**Title:** Informing Consumer Health IT Design: How Patients Use Social Networking Sites

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## Abstract

Purpose: The objective of this study was to develop patient-centered desig guidance for consumer health IT based on an understanding of patients' existing use of Facebook for communicating health information with their social network members.

Scope: As healthcare shifts to home and community settings, consumer health IT is increasingly promoted as a means of supporting patient self-management. Understanding how patients currently engage with existing IT solutions for the essential, yet burdensome, task of health information communication can guide consumer health IT design.

Methods: This study employed a sequential, mixed methods approach that consisted of three data collection phases: 1) qualitative exploration, 2) survey pilot, and 3 quantitative elucidation by means of a sample survey. Qualitative content analysis and descriptive and clustering statistical methods were used for data analysis.

Results: Given that the findings demonstrated seven unique approaches to communicating health information on and off Facebook, there is a need to design consumer health IT solutions that are versatile and responsive to this range of communication practices. This design approach is further necessitated by the fact that demographically different types of patients segment into each health information communication approach.

Key Words: Facebook, health information, communication, consumer health IT, engineering design.

**Purpose**

The broad, long-term objective of this work is to improve the quality of health care by creating consumer health IT that is aligned with the needs and preferences of diverse patient subpopulations. The objective of this specific study was to develop patient-centered design guidance for consumer health IT that supports health information communication with members of patients' social networks (e.g., family members, friends, online acquaintances) based on an understanding of patients' existing use of a popular online social networking site, Facebook, for health information communication.

This objective was accomplished through two specific aims:

*Specific Aim 1*: To generate general design guidance for consumer health IT based on an explication of the ways in which Type 2 diabetes patients engaged with Facebook leverage this technology to support health information communication with members of the social network.

*Specific Aim 2*: To generate design guidance for unique segments of the user population based on an understanding of how Type 2 diabetes patients engaged with Facebook cluster into different patterns or styles of health information communication with members of the social network.

**Scope**

*Background:* As health care shifts to home- and community-based settings (1, 2), patients must increasingly assume responsibility for and actively engage in self-care and self-management (3, 4). Multiple forms of consumer health IT, electronic technologies use to support lay-people with self-care and self-management, are being developed to support patients in this new role (5, 6). Unfortunately, the design of health IT often proceeds without an understanding of how the tasks of health management are performed by the intended users. The result is that designers create and expect users to embrace systems that are designed for a non-existent, or imagined, world (7). Technologies that are not aligned with users' needs and preferences increase physical and psychological burden and decrease users' ability to appropriately use the technology, raising the potential for unintended consequences (8-13). As a result, it is essential to develop design guidance for consumer health IT based on an in-depth understanding of patients' actual worlds.

*Context:* The study focused on understanding how patients currently engage with the online social networking site, Facebook, for health information communication. We readily acknowledge that Facebook is not a consumer health IT; however, there is growing evidence that Facebook has been adopted by patients for health management, including health information communication (14-18), facilitating insight into patients' existing approaches to this task. Few consumer health information technologies include functionality to support this form of

communication despite evidence that communicating health information with members of their social networks is essential but burdensome for patients (19). Design guidance that has been generated for this form of communication has primarily focused on assessing patients' offline health information communication (20-22), and therefore does not account for the ways that patients leverage existing online tools for communicating health information with members of the social network. Furthermore, no design guidance for this task has been generated which defines the needs and preferences of unique segments of the patient population. This mixed methods study innovatively merged the disciplinary traditions of human factors engineering, biomedical informatics, and sociology to develop design guidance for consumer health IT.

This study focused on assessing the ways i  which Type 2 diabetes patients engaged with Facebook leveraged this technology for communicating health information with members of their social network. When attempting to draw design guidance, designers focus on assessing domains that exemplify the characteristics of interest. Type 2 diabetes patients were selected for this study because they have a condition that requires daily monitoring and life-style choices and because they tend to rely on communication with others. Thus, Type 2 diabetes patients are likely to engag in the health information management task of interest, health information communication with members of the social network (23).

The study consisted of three phases. Phase one consisted of a qualitative exploration of Facebook users' health information communication work systems. Phase two consisted of developing and piloting a survey instrument grounded in phase one results. Phase three consisted of a large sample survey and synthesis of qualitative and quantitative components into design guidance.

*Settings:*

Phase one: Recruitment took place directly through Facebook. To the extent possible, all interviews were conducted over Skype, an application that facilitates Internet-based voice and video calls. When Skype calls were not feasible or preferred by participants, interviews took place over the phone.

Phase two: Recruitment took place via Facebook. All interaction between the researchers and the study participants for this phase occurred via Facebook, Blackboard Collaborate, and phone.

Phase three: All recruitment for this phase took place via a commercial survey access panel provided by Survey Sampling International (SSI). Interaction with study participants took place via Qualtrics.

*Participants:*

Phase one: Facebook users who were over the age of 18, resided in or were citizens

of the United States, spoke English, and had a diagnosis consistent with Type 2 diabetes were be considered eligible for this phase of the study. Twenty-five individuals participated in phase one with about equal gender distribution. The sample included individuals from all of AHRQ's racial and ethnic categories of interest except Native Hawaiian/Pacific Islander. However, we were unable to recruit as many individuals identifying as American Indian/Alaska Native and Asian as we had targeted.

Phase two: Facebook users who were over the age of 18, resided in or were citizens of the United States, spoke, read, and wrote English, and had a diagnosis consistent with Type 2 diabetes were considered eligible for this phase of the study. Individuals who participated in phase one were not considered eligible for this phase. Thirteen participants took part in phase two. Recruitment ended after theoretical saturation was reached.

Phase three: Eligibility criteria remained the same as phase two. Individuals who participated in any previous study phase were not considered eligible for phase three. Seven hundred participants took part in phase three. Six hundred and fifty participants remained after applying measures (e.g., eliminating "speeders," participants who skipped multiple questions) to preserve data integrity. Over half of the sample consisted of racial and ethnic minority groups of interest to AHRQ.

*Incidence and Prevalence:* Given that the population of interest for this study was individuals with Type   diabetes engaged with Facebook, incidence and prevalence numbers are not readily available. Estimates of these rates, however, may be made under the assumption that a diagnosis of Type 2 diabetes is independent of the decision to engage with Facebook. Estimates of prevalence were reported under this assumption in our 2014 publication in the *Journal of Medical Internet Research* (24)*.*

**Methods**

*Study Design:* This study employed a sequential, mixed methods approach to empirically assess and draw design guidance for consumer health IT from the health information communication of work systems of patients with Type 2 diabetes engaged with Facebook. The study consisted of three data collection phases: 1) qualitative exploration, 2) survey pilot, and 3) quantitative elucidation by means of a sample survey. All data were self-reported and collected retrospectively. Analysis of qualitative data was informed by qualitative content analysis methods (25-29) but modified to meet the purpose of guiding design rather than building theory. Analysis of quantitative data was guided by descriptive methods and clustering methods suitable for use in market segmentation. Results of the qualitative and quantitative analysis were further synthesized into design guidance by methods of persona development (30-34).

*Data Sources/Collection:* A full description of how we set up our Facebook group as a platform for recruitment (phase one and phase two) may be found in our 2014

publication in the *Journal of Medical Internet Research* (24).

Phase One Data Collection: Maximum variance sampling was based first on the 5 racial and 2 ethnic groups of primary interest to AHRQ and then on other demographic characteristics, such as gender, socioeconomic status, health status, and geographic location. Data were collected through Skype or telephone interviews. Interviewees were first asked general questions about their social networks and about how they use Facebook. They were then asked systematically about components of their health information communication work system. In this study, the health information communication work system was operationalized based on the human factors literature (35) as to whom and why health information is communicated (social subsystem), what health information is communicated and how (technical subsystem), and the economic, political, cultural, and health status contexts in which this communication occurs (external environment). These questions probed health information communication practices both on and off Facebook.

Phase Two Data Collection: As with phase one, maximum variance sampling was based first on the 5 racial and 2 ethnic groups of primary interest to AHRQ and then on other demographic characteristics, such as gender, socioeconomic status, health status, and geographic location. All participants were sent a link to the survey instrument (developed based on phase one data and data from the PI's previously funded AHRQ dissertation grant) in Qualtrics. Participants were asked to complete the survey and note any difficulties or uncertainties they encountered (36). Participants partook in focus groups that were facilitated using Blackboard Collaborate and telephone. Five focus groups (group oral debriefings), each with two to four individuals, were conducted. Prior to speaking with participants, we reviewed participants' completed surveys for any signs of trouble, such as missing data. In the focus group, the survey instrument was reviewed page-by-page and question-by-question to solicit comments and revisions from phase two participants.

Phase Three Data Collection: Given that we were unable to recruit sufficient numbers of participants through our Facebook group, a commercial survey access panel (provided by SSI) was used for phase three recruitment. We oversampled participants identifying as racial and ethnic minorities to enable subgroup analysis. Individuals recruited through SSI were provided with a link to the survey on Qualtrics.

*Interventions:* This was not an interventional study.

*Measures:* The survey instrument consisted of eight sections focusing on: 1) eligibility criteria, 2) general Facebook use, 3) health information communication on Facebook, 4) health information communication off Facebook, 5) hypothetical health information communication scenarios, 6) privacy, 7) contextual factors, and 8) demographics. The majority of the measures used were developed inductively

based on the findings from two qualitative studies (phase one and PI's previous work). Some of the demographic questions were taken from other instruments including those used by the U.S. Census Bureau and UVa Center for Survey Research.

*Limitations:* This study was subject to three primary limitations. First, the data collection approaches were subject to recall bias. To mitigate this effect, participants in phase one were asked to review their Facebook activity prior to study participation and reference to Facebook activity was allowed in phases two and three. Second, qualitative analysis and interpretation was susceptible to the assumptions and biases of the researchers. To mitigate this effect, two researchers were engaged in qualitative analysis and met regularly to ensure consistency in coding. Finally, the findings may not be generalizable to all patients because the study focused on one chronic health condition and one specific social networking site. However, given that Type 2 diabetes may be considered a prototypical health condition (a chronic condition affecting a growing number of individuals) and the dominance of Facebook, we believe that the design guidance drawn from the study will represent a meaningful starting point for designers.

## Results

*Principal Findings:*

Phase One: Phase one findings provided insight into the range of individuals with whom participants communicated health information, how this information was communicated on and off Facebook, the types of health information communicated, and the rationales for this communication. Participants communicated health information with the range of individuals documented by Valdez and Brennan (2015) (23) as well as with people they met through Facebook, people they met online but not through Facebook, and people with whom they have never interacted but had requested to be a Facebook friend. Information was communicated through a wide range of public and private communication modes on Facebook, including timelines, groups, and private messages. In addition to posting and commenting, participants communicated health information through Facebook specific mechanisms such as tagging and checking-in. Participants communicated health information that spanned the clinical (diagnoses, medications, test results) and self-generated (symptoms, side-effects, observations about one's own health). They also communicated information related to the larger health system (experiences with care providers, billing and insurance issues) as well as requests for emotional, spiritual, instrumental, and informational support. Rationales for communicating or not communicating on Facebook were related to the themes presented by Valdez and Brennan (2015) (23) as well as the characteristics of Facebook (e.g., privacy on Facebook and the number and type of people that can be reached on Facebook).

Phase one findings also provided insight into other dimensions of health information communication on Facebook, including considerations of privacy. Participants expressed their rationales for changing their default privacy settings.

These rationales included limiting their contact with certain individuals, avoiding identity theft, and having had their account set up by someone else. Participants also shared other ways in which they protected their privacy on Facebook. These included using a different name, running anti-spyware, prohibiting other applications from posting to their account, and not sharing personal or private information.

Phase two: Phase two focused on changes that needed to be made to the surve prior to the full scale launch in phase three. Key findings related to necessary changes included reordering the questions, rewording some questions, and adding/re-wording some answer choices. Participants noted that the survey instrument would be easier to follow if the questions were grouped by whether or not they pertained to on or off Facebook communication, rather than by work system element. The survey was re-ordered to follow the recommended flow. Another key finding was that participants viewed the group component of Facebook as a space distinct from other components of Facebook (communication with peers experiencing the same condition versus communication with social network members). Answer choices were expanded for some questions to reflect this distinction and additional questions were added to explore this distinction. Some participants noted that the survey was too lengthy. To address this issue, we created two versions of the survey enabling us to obtain answers to all relevant research questions.

Phase three: Phase three analysis focused on clustering participants into groups by their approach to health information communication on and off Facebook. This analysis yielded seven distinct approaches to health information communication differentiated by general practices of Facebook use, health information communication practices on Facebook, and health information communication practices off Facebook. Phase three analysis also focused on determining differences between the types of individuals following each health information communication approach. Approaches were differentiated in terms of multiple characteristics including age, health insurance status, employment status, marital status, and general health status.

*Outcomes:* Beyond the results reported above, outcomes of this study include a protocol for recruiting individuals on Facebook to participate in consumer health IT related studies and a survey instrument focused on health information communication practices.

*Discussion:* The intent of the proposed study was to complement and build upon the existing consumer health IT design literature related to how patients communicate health information to members of their social network. Previous studies (20-23) seeking to understand this phenomenon have been largely qualitative and focused on communication not mediated by information technology. This study confirmed previous findings related to with whom, how, why, and what patients communicate health information. Given its unique focus on Facebook, however, it also extended

these findings by identifying new categories of individuals with whom health information is communicated, as well as new mechanisms and rationales for this communication.

Few previous studies of health information communication practices have engaged participants identifying as racial and ethnic minorities. This is problematic given evidence that racial and ethnic minorities sometimes have information technology use practices that differ from those of the majority population (37). The current study successfully engaged racial and ethnic minorities, particularly in phases one and three. This enables some generalizability of our results across demographic groups. However, it is important to note that despite recruitment methods on Facebook (phases one and two) that specifically targeted racial and ethnic minority groups, we still recruited fewer individuals identifying with these groups than we had aimed. Further work is needed within the consumer health IT community to find ways to engage racial and ethnic minorities in our research practices.

*Conclusions, Significance, and Implications:* This study contributed to our knowledge of how patients engage in the burdensome, yet essential, task of health information communication. Such knowledge is imperative to creating consumer health IT solutions that are grounded in empirical knowledge of how patients perform this aspect of health management in their everyday life.  Given that the finding demonstrated seven unique approaches to communicating health information on and off Facebook, there is a need to design consumer health IT solutions that are versatile and responsive to this range of communication practices. This design approach is further necessitated by the fact that demographically different types of patients segment into each health information communication approach. Creating a design solution that is only responsive to a few segments will result in the unintended consequence of excluding certain types of individuals from finding technologies that fit their everyday lives.

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**List of Publications and Products**
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**In Preparation**

1. Valdez RS, Guterbock TM, Fitzgibbon K, Williams I, Menefee H, Wellbeloved-Stone C, Bears J. Health information communication profiles. To be submitted to the Journal of the American Medical Informatics Association.
2. Menefee H, Thompson MJ, Guterbock TM, Williams I, Valdez RS (corresponding author). How health information is communicated on Facebook: Mechanisms and rationales. To be submitted to the Journal of Medical Internet Research.
3. Guterbock TM, Valdez RS, Williams I, Menefee H. What would you share? A factorial survey experiment on health information communication. To be submitted to the Journal of Health and Social Behavior.