

***Grant Final Report***

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**Creating a Foundation for the Design of Culturally Informed Health IT**

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# Abstract

**Purpose:** The specific aim of this study was to create a foundation for a design strategy that leads to culturally-informed consumer health IT. A systematic understanding of the needs of individuals embedded in diverse cultural contexts will enable designers to create consumer health IT responsive to the breadth of patients' routines.

**Scope:** There is a need to expand initiatives to reduce racial and ethnic health care disparities through culturally-competent health care to include consumer health IT. This dissertation develops a systematic understanding of culturally diverse patients' health management needs within the context of one task: health information communication with members of the social network. Eighteen participants were recruited using maximum variance sampling from two federally qualified health centers located in a small Midwest city.

**Methods:** This dissertation took a mixed methods approach grounded in both cultural anthropological and systems engineering principles and methods to assess patients' daily routines of health information communication. Daily routines of health information communication were conceptualized using systems engineering theory: what health information is communicated and how (technical system) and to whom this knowledge is communicated and why (social system) within a cultural context (broader environment).

**Results:** This study illustrates the complexity and diversity of participants' daily routines of health information communication in terms of the types of people, information, modes, and rationales provided. This study also highlights challenges of traditional targeted approaches to incorporating cultural considerations in the design process and provides support for a tailored approach.

**Key Words:** consumer health IT; disparities; culture; engineering design

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# Final Report

## Purpose

The long-term objective of this work is to foster reduction in racial and ethnic health care disparities through creation of new, culturally-responsive approaches to the design of health information technologies (health IT) intended for use by lay people such as patients and members of their social network (e.g., family members, friends, neighbors). The specific aim of this dissertation was to create a foundation for a design strategy that leads to culturally-informed consumer health IT. In this approach mixed methods drawing on both cultural anthropological and systems engineering methods were used to systematically assess culturally diverse patients' daily routines (Jimison et al., 2008) of health information communication. A systematic understanding of the needs of individuals embedded in diverse cultural contexts will enable designers to create consumer health IT responsive to the breadth of patients' practices.

## Scope

## Background

The provision of culturally-competent health care is one approach to addressing racial and ethnic health care disparities that has been advocated by many national bodies, including the Agency for Healthcare Research and Quality (AHRQ), National Library of Medicine (NLM), and Institute of Medicine (IOM) (e.g., Brach & Fraserirector, 2000; Siegel et al., 2005; Smedley, Stith, & Nelson, 2003). To date, the development of culturally-competent health care has predominantly focused on evaluating and addressing how provider-delivered care, health care systems, and health promotional campaigns may be made sensitive to cultural differences (Brach & Fraserirector, 2000). This work has only been limitedly extended to the design and deployment of health IT, including consumer health IT, despite anthropological and engineering evidence demonstrating its need and relevance (e.g., Choi, Lee, & Kim, 2006; Forsythe, 1996).

Now is the time to build a foundation for the design of culturally-informed consumer health IT. As the location of care shifts from health care institutions to home and community based settings (Bureau of Labor Statistics, 2010; National Association for Home Care and Hospice, 2010), the patient's role is increasingly being transformed from a passive recipient of care to a partner actively engaged in making decisions and taking actions. With a myriad of consumer health IT emerging in the marketplace (e.g., self-monitoring tools, personal health records, decision support systems) that facilitate these new health management responsibilities (Keselman, Logan, Smith, Leroy, & Zeng-Treitler, 2008), it is imperative that we create consumer health IT appropriate for a larger portion of the patient population.

The health and medical informatics community has recognized the importance of creating culturally-informed consumer health IT (Gibbons et al., 2009; Kaplan, Brennan, Dowling, Friedman, & Peel, 2001; Valdez, Gibbons, Siegel, Kukafka, & Brennan, 2012), however, to date,

only a limited amount of consumer health IT has been created that is purposefully responsive to cultural differences (Montague and Perchonok, 2012). This limited amount likely stems in part from the fact that methods predominantly used to create such culturally-informed technologies are extremely costly in terms of the required time and resources: designers of culturally-informed health IT have relied primarily upon participatory methods (e.g., Senathirajah, Kukafka, Guptarak, & Cohall, 2006; Siegel et al., 2005), which involve long-term immersion and partnership with a cultural group, to expose cultural influences on health care behaviors. Furthermore, traditional approaches do not purposefully consider that an individual user may have multiple meaningful cultural affiliations. Thus, targeting one cultural group at a time may have limited scalability and feasibility.

Consequently, although participatory and field-based approaches remain deeply important for gaining nuanced knowledge of cultural differences, we cannot expect to quickly advance development of culturally-informed health IT by relying solely upon these methods. Designers need empirically derived design considerations that can be used to more efficiently guide the creation and evaluation of culturally-informed health IT. Specifically, systematically elucidating the range of practices across people identifying with diverse cultural groups would enable designers to make technologies that are capable of being responsive to a wide range of culturally salient practices, potentially enhancing scalability and allowing users identifying with multiple cultures to achieve better fit with the technology.

## **Context**

This dissertation develops a systematic understanding of culturally diverse patients' health management needs within the context of one health information management task: health information communication with members of the social network. A focus on health information communication was chosen for four primary reasons. First, previous work has documented that communicating health information with members of a social network is a particularly burdensome aspect of health information management (Pratt, Unruh, Civan, & Skeels, 2006). Second, despite this need, there has been limited assessment of domestic communication pathways; health IT development has predominantly focused on communication pathways between and among the patient, his clinicians, and his primary caregiver (e.g., Gustafson et al., 2002; Lewis, Gunawardena, & El Saadawi, 2005; Mahoney, Tarlow, & Jones, 2003). Technologies that have been created to support daily routines of health information specialize in supporting only limited types of domestic communication pathways, for example communicating precise logistic or clinical information with immediate family members (e.g., Microsoft HealthVault, Epic MyChart) or communicating broader information for social support to a larger network (e.g., Caringbridge.org and Carepages.com). Third, sociological and anthropological evidence suggest meaningful differences in how this aspect of health information management is performed across cultures (e.g., Blackhall et al., 1999; Fadiman, 1997; Janzen, 1987). Finally, our limited understanding of patients' daily routines of health information communication is primarily semantic rather than structural in nature (Chatters, Taylor, Lincoln, & Schroepfer, 2002; Janzen, 1987), limiting the ease with which guidance may be drawn for design.

## Settings

Recruitment took place at the Access Community Health Center Clinics located at 2202 South Park Street and 3434 East Washington Avenue in Madison, WI, USA. These study sites were chosen because they serve a culturally diverse patient population, but predominately serve a lower income and medically underserved community. Thus, these sites facilitated maximum variance sampling over the phenomenon of interest (cultural context) while simultaneously facilitating methodological control by limiting other types of variability (Creswell, 2009) related to socioeconomic status, geographical location, and clinical protocol. Over 60% of the patient population does not have Anglo-European ancestry. A focus on a lower income and medically underserved population was appropriate given the recognized need reduce health care disparities by creating consumer health IT for this population.

Interviews took place either at one of the two Access Community Health Center clinics or in participants' "homes," depending upon participants' preferences. Participants were asked to select an environment that was most convenient and comfortable for them to limit attrition and to facilitate openness.

## Participants

Eligible patients were those that were over 18, spoke English, and had a diagnosis consistent with type 2 diabetes. Participants were limited to those who could speak English for a combination of practical and methodological reasons: ensuring rigor in a multilingual study would have required translation and testing of all data collection instruments for equivalency and would have required translation both during the interview and during transcription. The resources required to conduct such a rigorous multilingual study were not available. To ensure the broadest possible participation, however, participants were only required to speak (not read or write) English.

Patients with Type 2 diabetes were chosen as a focus for this study because they had to manage a chronic disease affecting a growing number of individuals, and their experience may be considered as prototypical of complex health problem. Furthermore, effective management of diabetes requires, more than many other conditions, intense personal engagement. Finally, diabetes is a health problem that disproportionately affects racial and ethnic minorities (CDC, 2011).

## Methods

### Study Design

This dissertation took a concurrent, mixed methods approach (Creswell, 2009) to empirically assess culturally diverse patients' daily routines of health information communication. Eighteen patients who self-identified their racial, ethnic, and national culture participated in the main study. Approaches grounded in systems engineering and cultural anthropology were used to conceptualize patients' daily routines, guide data collection, and analyze and interpret the data

obtained. A small pilot study was used to inform the final study protocol for the main study. All data were self-reported and collected retrospectively. Numerical data were analyzed using descriptive not inferential methods, as this work is not aimed at establishing causality. Analysis of qualitative data was informed by conventional content analysis methods (e.g., Denzin and Lincoln, 2005; Hsieh and Shannon, 2005) but modified to meet the purpose of guiding design rather than building theory.

In this dissertation patients' daily routines related to health information communication were conceptualized using systems engineering (specifically human factors engineering) theory (Pasmore, 1988). This theory considers how elements of the social and technical systems interact within a broader environment in the production of work. The "work" of health information communication involves many activities, including keeping members of a social network informed of health problems and engaged in health choices (Moen & Brennan, 2005). This dissertation focused on evaluating what health information is communicated and how (technical system) and to whom this knowledge is communicated and why (social system) within a cultural context (broader environment). Thus, a daily routine was characterized by elements such as the number and types of people involved, the types of technologies used, and the rationales for communication.

## Data Sources and Collection

**Sampling.** To achieve the goal of elucidating the daily health information communication routines of patients holding diverse cultural identities, maximum variance sampling (Patton, 2001) was used to recruit participants into the main portion of the study (two interviews). Maximum variance sampling (Patton, 2001) based upon a demographic survey was first based on self-identified cultural contexts and then on other demographic characteristics such as gender and IT use. In this study culture was conceptualized in a way that aligns with previous AHRQ initiatives addressing the intersection between racial and ethnic health disparities and culturally-competent care (Brach and Fraserirector, 2000). Thus the racial and ethnic categories used are also aligned with those used by AHRQ (2011). However, because AHRQ also acknowledges interest in the composition of these broad cultural groups in the *National Healthcare Disparities Report* (AHRQ, 2011), information was also collected on nationality and any other cultural characteristics that participants deemed salient.

Convenience sampling (Patton, 2001) was used to recruit participants into the validation exercise (journaling using an iPod Touch). Given the potential burden of the validation exercise, convenience sampling was used to ensure that twenty percent of the sample engaged in the activity.

Six participants were recruited into the pilot study, eighteen into the main study, and four into the validation exercise. Of note is that although the sample size is smaller than originally intended (18 instead of 30 for the main study and 4 instead of six for the validation exercise), data collection for each participant was more exhaustive than originally proposed (two interviews with each participant instead of one; use of an electronic journal for five days instead of 12 hours of shadowing).

**Participant Flow through Study.** Patients meeting the eligibility criteria received a scripted invitation by their nurse practitioner, dietician, or diabetes educator to participate in this study. Interested participants were given a recruitment packet, which contained an information sheet

detailing the study and a demographic survey. The recruiter aided patients who expressed interest in study participation but who had a difficult time reading and writing English with understanding the information sheet and completing the demographic survey. All patients who completed the demographic survey received a token of appreciation.

Those selected for study participation (based upon the maximum variance sampling described above) were contacted by telephone by the researcher (RV) to arrange a time and place for the first interview. The researcher attempted contacting a participant five times to schedule the first interview before determining that a participant was lost to follow-up. Similarly, the researcher allowed for three no-shows of scheduled first interviews before determining that a participant was lost to follow-up. All participants received a reminder phone call the day before any scheduled interviews or meetings (for journaling).

The second interview was scheduled at the end of the first interview. Every attempt was made to schedule the interview within two weeks of the first interview to guard against maturation effects (Trochim and Donnelly, 2006). The average time between the first and second interview was 14.6 days. Participants with the longest times between interviews had extenuating circumstances requiring rescheduling of the second interview (e.g., change in work schedule, hospitalization). Participants received \$20 in compensation at the end of the second interview.

At the end of the first interview participants were also invited to participate in the journaling activity until four participants (20% of the sample) had completed this validation exercise. At the end of the second interview all journaling participants were taught how to use the recording device and were instructed on when to begin and end journaling. Participants received a reminder phone call on the day before journaling was to begin and a phone call one day after journaling commenced to address any questions. The researcher met with the participant after the journaling was completed to download and review the journal. Participants were allowed to keep the recording device after completion of the journaling exercise.

## Interventions

**Demographic Survey.** All participants expressing interest in the study were asked to complete the 25-item demographic survey. Items on the survey addressed age, gender, household status, education, socioeconomic status, education, cultural background, health status, insurance status and IT use. This survey was constructed based upon previous surveys developed by our group for the Advanced Technologies for Health@Home project (Zayas-Caban, 2002), the US Census survey, and feedback from committee members, grant reviewers, and agency officials.

**Interviews.** The interview method used in this study was grounded in both cultural anthropological and systems engineering principals and methods (please see Valdez, Patton, Brennan, 2010 for a more detailed description of the methodology). Briefly, the interview protocol combined the social network analysis and ethnographic interviewing traditions from cultural anthropology with the concept of a work system and systematic approaches to data collection from systems engineering. In this study the work system was conceptualized as a technical subsystem (what information is communicated and how) and social subsystem (to whom information is communicated and why) contained within an external environment (cultural context). All participants took part in two interviews as described below. The average total interview time was 2 hours and ranged between 1 hour and 17 minutes to 3 hours and 23 minutes. All interviews were professionally transcribed prior to data analysis.

The first interview consisted of two phases. In the first phase the researcher guided participants through a structured interview to create a visual depiction of their affective social network (Antonucci & Akiyama, 1987). This method involved asking the participant to place people into three concentric circles around the word “you,” where each circle represents a level of closeness. A list of potential people that a participant may want to include was provided to help the participant with this activity. For each member of the participant’s social network, the researcher asked about the member’s age, gender, whether or not the individual would be considered as a family member, geographical proximity, and frequency of contact.

In the second phase of the first interview the participant was asked about if, why, and how he or she communicates four types of health information with each member of the social network. The four types of health information included: 1) daily observations of health status, 2) test results from clinical visits, 3) information on diabetes self-care and self-management, and 4) time and place of doctor’s appointments. These were chosen because they include 1) emotionally sensitive and non-sensitive health information, 2) information generated by both the provider and the patient, and 3) logistic, personal, and reference information (Moen & Brennan, 2005) and are likely to be communicated between patients and members of their social network in different ways and for different reasons, thereby providing a more comprehensive understanding of the daily health information communication routines.

The second interview consisted of three phases. The first phase consisted of reviewing the information presented during the first interview. Participants were first presented with their social network and asked if they would like to make any changes after having had some time to reflect on the first interview. They were then presented with the rationales they provided for why they do or do not communicate and how they communicate the four types of health information to three randomly selected members of their social network (one from each circle) and asked if they found this information to be accurate or would make any changes. Although it would have been ideal to have participants review all of the information they provided, we decided not to do this because of the heavy time burden on the participant.

In the second phase of the second interview, participants were asked about their cultural identities. The researcher asked the participant a series of seven open-ended questions about each of the cultural identities noted in the demographic survey. These items included questions such as “In your own words, what does it mean to be \_\_\_\_\_ [insert identity]” and “How do you think that your identification as \_\_\_\_\_ [insert identity] affects your practices of health information communication with people in your network.” These questions were developed in conjunction with Dr. Maria Lepowsky, the cultural anthropologist on the researcher’s committee.

In the third phase of the second interview, participants were asked a series of questions about their use of information and communication technologies. The researcher asked the participant a series of six open-ended questions (and related sub-questions) about this topic. These items included questions such as “Please tell me about how and why you use the Internet/ICT to help manage your health and health information” and “In what ways, if at all, have the Internet/ICT improved your ability to communicate with members of your social network.” These questions were developed with feedback from Susannah Fox of the Pew Internet & American Life Project.

**Journaling.** In the journaling activity, participants were asked to keep track of their communication with members of their social network for five days (two days before a clinical appointment, the day of a clinical appointment, and two days after a clinical appointment). We

asked participants to journal around a clinical appointment because it was more likely that participants would generate new health information to communicate during this period. The journal created was voice-based and recorded on an iPod Touch. An iPod Touch was used as a recording device because it enabled directions and social network member information to be stored in the Notes application, allowed for reminders (every two hours) to be created in the Clock application, and was extremely portable, facilitating integration into everyday life.

## Measures

We originally proposed meeting the specific aim of the study by answering two research questions:

1. What are the daily routines of health information communication exhibited by patients who hold diverse cultural identities?
2. What design considerations for consumer health IT result from knowledge of these daily routines?

In the process of conducting this study and having discussions with committee members it was determined that the specific aim would best be met by merging these questions. Originally we had proposed to answer the first question by creating individual representations of each participant's daily routine of health information communication and then determining design considerations in terms of functions and means by consolidating the data. As the study progressed, we determined that getting to functions and means would prematurely constrain the design space, creating prescriptive guidance where descriptive guidance would be more appropriate. For this reason the design considerations created in this study are an aggregate representation of participants' daily routines of health information communication. These design considerations will enable designers to access a systematically generated understanding of the ways people of diverse cultural backgrounds approach health information communication with their social network. Designers can then combine this knowledge with their extant knowledge (e.g., of technological capabilities) to create new forms of consumer health IT.

**To Whom Health Information is Communicated.** We determined to whom health information is communicated by using conventional content analysis (e.g., Denzin and Lincoln, 2005; Hsieh and Shannon, 2005) to group social network members into clusters based on their relationship to the participant. We also used descriptive statistics to characterize the demographic characteristics of the social network members (i.e., age, gender, geographical location) and the typical interaction between participants and social network members (i.e., typical frequency of contact, language of interaction).

**What Health Information is Communicated.** We determined what health information is communicated using descriptive statistics to identify the number and percentage of social network members to whom participants communicated each type of health information.

**Why Health Information is Communicated or Not Communicated.** We determined why health information is communicated or not communicated using conventional content analysis

(e.g., Denzin and Lincoln, 2005; Hsieh and Shannon, 2005) that was modified to meet the purpose of guiding design. The main modification was to retain a larger number of categories where it was determined that the implications for design might be lost if categories were merged. Thus to some extent parsimony was traded for more explicit exhaustiveness. Although we had originally proposed using Weber’s categorization of social action (Gerth and Mills, 1946), this was replaced by a more inductive approach would enable a characterization strongly grounded in the participants’ experiences.

**How Health Information is Communicated.** We characterized the modes of communication used and the rationales for use of these modes how health using conventional content analysis (e.g., Denzin and Lincoln, 2005; Hsieh and Shannon, 2005). The analysis procedure for rationales was again modified to meet the purpose of guiding design.

**Cultural Context.** We used conventional content analysis (e.g., Denzin and Lincoln, 2005; Hsieh and Shannon, 2005) to extract the characterization of participants’ cultural identities, the meanings and values ascribed to these identities, and the perceived relationships between cultural identity and health information communication practices.

**Recall Bias.** We used a combination of conventional content analysis (e.g., Denzin and Lincoln, 2005; Hsieh and Shannon, 2005) and descriptive statistics to characterize the extent to participants’ journal account of their health information communication practices differed from those reported during interviews.

## Limitations

One limitation of the study resulted from the sample composition. Although a wide range of cultural identities were represented in this study it was not possible to represent all of the cultural identities that were of interest. Originally we proposed the following targeted enrollment:

**Table 1. Demographic targets**

**Table 1a. Ethnic category**

	<b>Females</b>	<b>Males</b>	<b>Total</b>
Hispanic or Latino	3	2	5
Not Hispanic or Latino	12	13	25
Total	15	15	30

**Table 1b. Racial categories**

	<b>Females</b>	<b>Males</b>	<b>Total</b>
American Indian/Alaska Native	3	2	5
Asian	2	3	5
Native Hawaiian or Other Pacific Islander	3	2	5
Black or African American	2	3	5
White	5	5	10
Total	15	15	30

Our actual enrollment is shown below:

**Table 2. Demographic statistics**

**Table 2a. Ethnic category**

	<b>Females</b>	<b>Males</b>	<b>Total</b>
Hispanic or Latino	2	0	2
Not Hispanic or Latino	7	9	16
Total	9	9	18

**Table 2b. Racial categories**

	<b>Females</b>	<b>Males</b>	<b>Total</b>
American Indian/Alaska Native	0	0	0
Asian	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0
Black or African American	4	4	8
White	5	5	10
Total	9	9	18

Although the recruitment and research team made every effort to meet our recruitment target in terms of ethnic and racial diversity as defined by the above table, meeting the target proved infeasible due to demographic shifts in the patient population and patient availability in joining the study (for example, one patient who identified as Native American completed the demographic survey but then was unable to find time for the interview because of domestic responsibilities). However, the table belies the actual cultural diversity present in the patient population. For example, within the racial category of “White” there were participants identifications included Arabic, Jewish, Irish and German to name a few. The total range of self-identified cultural affiliations included: African American, American, Arabic, Black, Caucasian, Diverse, Educated, English, Father Mexican Immigrant, French, German, Heinz 57, Hispanic, Irish, Jewish Heritage, Lebanese, Lithuanian, Low Income, Mexican, Middle Class, Middle Eastern, Poor Trash, White, and Will Not Answer. Furthermore, there were participants who in their racial identification (used to populate the table above) indicated that they were “White” but in the interview noted their identification with other categories such as “Native American” (contained within the self-identification as “Heinz 57”). Thus while it was not possible to meet our original enrollment target, we still were able to recruit a culturally diverse sample.

Another limitation was the sample size. The study design was focused on gaining an in-depth understanding of the daily routines of health information communication with of a culturally diverse sample. Although we were able to gain this in-depth understanding, the depth came with a trade-off in terms of sample size. From our study it is not possible to say that all daily health information communication practices are represented. However, the in-depth work with a culturally diverse sample provides a strong foundation for future work that focuses on validating and expanding this foundation with other populations.

Qualitative analysis and interpretation is particularly susceptible to the biases and assumptions of the researcher. To mitigate the systematic effect of any potential biases and assumptions, two researchers were engaged in 20% of all data collection and analysis activities. Furthermore, throughout the data collection and analysis processes the researcher met regularly with peers (PhD students in Industrial and systems Engineering and Nursing) during which the

researcher's biases were probed, meanings explored, the basis for interpretations clarified, and working hypotheses tested (Lincoln and Guba, 1985). Similarly the researcher regularly met with committee members to discuss developing analytic categories and interpretations. Finally, the researcher kept a journal during both data collection and analysis containing both a reflection on biases and assumptions and rationales behind methodological decisions. Contents of this journal were discussed with Dr. Patricia Brennan, the advisor of this dissertation research.

## Results

We present here a brief overview of the results because of our intention to publish the comprehensive results in a peer-reviewed journal such as the Journal of the American Medical Informatics Association or the International Journal of Medical Informatics. This plan was reviewed and approved by AHRQ on July 27, 2012.

### Principal Findings

In this study, the concept of daily routine of health information communication was operationalized using theory from systems engineering (Pasmore, 1988). This dissertation focused on examining what health information is communicated and how (technical system) and to whom this knowledge is communicated and why (social system) within a cultural context (broader environment). The principal findings, therefore, are reported by dimension of the work system with a final section related to recall bias.

**To Whom Health Information is Communicated.** As observed through visual representations of their social networks, participants included both specific individuals and groups of individuals (e.g., nieces, grandchildren, friends). The size of participants' networks ranged from 7 to 17 units (the number of labels – whether individuals or groups - written onto the visual representation of the social network). This, in turn, translated into 7 to 87+ individuals. Because some participants couldn't remember the exact number of individuals contained within a group of people (e.g., the number of friends that they had), the upper bound on the number of individuals can only be specified as greater than 87 individuals. Participants communicated health information or would communicate under some circumstances with between 6 and 17 units and between 7 and 80+ individuals.

Participants' social networks included individuals who may be classified into ten different categories. These categories include biological relatives, defined as those with whom the participant has a blood relationship (e.g., parent, sibling, grandchild, 2<sup>nd</sup> cousin); professional relationships, defined as those grounded in the participant's employment status (e.g., employer, co-worker); and religious figures, defined as supernatural beings (e.g., God, Jesus). In aggregate, participants communicated health information or would communicate under some circumstances with members of all ten categories. The final presentation of this work will include a description of all ten categories and findings related to other demographic (e.g., age, gender, geographical location) and relational characteristics (e.g., language of communication, frequency of contact) of the social network members.

**What Health Information is Communicated.** All participants communicated all four types of health information or would communicate it under certain circumstances to least one unit in their social network. When described in terms of percentage of units in the social network, participants communicated the time and place of their doctor's appointments or would communicate under certain circumstances with between 19% and 100% of their social network. For information about diabetes self-care and self-management the range was between 38% and 100%; for daily observations of health status between 27% and 100%; and for test results from clinic visits between 25% and 100%. The final presentation of this work will be further broken down in terms of individuals (as opposed to units).

**Why Health Information is or is Not Communicated.** Analysis of rationales yielded 19 categories for both "reasons to communicate" and "reasons not to communicate." An example of a "reason to communicate" included the category "benefit," defined as "the participant believes that the social network member would gain an advantage from having the information." Evidence supporting this category included the following quotes:

*"Because I don't want them to get to what I have, a diabetic like me... For they health."*

*"Well, what's education on me is also good education for him."*

An example of a "reason not to communicate" included the category "connect," defined as "the participant and social network member have limited interaction." Evidence supporting this category included the following quotes:

*"She and I just don't talk that often."*

*"[We talk about] anything hardly. Unless we spend some time together for something you know but most of the time I don't hear from him."*

In addition to the categories for "reasons to communicate" and "reasons not to communicate" the analysis yielded conditioning factors that shaped the relevance of the categories under for a particular individual in the social network. An example of a conditioning factor was "categorical," defined as "the social network member's belonging to a social or demographic group." To continue with this example, under the category "benefit" the conditioning factor "categorical" would explain why the information was of benefit to the social network member. In the quote below, a participant notes that the information is of benefit to the social network member because of her membership to the family (a social group):

*"Just so that she knows that something's going on in our family, and then there were questions as to, you know, —our parents, well, my dad was but my mom was never very honest about health information, her own health information, because she had polycystic kidney disease that led to one sibling actually dying because that information wasn't passed on. So we're all pretty—like if it's important, it'll get to where it needs to go."*

The final presentation of the results will include a complete list of the categories and conditional factors.

**How Health Information is Communicated.** The modes of communication participants used to communicate health information with members of their social network included those that were both technology-mediated and non-technology mediated. Technology mediated forms of communication included cell phone, landline, email, video chat, Facebook, texting, and paper journals. Non-technology mediated forms of communication included face-to-face communication, overhearing, prayer, and meditation. The final presentation of the results will also include a comprehensive list of rationales that participants provided for using these technologies (formatted as described in the previous section) and a list of rationales that participants provided for their use of IT for both general and health management purposes.

**Cultural Context.** Participants' conceptualization of cultural identity included race, ethnicity, nationality, socioeconomic status, education, life experience, and religion. Furthermore, in aggregate, participants noted that these cultural identities had multiple dimensions including language, food, physicality, ideology, and opportunities. Participants further noted that for some identities, they had strong affinity some of its aspects and weaker affinity to other aspects. For example, one participant noted a stronger affinity toward the food but a weaker affinity toward the language of his German identity:

*“You’ve got some of the things that the nationality handed down to us, I guess. The foods we eat are kinda German. Well, Lithuanian could be, too, like bratwurst and sauerkraut. Then my mom used to make milk soup, which you put plums in it and fruit or apples, maybe raisins. Certain dishes that she told me about, I like making ‘em, too.”*

*“[My father] also liked to write in German. That’s something he did. Well, I don’t feel any need to do that or anything. . . . I don’t really remember much about German language anymore.”*

Participants expressed a wide range of views on if and how a given cultural identity impacted their daily routines of health information communication. Some participants perceived a clear relationship between their cultural identity and their health information communication practices whereas others perceived that their cultural identity didn't impact their health information communication practices. Still others were unsure of the relationship between their cultural identity and their health information communication practices:

*“Yeah, I think its consequence—being Mexican, it means to be close to your family. What I say before, Mexican people, it’s all one, and you look for your family when something happens to you, like you have problems with your health, or something happened with you, you try to communicate your family to feel that somebody’s close to you to help you.”*

*“I don’t think it affects too much about communication.”*

*“I don’t know if that really makes a whole lot a difference.”*

The final presentation of results will include a comprehensive description of the dimensions cultural identity described by participants and perceived relationships between participants' and

their social network members' cultural identity and the participants' health information communication practices.

**Recall Bias.** In the journaling data obtained participants only noted communicating with social network members with whom had indicated communication during the interview. However, participants did note communicating with individuals outside the social network they did not note communicating with during the interview. These individuals were all members of the staff at the community clinic. Over the collective 20 days of journaling only one entry directly contradicted information presented in the interview: One participant had noted that he did not communicate the time and place of his doctor's appointment or information about diabetes self-care or self-management via the phone during the interview, but recorded this behavior in the journal. The final presentation of results will also include information about recall bias as relates to the reasons participants presented for communicating health information to members of the social network.

## Outcomes

In addition to the principal findings described above this dissertation informed the creation of three conceptual frameworks related to the design of culturally-informed consumer health IT, two of which have been published in the refereed literature. The third framework has been presented at an international conference and is being prepared for publication. The first framework conceptualizes the tensions between using engineering and cultural anthropological approaches to consumer health IT design (Valdez, 2010). The second framework conceptualizes how cultural factors may be integrated into the design of consumer health IT (Valdez et al., 2012). The third framework conceptualizes how cultural factors form a part of a larger cohort of factors (functional, technical, and affective) in the design of consumer health IT (Valdez and Valdez, 2012).

## Discussion

This study illustrates the complexity and diversity of participants' daily routines of health information communication in terms of the types of people, information, modes, and rationales provided. This diversity appears to stem from both cultural and other characteristics of participants' life circumstances. By providing a systematic and detailed description of these daily routines in aggregate, we hope to facilitate designers' ability to create consumer health IT that is responsive to this diversity.

It is clear that some aspects of participants' daily routines of health information communication may benefit from consumer health IT support. For example for participants that noted that they did not communicate health information to a social network member because they do not connect often, consumer health IT that automates transmission of information may serve to remove a barrier. For other participants who noted that they communicate health information to benefit others, consumer health IT may enhance this goal by providing access to additional information or tools that a user could send along with the original message. Conversely there may be other aspects of participants' daily routines of health information communication where the creativity of designers working closely with patients will be needed to determine if and how consumer health IT could enhance health information communication. For

example, some participants noted that they communicate to supernatural beings about their health. How consumer health IT may facilitate or enhance this experience is not as clear. Indeed, as the dissertation evolved it became clear that the goal of the dissertation could not be to provide prescriptive guidance for the design of consumer health IT but, rather, to provide a systematic and aggregate understanding of culturally diverse participants' routines to serve as a key input into the creative design process.

This study also provided evidence that the challenges with implementing a traditional targeted approach to incorporating cultural considerations into the design process arise not only because of the time and challenges of translating cultural beliefs into design (Valdez et al., 2012), but because of the unique and important ways that people experience culture and how they perceive it to shape their daily routines. For example, participants' conceptualization of their own cultural identity as related to multiple characteristics (not only nationality, ethnicity, and race, but also life experiences) and their affinity with specific aspects of certain cultural identities (e.g., language, physicality, ideology) underscored the challenges to creating culturally-informed consumer health IT that uses a targeted approach (mapping one technology to one cultural group). Furthermore participants' variability in noting a clear relationship between their cultural identities and their health information communication practices highlighted that a targeted approach may leave some users wondering what targeted technology to use. A tailored approach that focuses on designing for the range of behaviors across people holding diverse cultural identities may allow a user to choose the best fit in terms of functionality without having to necessarily make a conscious link between their cultural identity and their behavior. Use of tailored approaches has been suggested for health communication (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003) and may also be relevant for the design of consumer health IT.

## **Conclusions**

Given the growing importance of consumer health IT in facilitating patient health and health information management there is a need to expand culturally-informed interventions in health care to include consumer health IT. This study serves as an important step toward creating culturally-informed consumer health IT by systematically elucidating culturally diverse individuals' daily routines of health information communication and providing evidence to support a tailored versus targeted approach to accommodating cultural diversity in the design of consumer health IT. Future research should build upon this foundation by designing and evaluating a consumer health IT tool to support health information communication with social network members for a culturally diverse patient population. Future research should also empirically evaluate the advantages and disadvantages of tailored versus targeted approaches to the design of culturally-informed consumer health IT.

## **Significance and Implications**

This dissertation advances the concepts, methods, and technologies driving the reduction of racial and ethnic health care disparities and the design of appropriate consumer health IT. Although previous work has taken place at the intersection of culture and consumer health IT design, the concept of "culturally-informed health IT" is novel. The development of this concept is an essential step in developing a rich dialogue between the members of a multidisciplinary

community charged with developing this type of technology. This work advances methods used to reduce racial and ethnic health care disparities by advancing a health IT-based approach.

Furthermore, this work advances methods used to create culturally-informed health IT by furthering the integration of systems engineering and cultural anthropological approaches to elucidating the intersection between culture and technology design. Finally, application of the design considerations developed in this dissertation will ultimately advance the design of culturally-informed health IT, particularly as related to consumer health IT that supports communication between patients and members of their social network.

## References

1. Agency for Healthcare Research and Quality. (2011). *2010 National Healthcare Disparities Report* (AHRQ Publication No. 11-0005). Rockville, MD: U.S. Department of Health and Human Services.
2. Antonucci, T. C. & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology*, 42(5), 519-527.
3. Bureau of Labor Statistics. (2010). Career guide to industries, 2010-11 edition. Retrieved January 30, 2010, from <http://www.bls.gov/oco/cg/cgs035.htm#outlook>.
4. Blackhall, L. J., Frank, G., Murphy, S. T., Michel, V., Palmer, J. M., & Azen, S. P. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine*, 48, 1779-1789.
5. Brach, C. & Fraserirector, I. (2000). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*, 57(1), 181-217.
6. Centers for Disease Control and Prevention. (2011). *National Diabetes Fact Sheet: National Estimates and General Information on Diabetes and Prediabetes in the United States*. Atlanta, GA: U.S. Department of Health and Human Services.
7. Chatters, L.M., Taylor, R.J., Lincoln, K.D., & Schroeffer, T. (2002). Patterns of informal support from family and church members among African Americans. *Journal of Black Studies*, 33(1), 66-85.
8. Choi, B., Lee, I., & Kim, J. (2006). Culturability in mobile data services: A qualitative, study of the relationship between cultural characteristics and user-experience attributes. *International Journal of Human-Computer Interaction*, 20(3), 171-206.
9. Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage Publications.
10. Denzin, N. K. & Lincoln, Y. (2005). *The SAGE handbook of qualitative research*. Sage Publications.
11. Fadiman, A. (1997). *The Spirit Catches You and You Fall Down*. New York: Farrar, Straus, and Giroux.
12. Forsythe, D. E. (1996). New bottles, old wine: Hidden cultural assumptions in a computerized explanation system for migraine sufferers. *Medical Anthropology Quarterly*, 10(4), 551-574.
13. Gerth, H. H. & Mills, C. W. (Eds.). (1946). *From Max Weber: Essays in sociology*. New York: Free Press.
14. Gibbons, M.C., Wilson, R.F., Samal, L., Lehmann, C.U., Dickersin, K., Lehmann, H.P., et al. (2009). *Impact of consumer health informatics applications*. Evidence Report/Technology Assessment No. 188. AHRQ Publication No. 09(10)-E019. Rockville, MD: Agency for Healthcare Research and Quality.
15. Gustafson, D. H., Hawkins, R. P., Boberg, E. W., McTavish, F., Owens, B., Wise, M., et al. (2002). CHES: 10 years of research and development in consumer health informatics for broad populations, including the underserved. *International Journal of Medical Informatics*, 65(3), 169-177.
16. Hseih, H-F. & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277 – 1288.
17. Janzen, J. M. (1987). Therapy management: Concept, reality, process. *Medical Anthropology Quarterly, New Series*, 1(1), 68-84.

18. Jimison, H., Gorman, P., Woods, S., Nygren, P., Walker, M., Norris, S., et al. (2008). *Barriers and Drivers of Health Information Technology Use for the Elderly, Chronically Ill, and Underserved. Evidence Report/Technology* (AHRQ Publication No. 09-E004). Rockville, MD: Agency for Healthcare Research and Quality.
19. Kaplan, B., Brennan, P. F., Dowling, A. F., Friedman, C. P., & Peel, V. (2001). Toward an informatics research agenda: key people and organizational issues. *Journal of the American Medical Informatics Association*, 8(3), 235-241.
20. Keselman, A., Logan, R., Smith, C. A., Leroy, G., & Zeng-Treitler, Q. (2008). Developing informatics tools and strategies for consumer-centered health communication. *Journal of the American Medical Informatics Association*, 15(4), 473-483.
21. Kreuter, M. W., Lukwago, S. N., Bucholtz, D. C., Clark, E. M., & Sanders-Thompson, V. (2003). Achieving cultural appropriateness in health promotion programs: targeted and tailored approaches. *Health Education & Behavior*, 30(2), 133-146.
22. Lewis, D., Gunawardena, S., & El Saadawi, G. (2005). Caring connection: developing an Internet resource for family caregivers of children with cancer. *Computers, Informatics, Nursing*, 23(5), 265-274.
23. Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
24. Mahoney, D. F., Tarlow, B. J., & Jones, R. N. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *The Gerontologist*, 43(4), 556-567.
25. Moen, A. & Brennan, P. F. (2005). Health@home: The work of health information management in the household (HIMH): Implications for consumer health informatics (CHI) innovations. *Journal of the American Medical Informatics Association*, 12(6), 648-656.
26. Montague, E. & Perchonok, J. (2012). Health and wellness technology use by historically underserved health consumers. *Journal of Medical Internet Research*, 14(3), e78.
27. National Association for Home Care & Hospice. (2010). *Basic Statistics about Home Care*.
28. Pasmore, W. A. (1988). *Designing effective organizations: The sociotechnical systems perspective*. John Wiley & Sons.
29. Patton, M. Q. (2001). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage Publications.
30. Pratt, W., Unruh, K., Civan, A., & Skeels, M. (2006). Personal health information management. *Communications of the ACM*, 49(1), 51-56.
31. Senathirajah, Y., Kukafka, R., Guptarak, M., & Cohall, A. (2006, November). Health information seeking and technology use in Harlem - a pilot study using community-based participatory research. Paper presented at the annual symposium of the American Medical Informatics Association, Washington, D.C., 704-708.
32. Siegel, E. R., Wood, F. B., Dutcher, G. A., Ruffin, A., Logan, R. A., & Scott, J. C. (2005). Assessment of the National Library of Medicine's health disparities plan: a focus on Native American outreach. *Journal of the Medical Library Association*, 93(4 Suppl), S10-20.
33. Smedley, B. D., Stith, A. Y., Nelson, A. R. (2003). *Unequal treatment: Confronting racial and ethnic disparities in healthcare*. Washington, DC: National Academies Press.
34. Trochim, W. & Donnelly, J. (2006). *The Research Methods Knowledge Base*. Atomic Dog.
35. Valdez, R. S. (2010). Designing culturally-informed consumer health IT: An exploration and proposed integration of contrasting methodological perspectives. *Proceedings of the Human Factors and Ergonomics Society*, 718-722.
36. Valdez, R. S., Gibbons, M. C., Siegel, E. R., Kukafka, R., & Brennan, P. F. (2012). Designing consumer health IT to enhance usability among different racial and ethnic groups in the United States. *Health and Technology*. doi: 10.1007/s12553-012-0031-6.
37. Valdez, R. S., Patton, T., & Brennan, P. F. (2010). To talk or not to talk: Exploring culturally diverse patients' health information communication choices. *Proceedings of the American Medical Informatics Association*, 812-816.
38. Valdez, R. S., & Valdez, J. A. (2012). *Design heuristics for health IT: functional, technical, affective, and cultural considerations*. Presented at the Applied Human Factors and Ergonomics Conference, San Francisco, CA.
39. Zayas-Caban, T. (2002). *Introducing information technology into the home: conducting a home assessment*. Paper presented at the annual symposium of the American Medical Informatics Association, San Antonio, TX, 924-928.

# List of Publications and Products

## Publications

Valdez RS, Gibbons MC, Siegel ER, et al. (2012). Adapting consumer health IT to enhance usability among different racial and ethnic groups within the United States. *Health Technol.* doi: 10.1007/s12553-012-0031-6

Valdez RS, Patton T, Brennan, PF. (2010). To talk or not to talk: Exploring culturally diverse patients' health

information communication choices. *Proceedings of the American Medical Informatics Association 2010*: 812-16.

Valdez RS. (2010). Designing culturally-informed consumer health IT: An exploration and proposed integration of contrasting methodological perspectives. *Proceedings of the Human Factors and Ergonomics Society 2010*: 718-22.

## Invited Talks

Valdez RS. (2011). Introduction to culturally-informed design. University of Wisconsin-Madison Industrial and Systems Engineering 961: Research and Design in Home Care.

Valdez RS, Valdez JA. (2012). Design heuristics for health IT: functional, technical, affective, and cultural considerations. Applied Human Factors and Ergonomics Conference.