Identifying Consumer's Needs of Health Information Technology through an Innovative Participatory Design Approach among English- and Spanish-speaking Urban Older Adults

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Keywords

Consumer health information, medical informatics, health information management, community-based participatory research, personal health records

Summary

Objectives: We describe an innovative community-centered participatory design approach, Consumer-centered Participatory Design (C^2PD), and the results of applying C^2PD to design and develop a web-based fall prevention system.

Methods: We conducted focus groups and design sessions with English- and Spanish-speaking community-dwelling older adults. Focus group data were summarized and used to inform the context of the design sessions. Descriptive content analysis methods were used to develop categorical descriptions of design session informant's needs related to information technology.

Results: The C^2PD approach enabled the assessment and identification of informant's needs of health information technology (HIT) that informed the development of a falls prevention system. We learned that our informants needed a system that provides variation in functions/content; differentiates between actionable/non-actionable information/structures; and contains sensory cues that support wide-ranging and complex tasks in a varied, simple, and clear interface to facilitate self-management.

Conclusions: The C^2PD approach provides community-based organizations, academic researchers, and commercial entities with a systematic theoretically informed approach to develop HIT innovations. Our community-centered participatory design approach focuses on consumer's technology needs while taking into account core public health functions.

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1. Introduction

As use of the Internet continues to spread among all age groups, access to health-related information via the Internet has potential to facilitate self-management of expected changes in health status over the lifespan. An estimated 53% of American older adults use the Internet or email [1]. A growing proportion of older adults is seeking health information online [2]. Seven in ten older adult Internet users look online for health information; moreover, between 25% and 62% of older adults searched health topics including disease specific information, certain medical treatments or procedures, doctors or other health professionals, hospitals or other medical facilities, health insurance, or food and safety recalls [2]. Researchers have shown that community-dwelling older adults without Internet experience are able to participate successfully in web-based self-management programs with sufficient training [3]. Electronic personal health information management systems (e.g., personal health records, Internet-based patient portals, and social network tools) can provide the platform for the delivery of self-management systems [4]. Engaging older adults in the use of web-based self-management systems may be possible when they are actively involved in the design and development of such systems.

Computers have been used successfully to facilitate self-management of chronic conditions. Based on a meta-analysis of 75 randomized controlled trials, computer-delivered interventions improved antecedents of health behavior (i.e. knowledge, attitudes, intentions), actual behavior, and general health maintenance [5]. For example, patients who used a web-based system to send blood glucose levels to their providers had better hemoglobin A(1c) control than patients not exposed to the system [6]. After 30 months, the intervention group continued to have significantly lower hemoglobin A(1c) levels (6.9 v. 7.5, p=0.009) [7]. In another study, patients who received a tailored, computer generated plan of care had an 8% decrease in hemoglobin A(1c) as compared to patients without a tailored plan of care [8]. Like diabetes management, falls prevention requires a multifactorial approach for managing risk reduction among older adults starting at the age of 55 years [9, 10]. Although there is a low risk of falling at the age of 55 years for both sexes, research has revealed significant rates of injury after a fall for females beginning at this age [11]. While researchers are tackling hospital-based falls prevention via provider-centered health information technology (HIT), there isn't much activity aimed at developing an effective web-based falls prevention system for community older adults [12].

The incidence of falls and injuries is increasing globally in communities [13]. Yet, the rates vary in different regions of the world; for example, in the southeast Asian region fall rates were between 6% and 31% while in Japan the fall rate was 20% [14-18]. In the Latin/Caribbean region fall rates ranged from 21.6% (i.e. Barbados) and 34% (i.e. Chile) [19]. The final review of the U.S. Healthy People 2010 goals revealed that age adjusted death from unintentional falls was more than 2 times larger than the intended 2010 target [20]. More than 90% of hip fractures among older adults are caused by falls and 75% of hip fractures occur in females [21]. Older adults who are discharged home after a medical illness have an increased falls rate in the first 2 weeks to 1 month (8.0 and 6.7 falls per 1000 person-days, respectively) [22]. The fast growing older adult population in the U.S. will more than double from 35 million to 72 million between 2010 and 2030, adding to the challenge of reversing and reducing injuries and deaths from unintentional falls [23].

The aims of this paper are to: (1) present an innovative approach, Consumer-centered Participatory Design (C^2PD), for identifying consumer's needs of HIT, and (2) report the results of applying C^2PD to design a web-based falls prevention system for community-dwelling older adults.

2. Methods

We partnered with a community-based organization (CBO) in New York City that focuses on providing social services to older adults. This CBO logs annually upwards of 10,000 resident encounters. The typical older adult who uses their services is foreign-born, Hispanic, falls below the poverty line, and has less than a high school education. Our principal CBO collaborator was the Assistant-Executive Director. This individual participated as a co-investigator and was responsible for enlisting clients of the CBO in our study.

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We recruited community-dwelling older adults who had or had not experienced a fall and were at least 55 years of age. Because having had a fall was not an eligibility requirement, older adults self-reported whether they had a history of falling. Older adults were not eligible for the study if they were not able to walk independently with or without an assistive device. The views of both non-fallers and fallers as young as 55 years of age were thought to be important in the development of a web-based fall prevention system. In the U.S., 61.7% of households has someone 55 years of age and older who reports Internet use [24]. For design session participation, informants were drawn from a pool of CBO clients who had attended computer/Internet training and reported weekly internet access. All informants provided written consent to participate in the study. The study was conducted in English and Spanish. The data that were collected from English and Spanish-speaking informants was not substantively different to warrant reporting results by language. Therefore, we provide one overall description of our English and Spanish-speaking informants (▶Table 1).

2.1 Consumer-centered Participatory Design

The C²PD approach is based in principles of community-based participatory research and human-centered distributed information design methods [25, 26]. Community participation is a critical component of the C²PD approach. Key elements of community-based participatory research (e.g., builds on strengths and resources within the community, promotes a co-learning and empowering process, facilitates collaborative partnerships, etc.) are integrated in the C²PD approach to the extent that the research endeavor can achieve any one or a combination of these principles depending on the purpose, context, and participants involved in the design and development of HIT [26]. Community members contribute uniquely to enhance understanding the potential influence of social and cultural dynamics of the community, and integrate the knowledge gained with action to improve their health and well-being [27, 28]. For example, our success at building trust with the executive and assistant directors of the CBO facilitated engaging their staff and clients in an interactive and iterative process of developing the web-based falls prevention system demonstrates the principles of building on strengths and resources and facilitating collaborative partnerships as well as promoting a co-learning and empowerment in community. Like human-centered distributed information design methods, the C²PD approach incorporates four components of design specification requirements (i.e., user needs): user, functional, task, and representational [25, 29]. In the C²PD approach, user needs derived from participatory design sessions will have varying degrees of relevance but all contribute directly to the design and development of a system. The user needs contribute directly to the functional, task, and representational components. Community members (i.e. potential consumers of HIT), informants in the design sessions, contribute directly by expressing their needs across the four components. This innovative approach, C²PD, harnesses the conceptual and methodological maturity of both community-based participatory research and human-centered distributed information design methods to facilitate the design and development of HIT that has the potential to improve individual and population health.

The C²PD approach is comprised of a set of focus group and participatory design sessions. Interactions with community informants are scheduled to last 90 minutes, and are audio and video recorded. Before conducting a series of 4 participatory design sessions, focus groups are conducted to elicit from community informants the knowledge they maintain about the study domain (e.g. fall prevention). The participatory design sessions contain activities that focus on the user, functional, task, and representational components of the C²PD approach. Informants who can commit to participating in all four design sessions are recruited for the study. Having the same informants should promote integrating knowledge from one design session to the next by reflecting with informants about what was learned from the previous session(s). Using this approach, we set out to develop the Self-assessment via a Personal Health Record (SAPHeR) system (▶Figure 1), which is intended to:

1. provide information on why preventing a fall is important,
2. guide creating a safe home environment,
3. provide textual and animated instructions on effective prevention activities,
4. provide an effective platform for monitoring falls prevention and daily activities, and
5. facilitate self-assessment of falls efficacy [30].

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2.1.1 Focus Groups: Preparatory Work

The focus groups in this current study centered on the knowledge and experience older adults had with falls and falls prevention. A focus group guide was used to cover topics including the experience of falling along with any associated injuries, knowledge of fall risk at home and in the community, consequences associated with falling after recovery (i.e. physical and/or emotional), experience of nearly falling, strategies for reducing the risk of falling, and knowledge related to fall prevention. Because not all informants had experience in all of these topics, they were asked to provide knowledge and views only on topics that were relevant to them. There were 14 English- and 16 Spanish-speaking focus group participants. Informants were on average 69 years of age. The majority of informants self-identified as Hispanic (80%). There was nearly an equal number of men (n=13) and women (n=14) and a majority (80%) of informants were at least high school graduates. The English and Spanish audio recordings were transcribed into English text documents. The data were summarized by two members of the research team based on the aforementioned topics and used to inform the construction of the participatory design sessions.

2.1.2 Participatory Design Sessions

The purpose and activities associated with each design session for the development of the SAPHeR system are described in ▶Table 2. There were eight informants in the English- and seven in the Spanish-speaking design session groups. The design session informants were on average 72 years of age. The majority of informants self-identified as Hispanic (60%). There was a greater number of women (n=8) than men (n=6) and a majority of informants (67%) were at least high school graduates. The effective sample size was 56 given that the original 14 informants participated in the entire series of design sessions.

The design sessions began with the purpose of identifying the characteristics of potential consumers, such as age; education levels; cultural background; cognitive capacities and limitations; expertise, knowledge, and skill of computer and Internet use; perceptual variations of information and communication needs, etc. [31]. Building on the first design session, the second design session focused on identifying what functions (e.g. alerts, medical knowledge, communication, other aids) should be supported by the SAPHeR system [25]. In the third design session, a series of activities were conducted to elicit participant's typical use patterns to achieve task goals [32]. Based on the data collected in the preceding design sessions, we concluded by using a high-fidelity prototype of the SAPHeR system to obtain feedback about whether information display formats were constructed appropriately for tasks to be carried out by potential consumers [25, 33].

2.2 Analysis of Design Sessions

The English and Spanish participatory design session audio recordings were transcribed into English text documents. Due to the sample size (i.e. number of design sessions conducted), the analysis was conducted manually rather than using software. A descriptive content analysis was used to analyze the textual data [34]. This method assumes that categories must be exhaustive and mutually exclusive. A category is a group of content that shares a commonality. Categories can be thought of as an expression of the manifest content of text used to generate concrete requirements for the programming team to construct the SAPHeR system. While the C^2PD approach is relational, the participatory design sessions were assumed to be mutually exclusive for the purpose of generating system requirements and specifications based on the informants' expressed needs.

Analysis of the participatory design session transcripts were completed in a step-wise iterative process. Two members of the research team, including the principal investigator, conducted a first pass examination of transcripts while simultaneously reviewing the video recordings to correct and clarify errors in the transcripts. Then, the principal investigator and another member of the study team read and reread the transcripts independently to identify recurring or specific content. Next, the principal investigator and team member conferenced to review, clarify, and draw consensus on the emerging content. Finally, categorical descriptions for each design session were created to summarize the informants' expressed needs.

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3. Results

The results are organized by the components of the C²PD approach: user, functional, task, and representational. We developed broad descriptions which capture the essence of informant's needs overall. Examples of informants expressed needs are presented and exemplify detailed requirements that were important to the design and development of the SAPHeR system.

3.1 User: Consumers need a varied, simple, and clear interface

Informants reported performing various different web activities when using the Internet. Their use of these web-sites required the completion of targeted (e.g. electronic mail) to broad tasks (e.g. online shopping, web-gaming, health information seeking, etc.). In general, informants preferred web-sites that were simple in appearance and use. One informant stated, "*I like this better…, basically when you're going to AOL or Yahoo or Google, it's so much you become overwhelmed and then you don't know which way you want to go.*" This need for simplicity however did not overshadow features that were appealing to informants. Informants were attracted and returned to web-sites that use imagery (i.e. photographs, videos, animation) to convey information being sought from a website. Another informant commented, "*I like the changing pictures.*" In this instance, the informant self-identified with images that portrayed active older adults. Informants were unanimous about the requirement for web-sites to take into account normal physiological changes associated with aging, such as visual acuity. As one informant stated, "*It looks like it's printed different…It's like it's not that clear. For seniors, I think it should be even clearer than clear.*"

3.2 Functional: Consumers need functions/content that varies and facilitates self-management

The functional activities that informants performed yielded evidence about differences in their functional needs, information seeking-behaviors, and health-related knowledge. ▶Figure 2 and ▶Figure 3 are 2-dimensional renderings of how informants' organized a set of functions/content to access health-related knowledge through the SAPHeR homepage. All informants took part in this activity which yielded six configurations that were used to inform the design of the SAPHeR homepage. Informants were not in agreement about what type of functions would best support learning self-management activities. One informant shared, "*Well, I like the idea of having the picture function, because it shows you and you could imitate that if you're trying to do the exercise.*" On the other hand, another informant stated, "*But I think I would like to see the movements. Because sometimes you can misunderstand the text, whereas seeing the movements you know what's going on.*" Informants expressed a number of strategies when searching for health-related information on the web that include different functions (e.g. search field, dropdown lists). Some informants shared that information seeking was often limited and/or motivated by their inability to spell health related terms or literacy associated with health-related topics. The following depicts one informant's information seeking-behavior, "*Sometimes you're just not too familiar with the terminology. So you scroll down and you say, well this one might be it, and you click. You take your chances…That's what I like about the list.*"

3.3 Tasks: Consumers need sensory cues that support varied and complex tasks

Informant's abilities and patterns of completing web-based tasks ranged from limited to wide-ranging and simple to complex, respectively. For some informants, task accomplishment seemed confounded by their ability to comprehend the task instructions. Among informants who understood the task instructions, some expressed that task accomplishment could be facilitated for consumers like them through the use of visual cues. As one informant stated, "*Do that, being it says click button to view. But maybe you should just put a round circle there so it's a button. So it's less confusing then to everybody.*" The patterns of task accomplishment for informants who had difficulty with task in-

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structions can be characterized as disperse, haphazard, and unintentional. Nonetheless, more times than not, informants were able to complete their assigned tasks. For those informants who understood the task instructions, their approach to task accomplishment can be characterized as informed (i.e. by previous experience) and precise. Still, there was one informant who had developed an approach to task accomplishment that can be characterized as semi-targeted and personalized. As this informant expressed, *"I just put in the address bar what I'm looking for…then it would come up with the different listings again."*

3.4 Representational: Consumers need an interface that differentiates actionable/non-actionable information/structures, and follows human-computer interaction principles

The activities used to explore representational properties of a high-fidelity SAPHeR prototype were assembled to illicit informant's internal and external perceptions about the acceptability of information, content, and functions contained in the system [35]. Informants were unambiguous about their ability to identify content that was static (i.e. non-actionable) and that which could be acted upon or actionable (e.g. links, tabs, etc.). Informants identified a number of tasks they thought could prove problematic for consumers like them. Among these were tasks critical to self-assessment and self-management of fall prevention. One informant questioned whether the use of radio buttons to complete a self-assessment form could be easily understood by potential consumers, stating *"Do they know how to use it though, to like if you have to put something [sic], the dots in the thing that you know?"* [clicking on a radio button to make their selection] When it came to informants creating entries in a self-management journal of physical activities and personal/medical reminders, the majority of them had difficulty distinguishing between the physical activity and personal/ medical reminder tabs. The following exchange between a member of the research team (i.e. M) and an informant (i.e. R) is an exemplar of this confusion, *"M: What about the contrast of the tabs? R: No, I think that you could…as I said, you could make them in colors. Activities could be in a color and then...well I can't see that?* [referring to the personal diary tab that could not be distinguished as separate from the activities tab]*"* Informants also raised issues related to perceptual principles of human-computer interaction, including the choice of color to distinguish between actionable and non-actionable content to enable task accomplishment. For example, *"No…if you put that like in a red. And then, you know, it would stand out a little bit more on that."*

4. Discussion

Unlike typical participatory design approaches, the C^{2}PD approach can address the challenge of designing consumer-centered HIT that meets the needs of different users with varied functional requirements engaged in wide-ranging tasks through a systematic interactive assessment and evaluation of user, functional, task, and representational needs of consumers [36-41]. The design and development of HIT is often conducted in isolation by system developers and without engaging consumers as partners in the process. The results of an isolated approach can be system failures that are not due to flawed technology but related to a lack of systematic consideration of human and other non-technology issues in the design and implementation processes [42-45]. Our innovative approach, based in human-centered distributed information design and principles of community-based participatory research, engages consumers in interactive activities that elicit their expectations and behaviors associated with information technology use to inform each iteration of prototype development [25, 29, 46].

The significant difference in the C^{2}PD approach compared to other participatory design approaches is the integration of potential community-based consumers of HIT as design partners across a systematic evaluation of user, task, functional and representational requirements [29, 47]. The participation of consumers is recognized as necessary in the design of HIT; however, is often realized only in usability testing and/or the refinement of a system [42]. The degree of consumer participation varies in published human-computer interaction (HCI) literature [48]. Previous examples of participatory design with community-dwelling older adults has focused primarily on functional needs, and

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less so on user, task, and representational needs of potential users [49-53]. Ho and colleagues found that of 21 articles that make reference to the concept of participation 8 actually used a participatory approach, and these studies employed a weak version of participation [54]. Namely, the lack of community engagement before embarking on the aims of the project. The C²PD approach engages consumers in reflective inquiry that is directly linked to their lived and computer/Internet experience at the onset of the development process. These collaborations can lead to a legitimate form of knowledge discovery that contributes to system development that is based in consumer's real world experiences [44].

Engaging consumers allowed us to account for personal, social, and cultural considerations in the design and development of the SAPHeR system [55]. The development of the SAPHeR system is the first personal health record-based older adult falls prevention self-management system to the best of our knowledge. We expect that by applying the C²PD approach consumers will experience increased efficiency and productivity, increased ease of use and ease of learning, increased user adoption, retention, and satisfaction, and decreased development time and cost including decrease support and training related to the use of HIT [31]. In order to assess these expected benefits, we will apply a usability approach that is based in human-centered distributed information design methods which will allow us to evaluate initially potential end-user's levels of efficiency and productivity, ease of use and learning, usefulness, and satisfaction [29].

The lives of most humans, including older adults, may be thought of as a system of information rich interactive environments filled with natural objects, artificial agents, and human agents [43, 45]. The assumption that "the needs and concerns of human agents are an intrinsically important part of system development and design is central to human-computer interaction" may have greater validity when designing HIT for older adults [56]. Health information technology, such as SAPHeR, intended primarily for use by older adults may be distinctly different from those associated with HIT for use by health care providers and younger Internet users. For example, mobile applications may be effective among health care providers and young Internet users however the results may not be the same among older adults given that an estimated 13% of this population accesses the internet through "smartphones" [57]. Engaging older adults is paramount in designing and developing HIT that can be integrated easily and effectively by them into their home and community environments.

5. Conclusions

The C²PD approach can be used successfully to identify consumer's needs that inform the design and development of HIT. Web-based health management systems, such as SAPHeR, embedded in personal health record platforms can increase health care access and quality of care among vulnerable and minority populations by making available actionable resources [4]. We have developed a community-centered participatory design approach that not only focuses on consumer's technology needs but also takes into account core public health functions and outcomes such as informing, educating, and empowering individuals about health issues; mobilizing community partnerships to identify and solve health problems; linking people to needed personal health services; and conducting research to develop new insights and innovative solutions to health problems [58]. The C²PD approach provides public health and community based organizations, academic researchers, and commercial designers with a systematic theoretically informed approach to develop HIT innovations.

Clinical Relevance Statement

We have advanced the idea of community as partner in our innovative approach to community-centered participatory design methods, Consumer-centered Participatory Design. This approach moves the field of human-centered design beyond typical needs assessment methods that are often based in understanding potential end-users knowledge of a clinical domain; uninformed by theory; and heavy reliance on focus group methods. The C²PD approach is based in principles of community-based participatory research and human-centered distributed information design methods, incorporates both focus groups and participatory design sessions, engages consumers to identify their needs of information technology, and takes into account core public health functions.

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Conflict of Interest

The authors declare that they have no conflicts of interest in the research.

Human Subjects Protections

The study was conducted in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects, and was approved by the Columbia University Medical Center Institutional Review Board.

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Fig. 1 Self-assessment via a Personal Health Record (SAPHeR) Homepage

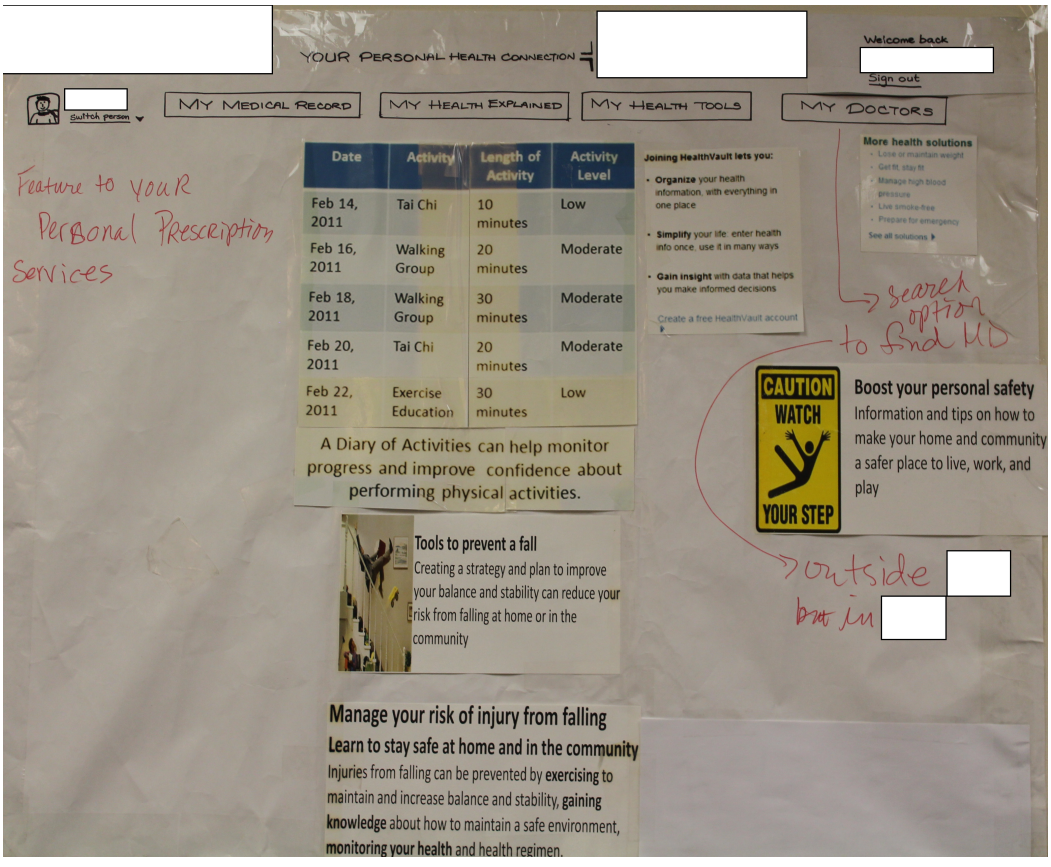

Fig. 2 Informants' 2-dimensional rendering of a SAPHeR homepage

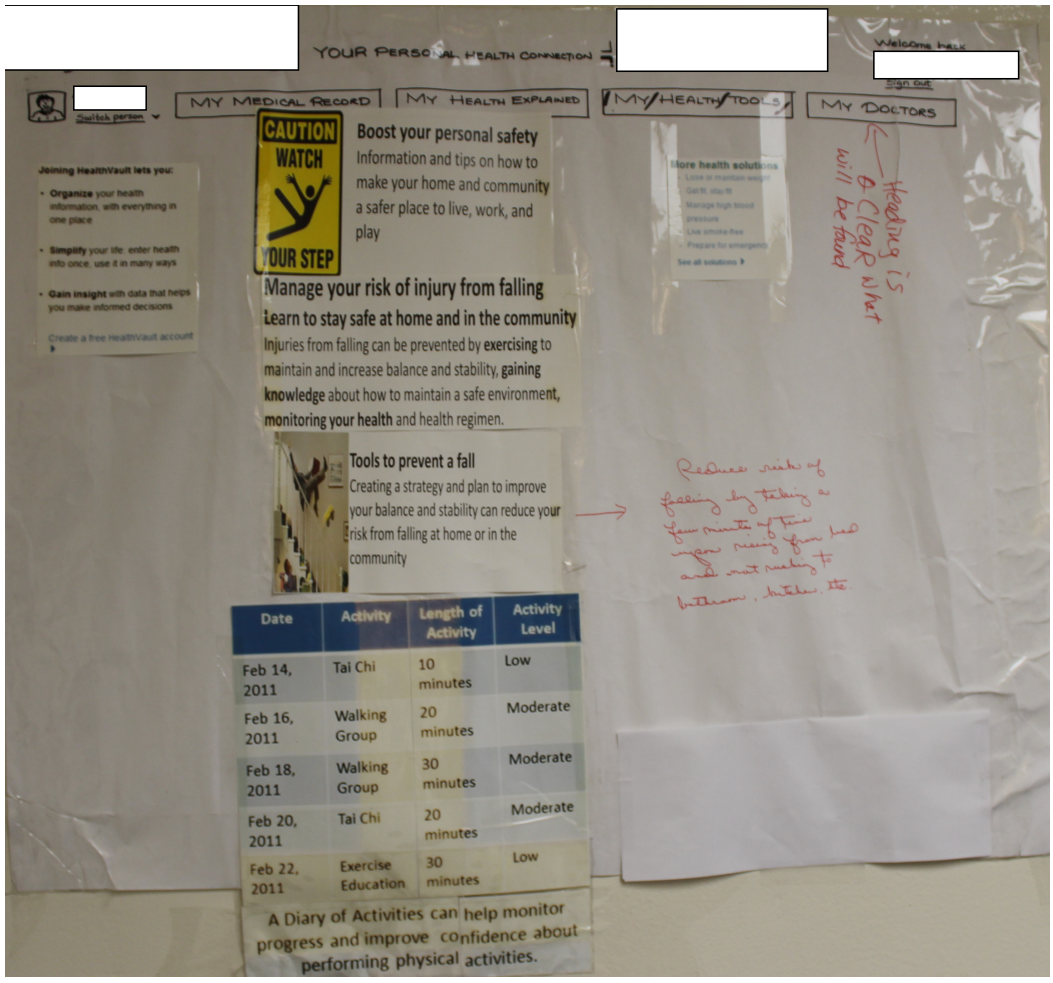

Fig. 2 Informants' 2-dimensional rendering of a SAPHeR homepage

Table 1 Characteristics of Focus Group and Participatory Design Session Informants*

Characteristic	n (%)	M (Range)
Focus Groups (N=30)		
Age		69 (55–89)
Gender		
• Female	14 (46.7)	
• Male	13 (43.3)	
Race		
• White	10 (33.3)	
• Black	5 (16.7)	
• Asian	0 (0.0)	
• Other	6 (20.0)	
• Hispanic	24 (80.0)	
Primary Language		
• English	4 (13.3)	
• Spanish	25 (83.3)	
• Other	1 (3.3)	
Education		
• Less than High School	6 (20.0)	
• High School	17 (56.7)	
• College degree	7 (23.3)	
Internet Use	28 (93.3)	
Participatory Design Sessions (N=15)		
Age		72 (61–77)
Gender		
• Female	8 (53.3)	
• Male	6 (40.0)	
Race		
• White	9 (60.0)	
• Black	1 (6.7)	
• Asian	1 (6.7)	
• Other	4 (26.6)	
• Hispanic	9 (60.0)	
Primary Language		
• English	3 (20.0)	
• Spanish	11 (73.3)	
• Other	1 (6.7)	
Education		
• Less than High School	4 (26.6)	
• High School	7 (46.7)	
• College degree	3 (20.0)	
Internet use	15 (100.0)	

Note: *Not all categories sum to 100% due to unreported or missing data.

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Table 2 Purpose and Activities of Participatory Design Sessions by C²PD* Component

Component	Purpose	Activities
User	To identify consumer characteristics necessary for a system that has the information base that matches their knowledge levels (i.e. expertise, skill, cognitive capacity, etc.).	1. Interactive feedback with flash cards of self-management activities. 2. Open dialogue 3. Browsing the Internet. The activities are intended to elicit from informants: (a) what self-management activities could be useful and feasible via a web-based interface, (b) extent of Internet use, and (c) features related to Website "stickiness."
Functional	To identify what content and functions should be included in a consumer-centered system.	1. Informants construct a 2-dimensional rendering of the planned system's Homepage using poster-paper, paper images, adhesive, and markers. 2. Informants describe what is acceptable or unacceptable about a variety of functions (e.g. visual aids that accompany textual information, instructional videos, and a menu of options) that are displayed using an ePHIMS†.
Task	To identify patterns and ability of consumers to accomplish web-based tasks.	1. Informants explain how to accomplish a set of tasks using a low-fidelity prototype developed from the poster-paper Homepage configurations. 2. Informants perform a set of tasks within an ePHIMS, including viewing or inputting personal information to scheduling an event.
Representational	To identify consumer's internal and external perceptions about the acceptability of information content, and functions contained within a high-fidelity prototype of the SAPHeR†† system.	1. Interactive feedback about the representation of textual information; including font size, type, interface coloring, as well as the use of various functions (e.g. video, animated graphical interchange format) to communicate self-management activities. 2. Informants consider if images paired with textual information convey the meaning of the text. Reasons and suggestions are elicited based on their reactions. 3. Informants explain how to perform and sketch a drawing of a self-management activity after receiving verbal instruction on how to perform the activity.

Notes: *C²PD: Consumer-centered participatory design, †ePHIMS: Electronic personal health information management system, ††SAPHeR: Self-assessment via a personal health record

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