pointedly to the prospect of increasing the follow-up with non-adherent patients, saying, "Unless they’re going to give us two more nurses per provider there’s just no way possible for them to call patients every thirty seconds to say hey did you go get this done? Did you go get that done?" It was also difficult for the providers to envision how such a system
might integrate with their existing procedures. Nevertheless, the overall sentiment was positive, as shown in this complicated exchange between one researcher and one clinician:

R: Would that [a reminder system] be useful for you or is that added work?

P: If it was possible that, every time we ordered a mammogram we just wrote it on a super bill and there as they were checking out or whoever was doing the billing there was a little button where there was a mammogram ordered, because every encounter form we fill it out, somebody is sending that information through a computer because they are billing electronically so if our billing system interfaced with the tickler [reminder] system it would be a piece of cake.

It was clear, though, that providers and staff work extremely hard, and care passionately about their patients despite having limited resources and time to address all patients’ concerns and screening needs. The clinicians welcomed the idea of a system that would better track screening compliance within their communities, especially for uninsured women. In particular, the clinicians and staff were generally unaware of, but were interested in knowing more about, screening and breast cancer rates within their communities. This lack of knowledge makes it difficult to determine how high a priority it is for their staff to learn how to use and implement a new patient tracking and reminder system for cancer screening like STEER.

**Implications for System Design**

Overall, our findings support previous research revealing a confluence of factors that might affect breast cancer screening rates and referral practices among patients and
physicians particularly in largely rural, low SES communities. Although our focus group needs assessment was originally organized around two geographic entities (Wakulla and Gadsden Counties) and three stakeholder groups (breast cancer patients, healthcare providers, and clinic staff), the analysis indicated that the STEER system cannot be designed and implemented just considering those differences. Rather, the system must be extremely flexible because differences in needs span so many other variables. In particular, high risk groups in rural settings face numerous challenges including those related to: low socio-economic status, financial issues and lack of health insurance, limited knowledge about breast cancer and cancer resources, lack of regular healthcare provider, and availability of screening facilities in their communities. In addition to the logistical challenges faced by these women, factors related to the overall healthcare system (e.g., a largely acute-focused system of care, provider time pressures, fragmented healthcare, and complicated provider requirements) all contribute to disparities in cancer screening behaviors and interventions in these rural communities. These findings also underscored the importance of addressing barriers at multiple levels and that in order to maximize the conditions for success, the STEER system must consider patients, providers, healthcare systems, and community settings in its design if it has any hope of improving mammography patterns particularly among vulnerable populations (Clark et al., 2009).

Our formative research thus far has provided us with important insights for conceptualizing an ideal system for each clinic. These findings remind us that what we consider part of the "system" must be broadly construed, and that it is important not just to automate and reify existing practices but to combine our needs assessment with the capabilities of new technologies to improve the "system" (Bates, 1986). The STEER system
must be conceptualized as one part of a larger system of healthcare settings and their workflows, financial and logistical considerations, and patient lifestyles and support systems. The research team is thus faced with the challenge of incorporating this suite of factors in the design of the STEER system.

Both clinics we studied have a variety of systems in place for reminding patients with health insurance about upcoming screening procedures. But for underinsured and uninsured women, there is no system in place for sending reminders about the need for regular mammograms. Furthermore, there is no coordinated system for tracking adherence to screening reminders. Rather, this is tracked when patients come in for routine clinic visits during which, given competing demands and priorities, there is limited opportunity to educate patients fully about the importance of screenings. Physicians and clinic staff appreciated the need for more education but also emphasized that without adequate access to resources (e.g. transportation, financial assistance) it would be difficult to convince women in their communities to adhere to breast cancer screening recommendations.

They agreed that developing a system that would enable them to keep better track of their patients and serve as a database for cancer care resources would be very useful in helping them deliver more timely screening reminders. Our research also shows how we can link these rural clinics’ efforts with educational and outreach efforts of the Tallahassee Memorial Healthcare’s Breast Cancer Patient Navigator (BCPN) Team. In essence, through STEER, the BCPN team can have ready access to women in these communities who will need extra support in making screening decisions.

At the same time, our research team has started conceptualizing how additional telephonic support and ties with local resources such as urgent care centers and the local
Department of Health clinics might help strengthen our efforts to reach more vulnerable populations in this community. We have also seriously considered adding support for patient recruitment via faith-based community groups in order to boost patient enrollment and improve access to those who need the most care.

A Note on the Participatory Approach

The STEER project builds on existing research espousing the use of bottom-up approaches for the conceptualization and design of healthcare systems (Gustafson, 2004; Gustafson, Taylor, Thompson, & Chesney, 1993). The intent in using this approach was to develop a system that might be more sustainable within local settings and to enhance the conditions for adoption by the intended primary users. Research has shown that despite the benefits of automation and health information technologies, health care providers are slow to adopt these systems (Berner, Detmer, & Simborg, 2005; Ford, Menachemi, & Phillips, 2006; Simon et al., 2007). As Chaudhry et al. (2007) noted in their research on the design of a web-based system for improving breast cancer screening, information technology alone is insufficient to effect the delivery of preventive services.

Implementing a participatory approach faces challenges. First, the variety of potential users of the system and the unique characteristics of each rural clinic setting necessitates a careful and iterative process of needs assessment, workflow analyses, and validation of prototype concepts, thus lengthening the design process. The design team has to be careful not to be constrained by their initial ideas for the design and to keep in mind the needs of each user and the realities of their work settings, while at the same time allowing for the variety of users, their information needs, and their assumptions about how a such a system should—and does—work (Bates, 1986). It is quite difficult to anticipate
and address all the needs and potential needs of the intended primary users of the system, given the high turnover rate of the health clinic staff. The STEER system not only has to be user-friendly, but it also has to be scalable and extensible to accommodate users’ needs as time progresses and situations change.

For example, at the time we conducted the needs assessment, the rural clinics still used different legacy systems for patient billing and largely paper-based systems for maintaining patients’ medical records. At the same time, they were also exploring a number of proprietary electronic medical records systems that would be implemented in the near future. Thus, our design team had to consider developing a modular system that could be readily integrated with a standard electronic medical records system.

**Future Research Directions**

The findings of the present study provides the foundation for the system development, implementation, and evaluation phases of our research project. Phase 2 of STEER will use the results of the focus groups to guide decision-making in the design of the integrated web-based reminder and tracking system. STEER will contain four modules: a patient management module, documents module, resources database and system administration module. Usability tests will be performed with potential users of the system, facilitating the evaluation of ease of use of the system and extent of integration across the four main modules. In Phase 3, we will implement STEER through the TMH Breast Cancer Patient Navigator Program and collect data on rural clinicians’ screening referral practices and patient adherence to breast cancer screening referrals 1, 3, and 6 months after system launch in each study site. Finally, we plan to conduct interviews with the health practitioners regarding their use of the system, adherence to procedural instructions and
their perceptions of STEER’s usefulness, usability and acceptability in each study site. If the STEER program proves successful, it has the potential of serving as a prototype for the development of health informatics systems for other rural healthcare practices to follow.
References


de Lusignan, S. (2005). Web-based health applications provide useful and cost-effective tools; however, they should include key clinical variables and incorporate a coding or classification system. *Informatics in Primary Care, 13*, 42-44.


