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Using design science and artificial intelligence to improve health communication: ChronologyMD case example

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ABSTRACT

Objective: This paper describes how design science theory and methods and use of artificial intelligence (AI) components can improve the effectiveness of health communication.
Methods: We identified key weaknesses of traditional health communication and features of more successful eHealth/AI communication. We examined characteristics of the design science paradigm and the value of its user-centered methods to develop eHealth/AI communication. We analyzed a case example of the participatory design of AI components in the ChronologyMD project intended to improve management of Crohn's disease.
Results: eHealth/AI communication created with user-centered design shows improved relevance to users' needs for personalized, timely and interactive communication and is associated with better health outcomes than traditional approaches. Participatory design was essential to develop ChronologyMD system architecture and software applications that benefitted patients.
Conclusion: AI components can greatly improve eHealth/AI communication, if designed with the intended audiences. Design science theory and its iterative, participatory methods linked with traditional health communication theory and methods can create effective AI health communication.
Practice implications: eHealth/AI communication researchers, developers and practitioners can benefit from a holistic approach that draws from theory and methods in both design sciences and also human and social sciences to create successful AI health communication.

1. Introduction

Policymakers worldwide are focused on containing rising healthcare costs while achieving improved health outcomes. In the US for example, estimated health care costs for 2011 were $2.7 trillion (17.9 percent of the Gross Domestic Product) [1]. As populations age in industrialized countries and the demand for healthcare increases faster than economic growth, policymakers are searching for cost effective ways to prevent and manage disease. Research from the World Health Organization [2,3] indicates that much of the "global burden of disease" is attributable to preventable behavioral factors, such as diet, exercise, blood pressure and blood glucose management. However, it has been frustratingly difficult to engage consumers to make changes that could significantly improve population health [4]. A US Institute of Medicine report [5] concluded that behavioral and social interventions offer great promise, but "their potential to improve the public's health has been relatively poorly tapped." Creating more effective health communication approaches is essential to educate and motivate people to adopt healthier behaviors.

1.1. Challenges to improve health communication

Health communication can be defined as "the central social process in the provision of health care delivery and the promotion of public health" [6]. Its goal is to empower people with evidence-based information about living a healthy life. Traditional health communication has tended to focus on generic, expert, one-way messages ("exercise every day") that are not adequately relevant to people's specific information preferences or life situations [7–10]. As a result, health communication interventions have often shown disappointing outcomes Researchers and practitioners have recommended that health communication be aligned with the

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user's literacy, language, culture, and social contexts and be accessible, understandable, interactive and motivating. Further, to have an impact at the population level, it must reach many people, affordably.

Transforming health communication to meet these many criteria has been challenging because: communication developers do not usually intensely involve the intended beneficiaries in the design process, and the resulting communication does not match users' needs; until the late 1900s, it was impossible to "personalize" mass media for individuals affordably; and theoretical and methodological guidance in this field needs to be strengthened.

1.2. The promise of eHealth and artificial intelligence technologies

eHealth communication––that mediated by the Internet or other digital media––offers unprecedented opportunities to overcome historic communication weaknesses of and extend improved communication to many people at low cost. It includes an ever-growing array of features that educators can use to match information from large databases to an individual's socio-demographic traits or preferences. Voice and text messages, online health communities, biometric devices, games, and other strategies are making it possible for people to access highly personal, socially-contextual and interactive health information.

Artificial intelligence (AI) features are central to many eHealth technologies. AI was first defined by McCarthy [11] as "the science and engineering of intelligent machines, especially computer programs" and as the "computational part of the ability to achieve goals in the world" [12]. AI seeks to mimic or enhance human intelligence capacities and has enabled the development of highly sophisticated communication, such as easy-to-use human-computer interfaces, SMS text reminders customized for individual patients, sleep, exercise and blood glucose monitors, and avatars that act as health coaches. eHealth communication using AI features is revolutionary: for the first time in history people can access personalized tools to understand and manage their health. Three decades of research show overall improved outcomes for eHealth interventions among diverse populations, across many health conditions, [4,10,13].

Research increasingly shows positive outcomes for eHealth strategies that include AI features. For example, the US Veterans Health Administration's National Care Coordination/Telehealth program uses a smart monitoring and communication system to electronically track and evaluate the daily health needs of veterans who are receiving chemotherapy and recuperating at home [14,15]. This home-based system identifies when veterans encounter health challenges and automatically triggers support systems to provide information and health services. These responses help veterans (and their caregivers) make informed health decisions [16]. Evaluations have shown that this program has improved veterans' personal control of their health, their health outcomes, and reduced health care costs [16].

However, not all eHealth interventions––even those with powerful AI features––have been effective, and most show modest results. Improved interventions will need to be more theoretically guided, interactive, culturally and psychologically engaging, and connected to people's social contexts and networks. Incorporating well-designed AI components will help eHealth communication resonate with the way diverse people use information in their lives.

1.3. Participatory design to improve eHealth/AI communication

Intensely involving intended users in its design is an important way to Improve eHealth communication [10,17,18]. Participatory, or user-centered design has been defined as "an approach to the assessment, design and development of technological and organizational systems that places a premium on the active involvement of...potential or current users of the system in design and decision-making processes" [19]. Participatory design techniques originated and are commonly used in architecture, engineering, computer science and other socio-technical fields [19,20]. Despite several decades of research demonstrating that participatory design can significantly improve eHealth communication [5,20,21], robust participatory design processes are still not widespread.

Fortunately, a major shift towards participatory design has occurred with the incorporation of AI components in eHealth communication. The computer engineers and information scientists involved in this communication routinely use participatory methods to test hardware and software with AI features. However, testing for usability is not sufficient to ensure that health content is understandable, engaging and motivating for diverse audiences. This gap may well explain why eHealth/AI communication has only shown partial success to date. For example, in 2011 a pioneering conference was held at Stanford University (California, USA) on "Artificial Intelligence and Health Communication" [22]. Participants presented fascinating eHealth projects that featured cutting edge AI features such as avatars for virtual, interactive health coaching. Although the systems were tested for usability, developers commented that many subtleties were missed, such as the cultural relevance and psychological resonance of the avatars for intended users. These issues interfered with user engagement and decreased expected behavioral outcomes. For better results, eHealth/AI developers should work with scientists from health, psychology and other social science fields to create more nuanced participatory design processes with users. The field of "Design Science" offers a promising avenue to link these collaborators synergistically.

2. Guidance from design science

2.1. Philosophical foundation of design science

Design science is the scientific study of design, introduced in 1963 [23]. Design sciences are considered one of three major categories of systematic study of knowledge (epistemology) that also include natural sciences and human sciences [24]. Researchers in natural sciences (such as physics, chemistry, etc.) seek law-based explanations about phenomena in the physical world, assuming that knowledge is discoverable and generalizable to multiple settings. Natural science inquiry dominated scientific thinking until the mid-20th century [25,26].

Human (or "interpretive") sciences are concerned with understanding "human and historical life" [27] and include social sciences and the humanities. This research perspective emerged during the last century and acknowledges that human actions are not as predictable as natural sciences laws, and phenomena should be studied from many perspectives in many settings [28,29].

Design sciences, or "sciences of the artificial" are concerned "not with how things are, but with how they might be" [26]. Researchers in design sciences study human-created (artificial) objects and phenomena designed to solve problems and meet goals. These creations ("artifacts") can be symbols, material objects, activities, services, and learning or living environments [30]. Design sciences include architecture, information systems, engineering, and others concerned with design processes [26]. Design sciences pose special research challenges related to the so-called "wicked" nature of problems [30]. Because problem understanding and problem solving happen concurrently, solution**s** should not be selected too early and there is no end to identifying problems and refining designs. Design science researchers study not only the impact of the artifact in the world, but also the incremental process of building it.

From an epistemological point of view, design sciences differ notably from the natural and human sciences [12,26,31,32]. The goal of design science research is the creation and utility of the solution, whereas in natural science research it is universal truth and prediction, and in human interpretive sciences, understanding phenomena in specific situations. In both the natural and human sciences, researchers focus on developing and testing theories. In design sciences, researchers focus on building and evaluating artifacts. One area in which human sciences have goals similar to those in design sciences is in social science "action research" intended to develop interventions iteratively [31,33].

Design science research methods also differ from those used in the other research paradigms. In design science, researchers study the "build and evaluate loop" [34] by using iterative, participatory methods (such as usability, simulations, etc.) to understand problems and develop solutions concurrently. Natural science methods are primarily observational, quantitative and statistical, and human science methods are often more qualitative and researcher-participative. Participatory action research methods in human sciences [33] share some similarities with those in design sciences [31].

2.2. Linking design science, health communication and AI

Health communication intersects multiple health, social science and technological fields. Historically, health communication research has been more rooted in the natural and human sciences than in design sciences. Health communication studies, with notable exceptions like those in action research, are typically "theory-driven" (define a priori hypotheses to test). We propose that eHealth/AI communication developers and researchers would greatly benefit from linking design science theory and methods to those they traditionally use. It is especially critical to design and test highly sophisticated AI features that are intended to mimic or enhance human reasoning and behavior. This challenge goes far beyond eHealth communication that is simply personalized for a recipient's characteristics to interventions in which recipients interact with information to solve higher-order problems.

Scholars in information science [34] have begun this important work by advocating for "synergistic efforts between behavioral science and design science researchers" [12]. This approach would combine an increased use of participatory design with grounding in health and behavioral science theory. AI design activities in eHealth communication are a strong way to catalyze linkages between experts in these two fields. In the next section, we describe a case study of an eHealth/AI project created and tested through such a partnership.

3. Case: the ChronologyMD project

3.1. Project background

Crohn's disease is a serious, incurable, recurring, inflammatory bowel disease (IBD) that affects more than 600,000 people in the US, with an estimated $15 billion (extrapolated from Kappelman et al., 2008) in direct societal costs [35]. Patients who are relapsing can suffer painful, debilitating symptoms, require expensive treatments, prolonged hospitalizations, and surgical operations [36]. When Crohn's flares up, patients may be unable to work [37] or keep social connections, and often suffer from depression. The standard of treatment is specific to each patient's symptoms and disease severity. Therefore, communication between patient and physician is critical to achieve and maintain remission and fight relapses quickly. However, it is difficult for patients to keep track of many, complex symptoms accurately and for physicians to make patient-informed treatment decisions. Addressing these challenges effectively requires an AI approach. To help patients and their healthcare providers better manage this disease, we developed ChronologyMD, a pilot eHealth/AI intervention.

The Robert Wood Johnson Foundation's Project Health Design (PHD) [38], a groundbreaking program to support innovation in personal health information technology, funded this project. PHD projects have used AI features to help participants identify and use "observations of daily living" (ODLs) [39] to improve health decision-making. ODLs are feelings, thoughts, attitudes and behaviors that can provide individuals with cues about their health.

3.2. Project description

Research objectives. This project was proposed by a patient with Crohn's disease who learned that by continuously monitoring his symptoms, he was more informed when meeting with providers, and a better partner in his treatment. Our primary research questions were: (1) Can we identify ODLs for Crohn's that would be personally relevant to patients and clinically important for providers? (2) Will patients use an eHealth/AI system to collect the ODLs and share them with their providers? and (3) Does tracking and sharing ODLs have an impact on patients' behaviors and on clinical decision-making?

Theoretical framework. The study was guided by theory in design science and in public health action research.

Study design. We used mixed quantitative and qualitative methods drawn from informatics and health and social science disciplines.

Research participants. We recruited a convenience sample of 30 patients with moderate to severe Crohn's from a University of California, San Francisco IBD clinic. Because most patients were already familiar with mobile phone applications, we recruited an intentional subset of patients without such skills. Healthcare providers included three gastroenterologists and one nurse practitioner. The University of California IRB approved the research protocol.

eHealth technology. The ChronologyMD team worked with the patients and providers to develop two mobile applications (Fig. 1) to help patients create visually aided narratives of their condition and responses to treatment. The ChronologyMD system incorporates both AI and non-AI components. Using iPads ™ and other AI mobile devices, patients can use the Chronology app to self-track ODLs (pain, energy, stress, medication taking, etc.); enter clinical data (blood tests, etc.); and automatically upload weight using AI devices: a Withings ™ scale, and sleep and exercise from a Fitbit ™ body monitor. The Crohnograph AI app enabled patients to view time trends for tracked ODLs and other data, explore possible associations among them, and show the data visualizations to their provider. The providers could document information from the visualization and conversations in clinical notes.

Design and evaluation methods. In keeping with design science guidance, we integrated problem identification, technology design and evaluation as an iterative, incremental "loop" [34] (see Section 3.3). Methods included focus groups, training observations, contextual inquiry/usability testing, personal interviews, helpline calls, phone and online surveys and records of patient data input into the system. Question domains covered ODLs, health status awareness, quality of clinical appointments, patient-provider collaboration, medication and appointment adherence, other behavior changes, interest in mobile health, and patient demographics. Some questions were iteratively revised as new issues or perspectives emerged.

Outcome measures included tracked (objective) input of patient data, patient- and provider-perceived acceptability and value of the system, reported behavior changes and recommendations for

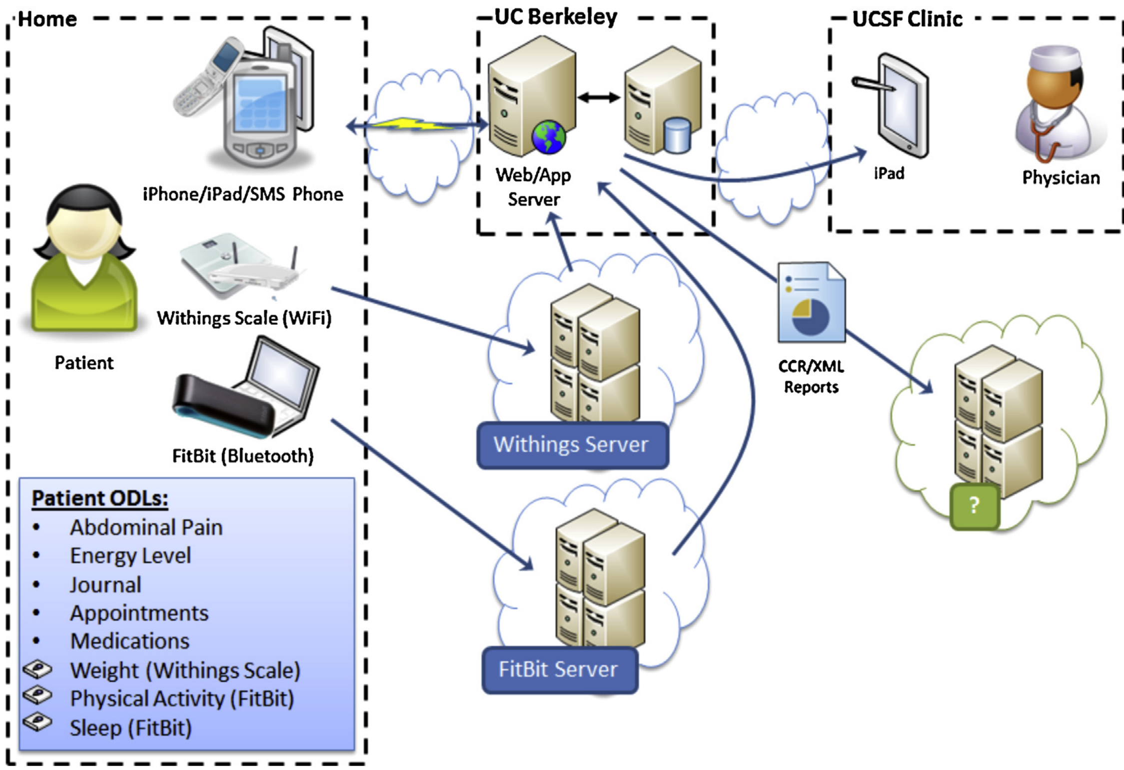

Fig. 1. ChronologyMD architecture.

improvement. We conducted online surveys using Qualtrics ™ software. We used thematic analysis to analyze focus group data, open-ended comments from interviews and online surveys. Analyses were primarily descriptive, rather than inferential, given our small sample.

3.3. Participatory design and AI components

We used the participatory methods described above to develop and refine all aspects of this study, especially complex AI features. The following timeline illustrates the interplay of methods and incremental decisions:

- November 2010-January 2011: We set up a project team with experts from health sciences, social sciences, and informatics. Our colleague with the original idea for the study and the primary application developer were both Crohn's patients and provided invaluable expertise to select the original ODLs and design prototype applications.
- January–March 2011: We conducted focus groups with patients and providers who reviewed draft ODLs constructed from literature about Crohn's. Their recommendations resulted in notable changes to the types and entry of ODLs on the app.
- March–June 2011: We conducted interviews with patients and providers to select devices and procedures to collect and use data easily. They selected the iPad ™ as the key device, with options to use other mobile devices, and made important recommendations about AI user interface design.
- September 2011: We launched the first system version, conducted in-person and online trainings, usability tests and interviews with patients. When patients asked for a way to enter new ODLs on the app, we added that feature. We established a helpline for ongoing support and feedback.
- September 2011–May 2012: We conducted online surveys to identify problems, recommend refinements, and obtain evaluation data. Patient feedback resulted in further training, app revisions, and changes to evaluation questions.
- June 2012: We conducted final focus groups with patients and providers to assess usage of and satisfaction with the system, its value in patient health management and clinical decision making, and suggestions for future system revisions.

Participatory design of system features. Participatory processes were essential to develop and refine the system's features as shown in Table 1 examples. ChronologyMD can be considered an "applied AI expert system," with both AI and non-AI components. For example, AI components include certain iPad ™ features, connected health monitoring devices, and data visualization displays. Other features of the system used non-AI algorithms such as those that captured ODLs and sent text reminders. Participatory design was important to develop and refine all components. Intensive user input was required to design the AI user interfaces so that patients could personalize and track data input and display, including from the biometric devices. Patients wanted to create new ODLs, customize their input, and easily view associations among their data.

3.4. Key study findings

Although this paper focuses on the design process and is not intended to provide detailed results, we highlight key findings here. Patients showed high usage of the ChronologyMD system and inputted over 28,000 ODLs during an 8-month period. The percentage of patients who tracked ODL-type symptoms and behaviors increased from 40% before the system launch to 92% after 8 months. Seventy-six percent of the patients reported that the system had high value to them and that they wanted to continue using it.

Patients reported many positive behavior changes from using the system, Automatic text reminders helped patients schedule

Table 1
Participatory design of ChronologyMD components.

Components and design challenges	Participatory methods used	Result of participatory input	Comments about components
System Architecture – Hardware Original plan was to use mobile phones, but data entry/visualization and cost were all challenges	• Patient and provider focus groups • Patient interviews • Contextual inquiry/ usability testing	iPads ™ used by patients to enter and view ODL data; iPads ™ used by providers to view data	iPad/iPhone ™ architecture created to collect and manage ODL & medication data
App Design Needed to define ODLs	• Patient and provider focus groups • Patient interviews • Training observations • Patient helpline	ODLs: pain, stress, energy, activity level, sleep, weight, medications, lab test results, journal (as catch-all ODL)	ODL capture engines written by ODL type & measurement requirements (Likert scale or other units)
App Design–Medications Patients want additional dosage and medication choices, and to enter medication adherence data retrospectively.	• Patient interviews • Patient helpline • Patient focus group • Usability testing	To be added in future iteration of technology	App now uses med mgmt data from FirstDataBank repository of prescription & OTC drugs and interactions; patients want to enter drug history.
App Design– Automatic Collection Patients wanted automatic collection of weight, sleep and exercise data.	• Patient interviews • Patient helpline • Patient focus group • Usability testing	Auto collection through the Withings scale and Fitbit monitor	Weight data collected when patients step on the Withings™ scale; activity and sleep data collected when patients wear Fitbit™ monitor.
App Design–SMS Text Patients wanted SMS text reminders to input certain ODLs, and take medications.	• Patient interviews • Usability testing • Auto-ethnography	SMS text ODL reminders for meds, pain, stress, energy, & journal with SMS text response	Auto SMS processing engine created with reminders/questions. Example: Patients can have daily text sent to rank & record pain on 1–5 scale.
App Design – Infusion Reminders Patients wanted reminders to make infusion appointments.	• Patient and provider focus groups • Patient and provider interviews • Auto-ethnography	Infusion reminders via SMS text	Patients said reminders improved scheduling their appointments
App Design – Data Visualization Patients wanted continuous display vs. bar graphs, and wanted smaller units of time.	• Patient and provider focus groups • Patient interviews • Usability testing	Graph using colored lines and timeline showing detail of hour/day	Visualization engine created for easy data views and parallel display of like items (e.g. Likert scale data) so patients & providers can explore correlations.

intravenous infusions on time, remember to enter ODLs, and improve medication adherence. The sleep and exercise sensors and the data display––important AI features––helped patients make sophisticated associations among health factors and change behavior accordingly. For example, patients noticed that when they got more sleep and exercise, they reduced stress and needed fewer narcotic drugs to manage pain. One patient commented:

"I am finding this very useful. I have used this data with other doctors outside of the study, and as a result of sharing this data with other docs, I have changed the meds that I was on. As a result of this med change, my quality of life has gone way up, my weight has gone from 112 to 119 lbs, and I am not vomiting daily. We have been looking at stress, pain and drugs based on this data. I have been off IV drugs since we started looking at this data, and I nearly died from them last year. I am now managing my pain via acupuncture, diet, and yoga, and I feel so much better than I did on the hardcore drugs. Besides, my doctor just told me that my blood levels are the best that they have been in years."

Another patient used his personal data tracking to manage pain and energy levels so that he could exercise with his son, rather than have to stay home. This patient had not been familiar with using mobile apps before the study. Patients had many recommendations to improve the system.

Providers considered the system of primary benefit to the patient, and observed that patients were significantly better prepared when they came for clinical visits, which improved the quality of the treatment decisions. Providers recommended that an algorithm be added to the app to calculate scores for validated indices (like the Crohn's Activity Index) to be entered into the electronic health record. Providers felt that this and other enhancements could help "change the standard of care" for Crohn's patients.

4. Discussion and conclusion

4.1. Discussion

eHealth communication shows great potential to improve health communication through highly interactive, personalized and mass-customizable features. The power of eHealth communication is largely attributable to the use of AI technologies and has resulted in a radical shift from generic health messages to information that can meet people's specific needs and preferences. Northouse and Northouse [40] describe health communication as a process that seeks to "change a person's physical, psychological and social world." eHealth/AI communication now enables researchers and developers to understand and interact with people's worlds in a deeply meaningful way. However, eHealth communication––even with AI features––will need to overcome important weaknesses before its potential is realized. Currently, few eHealth/AI developers have reported using specific theoretical guidance to design communication interventions [42]. Further, developers have often limited their design and evaluation methods to those in either design sciences or health and social sciences, which may explain the modest success of their efforts.

We suggest a more powerful path forward. Combining the theoretical frameworks and methods of design sciences *and* health and social sciences should significantly improve eHealth/AI communication. Our experience highlighted the importance of having a team with expertise in health, social science, and informatics disciplines. Design science and action research theory informed us about the value of helping patients take more control over their health and share decision-making with providers. The detailed user-centered methods of design science were essential to enable Crohn's patients to define their own information and technology needs – sometimes as fine as having health data in the form of hourly ODLs.

Applied AI expert systems, like ChronologyMD, pose special challenges for eHealth/AI developers. Intensive participatory design is needed for AI (and non-AI) features intended to represent and enhance the way diverse people take in and use health information. This issue is magnified for Crohn's patients who need to assess multiple health variables in real time. Participatory design is essential for successful AI systems, but makes it difficult to estimate the required time and budget. Our patients and developers worked closely for one year to create easy-to-use interfaces for data input and display and connection to biometric devices, resulting in significantly more time and cost than planned. Further, traditional "before and after" health communication evaluation designs are not adequate for iterative, user-designed projects that have a "build and evaluate" loop. With guidance from design science and action research, we used multiple evaluation methods and serially revised questions with user feedback. Overall, we learned that a strong focus on user-centered design and evaluation *from the beginning* is key to success and to avoid the weaknesses of past eHealth/AI efforts.

There are limitations to our study. Literature about the intersection between design sciences and health communication sciences is nascent, but strongly suggests the value of connecting these disciplines. Our case example is a pilot study and its results cannot be generalized beyond the small number of participants. However, we found overwhelming support for the ChronologyMD approach, which worked well even for patients who were not technologically savvy at the outset or who had complex information needs. This finding underscores the importance of careful, iterative design with the users and the capacity to continuously personalize AI features of eHealth systems.

Many challenges remain: design scientists and health and social scientists have followed different historical epistemological and methodological pathways. Fortunately, AI scholars and developers are establishing strong linkages between these disciplines – a significant step to improve health communication.

4.2. Conclusion

Harris [41] calls for transforming communication media from passive, closed and producer-driven to interactive, connected and user-driven. Participatory design with users is the primary way to make this transition. Although such processes have not been the norm in traditional health communication, eHealth/AI technology experts in design sciences routinely use them to test technologies. However, such technologists often lack sufficient input from health communication scientists. Design science theory and methods provide excellent guidance to join technical and social science expertise in a synergistic approach to participatory design. eHealth/AI projects are a strong catalyst to do so, and to strengthen the impact of eHealth communication.

4.3. Practice implications

eHealth communication researchers, developers and practitioners would benefit from learning more about and adopting the highly participatory methods of design sciences. This would be especially helpful to those involved in eHealth communication with significant AI components. Likewise, experts in design science would benefit from incorporating theory and methods from health communication and other health and social science fields to improve eHealth/AI interventions. Special journal issues and conferences focused on AI, participatory design and health communication would also be valuable.

Conflict of interest

None of the authors of the manuscript have a conflict of interest that would inappropriately influence, or be perceived to inappropriately influence their work.

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