

# Promoting access to health information

## A method to support older African Americans with diabetes

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### Abstract

**Purpose** – Describe the design of a health information and technology educational intervention that promotes health information sharing and technology use for older adult African Americans to support access to health information. The paper aims to discuss this issue.

**Design/methodology/approach** – The study team developed a novel method to design the intervention. It drew upon three approaches: intergenerational technology transfer, participatory design and community-based participatory research.

**Findings** – Older adult African Americans (55+) with diabetes and young adults (18–54) connected to them via familial or naturally occurring social networks designed the intervention, which was conducted in the two study sites in Michigan, USA. In total, 29 participants helped design the intervention. Four themes emerged concerning factors that promote intergenerational information exchange in the context of technology and health. First, focus on one technology skill. Second, working together in small groups is preferred. Third, patience is essential. Last, physical capabilities (i.e., eyesight, operating on relatively small screens) and literacy levels should be considered.

**Originality/value** – This novel method of having participants from the sample population select the health information materials and technology exercises serves as a guide for implementing health information and education interventions aimed at technology use to support self-management for vulnerable patient populations.

**Keywords** Diabetes, Health information, Health disparities, Health inequity, Older adult technology use, Technology for self-management

**Paper type** Research paper

### Introduction

Barriers to health information contribute to inequity in social connectivity and health literacy (Jeong and Kim, 2016; Wyatt *et al.*, 2005), which is “the ability to obtain, process, understand, and communicate basic health information needed to make informed health care decisions” (Berkman *et al.*, 2010). Various other factors, such as poverty, education, race/ethnicity and disabilities influence levels of health literacy. Specifically, low socioeconomic status and advanced age are associated with low health literacy. Causal connections have been described between low socioeconomic status and low health literacy (Knighton *et al.*, 2017). Also, adults age 65 or older have lower health literacy than individuals under the age of 65 (Kutner and Zhang, 2013). For example, Gazmararian *et al.* (2003) found 36 percent of older adults had marginal or inadequate health literacy skills and Kirk *et al.* (2012) found that two-thirds of older adults with diabetes had low or inadequate health literacy. Older adults with less than a high school diploma or equivalent level of education score significantly lower on health literacy scales than those with higher levels of education (Kirk *et al.*, 2012). Furthermore, low-resourced adults of all ages have lower health literacy (Kutner and Zhang, 2013). African Americans disproportionately have low health literacy levels, since African Americans in low-income urban communities experience social and technical barriers to health information (Kutner and Zhang, 2013; Osborn *et al.*, 2013).



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Understanding inequity in health literacy levels is vital because low health literacy is associated with chronic disease disparities. For example, individuals with adult-onset diabetes mellitus (diabetes) with low health literacy experience worse outcomes, primarily due to self-management behaviors discordant with recommendations (i.e., medication, diet, physical activity, attendance at follow-up appointments) (Funnell *et al.*, 2011). Chronic disease patients who are able to consistently follow recommended self-management behaviors experience good health outcomes because recommendations account for between 70 and 80 percent of the chronic disease treatment regimen (Wilson *et al.*, 2006). Self-management programs improve health outcomes by enhancing access to health information and improved self-efficacy for adherence to recommended self-management behaviors, and program effectiveness is enhanced through use of technology (Funnell *et al.*, 2011).

Chronic disease patients seek and use health information to better understand their health conditions and treatment options, primarily to support communication with healthcare providers (Zulman *et al.*, 2015). Health information seeking literature describes positive correlations between level of health information seeking and use, and patient engagement and self-management (Tu and Cohen, 2008). Adults aged 45 or older with chronic conditions are significantly more likely to seek health information than younger adults (Rooks *et al.*, 2019). Older adults' health information seeking behavior and use contributes to health and perceived well-being (Manafa and Wong, 2012). However, there is considerable racial and ethnic inequity in seeking and use of health information, primarily due to communication barriers (Ackerson and Viswanath, 2009). Across various medical encounters physicians perceive African American patients to be less effective communicators than white patients (Street *et al.*, 2007). In studies that examine physician-patient communication, physicians tend to be more contentious and more verbally dominant with African American patients than white patients (Johnson *et al.*, 2004). These findings suggest that support for health information seeking and use outside of the clinical environment is particularly vital for African American patients.

Consumer-oriented technology-enabled tools are continuously being designed to provide access to health information as patients are increasingly charged with the obligation to follow recommended self-management behavior. The proliferation of these tools is principally due to advancements in mobile computing capabilities (i.e., tablets, smartwatches smartphones) and communications (i.e., broadband, cellular networks) (Subhi *et al.*, 2015). Chronic disease patients may use consumer-oriented technology to search for disease-specific health information and aids that support self-management. For example, individuals with diabetes use smartphone applications (apps) to search for health information concerning symptoms and treatment options and collect personal health information to help them track medication behavior, physical activity and dietary choices (Nijland *et al.*, 2011; Ye *et al.*, 2017). However, considerable health and digital literacy skills are required to effectively access, evaluate, and use the vast and increasing availability of health information (Jaeger *et al.*, 2016; Walton, 2016). Further, technology has ushered in capabilities to individualize care – from predictive diagnostics to commodification of stem cells and cloned embryos (Wathen *et al.*, 2008). Technology-enabled capabilities have also buoyed the continued evolution of the concept of patient choice, perhaps most notably concerning diabetes self-management (Mol, 2008). Using diabetes care as the principal illustration, Mol argues that quality care, the “logic of care,” directly contrasts with the “logic of choice,” a series of routinized choices made by individuals armed with technology-enabled tools designed to support them by collecting their personal health information and tracking their behaviors. The contrast asserts that quality care results from collaborative, continuous efforts to consider information and insights into all aspects of a patient's daily life, not simply relying on the notion that the individual informed patient is free to merely choose health behaviors which are consistent with recommendations.

For nearly two decades information scholars have elucidated how technological advancements exacerbate inequity across various facets of society, from media to education to

labor and business (Henwood *et al.*, 2000). Individuals, various sensors and systems can amass and analyze vast amounts of personal health data. These capabilities bolster the promise of “big data” to change how we live, think and work (Lohr, 2015). But the collection and analysis of these data also fundamentally modifies “how we know” (Rieder and Simon, 2017). Thus, while technology may play a vital role in enhancing the quality of life and independence of older adults (Schulz *et al.*, 2015), they experience persistent barriers to adopting technology used to access health information (Peek *et al.*, 2016). Even with similar technology experience to younger adults, older adults experience higher cognitive load while using novel technologies (O'Brien *et al.*, 2008). Stereotypes of older adults being unable or reluctant to learn new technology also present barriers to adoption and use (Miche *et al.*, 2015). Older adults will reject a technology if they perceive that the skill development required to use the technology is too high; however, likelihood of adoption increases when older adults are given the opportunity to try out the technology in a safe, supportive environment (Barnard *et al.*, 2013). Harley and Fitzpatrick (2009) argue that “digital exclusion” that older adults experience is associated with social isolation; they posit that older adults experience fewer barriers if they experience technology use socially, through use with others (Harley and Fitzpatrick, 2009). Hence, there is an opportunity for older adults to use technology with each other and with younger adults to positively influence older adults’ perceptions of technology use (Brown and Strommen, 2018). Positive experience in technology use and adoption transfers to new technology learning (Barnard *et al.*, 2013).

Older adults with low-socioeconomic status and minority groups experience barriers to consumer-oriented technology designed to support chronic disease self-management primarily because technology-enabled health promotion approaches generally overlook known cultural and social factors that influence technology use (Lupton, 2015). Sociocultural barriers to technology-enabled health information sources can result in intervention-generated inequality – when technology-enabled health informatics approaches disproportionately benefit racial majority and mid/high-socioeconomic status populations. These interventions are less effective for underrepresented populations; consequently they exacerbate persistent chronic disease outcomes inequity (Lorenc *et al.*, 2013; Veinot *et al.*, 2018).

Although factors driving general technology use among older adults continue to be investigated, little is known of how older adults with chronic conditions may use technology to help them manage their health conditions. In fact, research has not yet examined what technology features may be effective at promoting health behavior change for older adults (Portz *et al.*, 2016). Specifically, there are considerable gaps in understanding technical skills among older adult diabetic patients (Mitzner *et al.*, 2013). These gaps persist despite increasing availability of health information online (Anderson and Perrin, 2015). Furthermore, in limited study populations, patients with low health literacy have benefited from diabetes self-management education (Kim *et al.*, 2004); however, there are considerable gaps regarding the use and efficiency of online educational materials for chronic disease patients with low health literacy (Mitzner *et al.*, 2013). African Americans are at higher risk for having chronic diseases, comorbidities, and risk of complications, and they are more likely to have low health literacy (Mitzner *et al.*, 2013). Consequently, it is critical that methodologies designed to support African American older adults’ access to consumer-oriented technologies designed to support recommended chronic disease self-management consider barriers to acceptance and use.

To help address persistent inequity in access to health information and requisite digital skills, I led a study team comprised of academic researchers and leaders of faith-based organizations (FBOs) to develop a novel method for investigating ways to enhance access to health information via consumer-oriented technology. We selected two study sites, one in Detroit and the other in Flint, Michigan because they exemplify underserved, urban areas that are particularly impacted by low health literacy and health disparities (Bilal *et al.*, 2018; Gaskin *et al.*, 2014; Ryvicker and Sridharan, 2018). The study followed a five-step process to

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design then conduct the intervention. The intervention was created and piloted in the first three steps. These first three steps are the focus of this paper. The impact of the intervention is detailed in two other papers. One paper currently under review details impact directly after participating in the finalized health information and technology intervention, which was conducted in the fourth step (Senteio, Soltow Hershey, Campbell and Mandal, 2019). The other paper describes the impact one month following the intervention via a telephone survey, which was administered in the fifth and final step (Senteio, 2018). The five steps are detailed below:

- (1) Conduct an established HIV/AIDS prevention and information session – the “HOPE party” (HIV/STI Outreach, Prevention, Education). Participants attended the HOPE party in order to experience an example of a community-based health information session with a technology component.
- (2) Design session: participants (designers) that attended the HOPE parties then attended a design session to develop (i.e., design) the health information intervention, which included selecting the technology. I refer to the design session and pilot session attendees as “designers,” as we referred to them during the design and pilot sessions.
- (3) Pilot session: the “designers” then attended a session which constituted a pilot of the health information intervention they helped design in step 2, which they entitled “D-Party” (“D” for diabetes, and “Party” to borrow the HOPE Party moniker). The pilot session served as “member checking” to confirm the smartphone as the technology selected, and topics and format of health information used during the session (i.e., brochures handouts, exercises).
- (4) D-Party: this was the finalized health and technology education intervention. The study team conducted four D-Parties using a different sample. None of the individuals who attended the D-Parties had been a part of the previous three steps. The study team collected pre- and post-surveys to measure the impact of the intervention.
- (5) Follow-up telephone interviews with D-Party attendees from step four, one month following their participation in the D-Party.

## Methods

The study methodology draws upon three established research approaches: intergenerational information exchange, participatory design and community-based participatory research (CBPR). A common theme across the approaches is a focus on the participants, which the study team accomplished by engaging with them meaningfully across the various steps of designing, then piloting, the intervention.

### *Three research approaches: intergenerational information exchange, participatory design and CBPR*

Intergenerational information exchange focused on consumer-oriented technology designed for health information is an approach that can create learning opportunities for both older adults and young adults, as individuals across generations seek new information (Kaplan *et al.*, 2013). An emphasis on both generational groups learning new skills, rather than on differences in age or technology competencies, is a key principle for effective intergenerational information exchange (Kaplan *et al.*, 2013). Although age groups may have dissimilar goals, connecting older adults with young adults can be effective because it enables them to converge around a specific topic, such as technology use, to support health. Successful technology-oriented intergenerational information exchange efforts apply a dynamic in which

young adults support older adults to navigate – or in some case simply enter into – a digital world. Older adults can also contribute to the information exchange for non-technology oriented goals such as conveying their experience living with chronic conditions and offering insights to maintain health and wellness. This approach can be particularly pertinent for older adults connected to young adults via familial or naturally occurring social networks because they share cultural environments that influence health and technology acceptance. When the primary intergenerational engagement dynamic is one of young adults mentoring older adults in technology skill development, as older adult participants become more knowledgeable about technology and comfortable sharing experiences, new modes of communication develop. According to Ghosh *et al.* (2014), older adults can become “empowered ‘prosumers’ of information in the digital world” (p. 11). Over time, the intergenerational communication dynamic can result in increased technology use.

Participatory design is an established approach that involves users in the design of technology-enabled tools and systems. In the early 1990s researchers across disciplines began attending annual participatory design conferences in the USA. These conferences had previously been held in Europe and focused on technology design for systems used at work (Muller and Kuhn, 1993). Since then, the field has extended to various academic disciplines across the USA and Europe, and in other parts of the world. At present, participatory design is a methodology that defines the research process as one that seeks to understand how individuals perform “everyday” activities of interest, and how to enhance said activities (Bazzano and Martin, 2017). From its inception, participatory design emphasized reciprocity and mutuality via “the mutual validation of diverse perspectives” (Muller, 2002). Participants’ interpretations and preferences are solicited and incorporated throughout the investigative process. A key distinguishing characteristic of participatory design is that participants help to envision and shape data collection and analysis, rather than simply being sources of data in order for researchers to analyze, decipher, and describe a certain activity or phenomena (Spinuzzi, 2005). Participatory design is particularly appropriate for health research with underserved populations to both understand barriers and design interventions to address them (Mikesell *et al.*, 2013).

CBPR is a research approach that includes representatives of the target population in all aspects of the research process, from ideation to authority and authorship (Israel *et al.*, 2012; Unertl *et al.*, 2016). The approach has become more vital because individuals belonging to minority and low socioeconomic status groups are less likely to participate in health promotion interventions and randomized control trials, thus the efficacy of health interventions designed to address persistent health inequity is not clearly understood (Hughes *et al.*, 2017). CBPR is being used increasingly for African American health equity research in collaboration with community-based organizations (CBOs) and FBOs because the approach is well suited to endorse that interventions are designed to meet the persistent health and wellness needs of target communities (Kanaya *et al.*, 2012; Ralston *et al.*, 2014). In predominately African American communities, CBOs and FBOs serve as mediators, and in many cases sources, of health information and health services. Historically, CBOs and FBOs have focused primarily on older adults providing health information to young adults. Consequently, the literature is sparse concerning health information interventions focused on African American young adults supporting African American older adults in the context of community-based health information access (Dodani, 2011; Hays and Aranda, 2015). Moreover, technology usage and adoption investigations typically focus on new adoption, rather than on understanding and leveraging technologies individuals may select and already have access to.

The study approach was informed by literature describing the specific benefits of intergenerational information exchange, participatory design and CBPR. The approaches promote intergenerational health information exchange because involving participants in

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the design of interventions enhances efficacy, specifically for health information access (Morton *et al.*, 2015).

I led the core study team which included a nurse professor and the deputy director of a FBO based in Flint, Michigan. Our core team formed in the early stages of designing the study and preparing the grant, and remained through the writing and preparation of manuscripts for publication. Study procedures were duplicated at the two study sites, one in Flint and the other in Detroit. Other staff from the FBO, including the Executive Director, were essential to the core study team from the project inception. As FBO staff had experience working on various wellness initiatives in both locations, they led participant recruitment, provided transportation as needed, identified community partners to host the sessions, assisted the facilitation of selected sessions, and supported data collection and analysis.

The study was designed to incorporate participants' perspectives and recommendations from the very onset of the project through analysis and interpretation of results. The conceptual basis for the approach is informed by two fundamental concepts of the socio-ecological model of health: multiple factors influence health behavior (e.g. individual, community); and health behavior is influenced by, and influences, the individual's social environment (DiClemente *et al.*, 2005).

### *Sample*

There were two groups of participants for the overall study: individuals aged 55+ who self-reported a diabetes diagnosis (older adults); and individuals aged 18 – 54 who were connected to the older adults via familial or naturally occurring social networks (young adults). All participants identified as African American. Working closely with staff at the Flint-based FBO, the study team initially used convenience sampling for the design sessions, then used snowball and chain-referral sampling, common for sampling hard to reach populations for health research (Penrod *et al.*, 2003). The study team recruited participants in Flint and Detroit by focusing on public housing facilities and churches. Participants were purposively sampled from these two cities because they both represent underserved, urban areas that are particularly impacted by inequity in health literacy and use of technology to access health information (Osborn *et al.*, 2013). During recruitment, older adults were asked to bring a young adult from their family or social networks, and young adults were asked to bring an older adult with diabetes. While not mandatory, this was strongly encouraged. The study team closely monitored prospective attendees to ensure a balance between older adults and young adults. As a result, a balance of older adults and young adults attended each of the sessions. Participants were compensated \$40 for each session they attended. All participants provided consent and the Rutgers University Institutional Review Board (IRB) approved the study protocol on July 4, 2016 (IRB No. 16-793).

### *Data collection and analysis*

The study team administered a paper-based survey prior to each of the health information and technology design, pilot and intervention sessions to collect demographic information (e.g., age, education level, household income and health conditions). The design and pilot sessions were digitally recorded, and the recordings were transcribed. Note takers at the design and pilot sessions captured comments and observations. The core study team also added our comments and observations to the session notes over the course of deliberations over findings in advance of finalizing the intervention. Also, preliminary results were shared and discussed with mentors with extensive backgrounds in gerontology, gerontechnology and health informatics. Preliminary results were also presented and discussed at national and international conferences focused on aging, health equity, public health and health informatics.

## Results

### *Participants*

In total, 29 participants attended the HOPE parties. Of the 29, 11 of them attended the design sessions and 14 of them attended the pilot sessions (see Table I). In all, 14 participants attended the Flint HOPE party, six older adults and eight young adults. Nine participants attended the first HOPE party in Detroit (eight older adults, one young adult) and six attended in January, all young adults. The January HOPE party in Detroit served as a make-up for several young adults who were not able to attend the first HOPE party. Since attendance at the HOPE party was to simply provide potential designers with an idea of what a health information and promotion session was like, having only one young adult at the first Detroit HOPE party, and holding a make-up session for the young adults who could not attend the first Detroit HOPE party, did not hold consequences for that event. We conducted the “design sessions” in Flint and Detroit with six and five “designers” attending, respectively. In Flint, the same six individuals who attended the design session attended the pilot session. In Detroit, the five individuals who attended the design session attended the pilot session, and three additional individuals attended the pilot session (one older adult, two younger adults) in order to create an even number of older adults and younger adults.

The sample contained near-equal balance of older adults ( $n = 14$ , mean age 63.2) and young adults ( $n = 15$ , mean age 28.2) (see Table II).

### *Results from HOPE parties; design sessions; and pilot sessions*

*HOPE parties.* The core study team collaborated to recruit participants and conduct the HOPE parties in December, 2016 and January, 2017. The Flint-based FBO has conducted HOPE parties since 1996. They have been attended by various individuals aged 12 – 90 across Michigan, the vast majority of which are African American. The HOPE parties are three-hour participatory sessions that, after introductions and establishing ground rules, provide basic sexual health information and models for recommended safe sexual health behavior, such as negotiating safe sex and sexual communication. HOPE parties provide sexual health information through role playing and case studies. The HOPE parties provide culturally specific health information in informal settings, and several peer-reviewed journal articles have been published describing the project and the impact of HOPE parties (Prevention Research Center – Michigan, 2017). The study team decided that all participants for the design and pilot sessions should attend a HOPE party to offer them the experience of attending a health information intervention. Participants were informed that they were attending the HOPE parties in order to stimulate thinking to help design a new health information and technology intervention focused on health information specific to diabetes.

Step	Site – Date (location)	Participants (YAs – Young Adults)
(1) HOPE party ( $n = 29$ )	Flint – December 27, 2016 (Church)	14: 6 older adults, 8 YAs
	Detroit – December 28, 2016 (Technology Center)	9: 8 older adults, 1 YA
	Detroit – January 21, 2016 (Elder Public Housing Facility)	6: 6 YAs
(2) Design session ( $n = 11$ )	Flint – February 18, 2017 (Church)	6 “designers”: 3 older adults, 3 YAs
	Detroit – February 17, 2017 (Elder Public Housing Facility)	5 “designers”: 3 older adults, 2 YAs
(3) Pilot session ( $n = 14$ )	Flint – April 1, 2017 (Church)	6: 3 older adults, 3 YAs
	Detroit – April 1, 2017 (Elder Public Housing Facility)	8: 4 older adults, 4 YAs

**Table I.**  
Study participants

	Total	OA	YA	Flint total	OA	YA	Detroit total	OA	YA
Mean age ( <i>n</i> )	45.1 (29)	63.2 (14)	28.2 (15)	40.8 (14)	60.7 (6)	25.9 (8)	49.1 (15)	65.1 (8)	30.9 (7)
<i>Gender</i>									
Male	20	11	9	8	3	5	12	8	4
Female	9	3	6	6	3	3	3	0	3
<i>Education</i>									
Some HS	7	3	4	3	1	2	4	2	2
HS Grad/Equiv.	6	4	2	2	1	1	4	3	1
Some college	10	2	8	5	0	5	5	2	3
College Grad.	6	5	1	4	4	0	2	1	1
<i>Annual household income (\$000s)<sup>a</sup></i>									
< 14.9	13	5	7	4	1	3	8	4	4
15–29.9	9	5	4	6	3	3	3	2	1
30–39.9	2	–	2	–	–	–	2	–	2
40–49.9	–	–	–	–	–	–	–	–	–
50–69.9	3	–	3	2	–	2	1	–	1
70+	3	3	–	1	1	–	2	2	–
<i>Chronic conditions</i>									
Hypertension	16	13	3	8	6	2	8	7	1
Back pain	13	8	5	4	2	2	9	6	3
Arthritis	8	8	0	2	2	0	6	6	0
Asthma	8	2	6	2	1	1	6	1	5
Depression	5	2	3	2	1	1	3	1	2
CHF	2	2	0	0	0	0	2	2	0
CVD	2	2	0	1	1	0	1	1	0
ESRD	2	1	1	1	0	1	1	1	0

**Table II.**  
Demographic  
information of study  
participants

**Notes:** OA, Older adults; YA, young adults; CHF, congestive heart failure; CVD, cardiovascular disease; ESRD, end-stage renal disease. <sup>a</sup>Some participants did not provide income information

*Design sessions.* Selected HOPE party participants collaborated with the core study team to design the health information and technology intervention. The design sessions lasted 90 minutes and after introductions and a brief icebreaker, I facilitated the design sessions by soliciting ground rules from participants (designers), which were captured on large poster boards and posted on the walls. Rules included that there were “no foolish questions,” to respect one another, mobile phones should be kept on silent, and to have fun. The agenda from the HOPE parties was also posted to help familiarize participants on what topics were covered. Next, I as the facilitator introduced the purpose to the design session, emphasizing that the goal was to create a “session” for people they represented, that the session attendees would “look like you, live in your communities and come from similar backgrounds.” I emphasized to the designers that they were selected because: they had unique insights regarding culturally appropriate health information sources and technology acceptance and use; the potential impact that young adults can have on older adults for health information exchange and technology use; and the potential impact older adults can have on young adults explicitly through sharing health information concerning their experience living with diabetes, and any other chronic conditions. Designers were asked to reflect on the HOPE party, specifically on what they enjoyed and what could be improved upon. Particular topics included level of interaction, level of detail of health information, what questions were answered, remaining questions, and sharing of health information both during the HOPE party and in the time since. Next, designers were asked to reflect upon what diabetes information they think is important to the people they represent (e.g., risk factors, treatment



options, barriers to following recommended self-management). Similarly, designers provided input on different technology (e.g., smartphones, websites and various devices) that they might have access to which may be appropriate for the seminar. Designers discussed the feasibility of various technology options, including the potential to incorporate more than one type of technology (e.g., desktop, tablet and smartphone) into the sessions. Designers considered the pros and cons of each. I suggested that designers consider the option of the sessions being held in a computer lab so that each potential attendee could have access to a computer during the session. The designers agreed that one technology would be most effective in order to provide focus during the session. The designers maintained that the smartphone would be most appropriate given that they assumed that both older adults and younger adults would have one and would have at least some familiarity with them. They contended that access and a degree of familiarity with the smartphone would make it more likely that session attendees would be able to refer back to the technology after the session. This was an important consideration as the designers asserted that attendees may want to revisit a health information source (e.g., website or “app”) after the actual session. I concluded the design session by reviewing the poster boards where the core study team members had been capturing notes to confirm administrative details and session content (e.g., duration, facilitator characteristics, types of handouts and technology used).

*Pilot sessions.* Designers at each site attended a “pilot” session six weeks following the design session to confirm that their input had been accurately captured for the D-Party – specifically the practicality of using smartphones, the technology selected for the intergenerational health information and technology exchange. The pilot sessions served to accomplish member checking, a qualitative construct that helps to validate the perspective of the study participants (Creswell and Miller, 2000). The pilot sessions also served to confirm the appropriateness concerning the content and time allocated to the topics, exercises, and handouts. The pilot session also lasted approximately 90 min. I now detail the four sections of the pilot session: introduction; “Diabetes 101”; strategies to support self-management; and small group work and debrief.

The pilot session began with an introduction (10 min) in which I, again as the facilitator, confirmed the session goals, which were twofold: understand how D-Party attendees may access and use diabetes-related health information with the support of technology; and understand how young adults can help older adults to learn about that technology.

I then took 15 min to review basic diabetes health information, which we called “Diabetes 101.” We reviewed and selected information and format that reflected what designers indicated would be useful for D-Party attendees. It was critical that a clinician was part of the core study team, because the nurse practitioner helped to select paper handouts, all of which are available for free on the American Diabetes Association webpage. The handouts provided health information for four diabetes topics, which designers determined attendees would find most relevant: Type 1 vs Type 2 diabetes; treatment options; warning signs and symptoms; and basics of self-management (i.e., diet, exercise, fasting blood sugar-FBS checking/“finger sticks,” medications, and preventative screens which patients should discuss at their follow-up appointments). During discussion of diabetes warning signs, the Detroit older adult designers shared their own experiences with warning signs and detailed their own pre-diagnosis experiences. The older adults shared personal accounts of when they first realized that something may be wrong which prompted them to seek care. Although this sharing and disclosure was not part of the planned agenda, given the richness of the conversation we as the core study team decided to allocate time for it, and I solicited similar information when facilitating the Flint pilot session which followed the Detroit pilot session. In addition to helping to select print materials, having a clinician on the core study

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team and in attendance was critical to answer designers' questions concerning diabetes warning signs and treatment options. Designers also reviewed and played a diabetes word search game, which designers determined would help make the session fun and engaging.

For the next 15 min, designers reviewed specific health information that included strategies the designers shared which help them to follow self-management recommendations. For example, designers reviewed material and discussed strategies to ask their providers (e.g., primary care physicians, endocrinologists, dieticians, diabetes educators) about medications during follow-up appointments (e.g., "Why is this medication recommended if I feel fine?"). In addition, designers offered their own strategies for self-management that they were familiar with (e.g., remembering to take medications by doing so as part of their daily hygiene routines like brushing their teeth, and asking a friend or family member to accompany them to their follow-up appointments). Last, designers shared information concerning how mood can influence self-management behavior, specifically common unhealthy coping behaviors (e.g., smoking, overeating, and avoiding people or social situations) in addition to healthy coping (e.g., exercising, using their personal networks for support).

The next 50 min were spent working in small groups, followed by a debrief. I as the facilitator gave a brief background on smartphone apps that both provide health information and support recommended self-management. I then asked designers to form pairs or small groups, take out their mobile phones, and discuss and explore technology designed to support self-management. All designers had smartphones. Designers were asked to work together in dyads or small groups for 20 min, then come back together to share what health information they found and what technology they used. As the small groups worked together, I and the other two members of the core study team walked around the room to observe the groups and noted what the dyads and small groups worked on. Immediately following the small workgroup session, I solicited feedback on the work by asking the following questions to seed a discussion, which lasted 30 min:

- (1) What technology did you use to find health information? (20 min):
  - For Older Adults: How was your experience having young adults show you how to use technology to find health information? What should young adults keep in mind when teaching you how to use technology to find health information?
  - For Young Adults: How was your experience showing older adults how to use technology to find health information? What should older adults keep in mind when learning to use technology to find health information?
- (2) Reflect upon what worked well, and what did not? What recommendations do you have for the D-Party? What should we consider? (10 min)

### *Summary results*

Four themes emerged concerning the design, pilot and implementation of the health information and technology intervention. First, a mixed group of attendees is appropriate. Second, the intervention should include health information about diabetes and use of technology. Third, focus on one technology, the smartphone. Last, intervention attendees should use the technology themselves to look for health information. As stated in the 10 minute introduction, detailed outcomes of the finalized intervention sessions are described in a manuscript currently under review (Senteio, Soltow Hershey, and Campbell, 2019) and another publication (Senteio, 2018).

### **Discussion**

In this paper I describe the methodology used in the development of a health information intervention designed to support use of technology for African American older adults with

diabetes. The paper details how the intervention was designed and piloted. The study design was motivated by the pressing need to support African American older adults with chronic conditions access to health information. The study team sought to create, test and describe an approach to assist them in their use of consumer-oriented technologies designed to provide access to health information and support chronic disease self-management consistent with clinical recommendations.

This study offers novel insights for how to engage populations who are underrepresented in research and who experience inequity in access to health information and technology. The designers asserted that a mixed group of older and young adults was appropriate. The designers also recommended a session that included health information and the opportunity to use familiar technology, specifically the smartphone which all designers owned and brought with them. Last, a “hands on” working session to use the smartphone was suitable. Findings are applicable to research across various disciplines to consider in investigations to attempt to understand and address barriers to health information and consumer-oriented technology use. Insights are applicable to researchers in: information science, community health informatics, health equity and health education. Findings are particularly relevant for impact researchers who design and test community-based health and technology interventions.

The main limitation to this study is that all participants had smartphones with data plans that enabled access to the internet. There were no “feature” phones among the sample. Future work in similar populations that experience inequity in access to health information, and technology acceptance and use, should consider participants who may not have smartphones. Also, attendance at an established health educational intervention (i.e., the HOPE parties) may not be feasible or available to future research teams. Attendance at this initial step was vital in preparing “designers” by offering an example of a health information intervention; it also served to enable the study team to come together given that it was comprised of FBO staff and academic researchers who had not previously collaborated on a research project. This initial step was important to initiating the study and positioning it for success given the various coordination of activities necessary to schedule, recruit, and conduct the design and pilot sessions.

## **Conclusion**

This is the first study that combines three established approaches: intergenerational information exchange, participatory design and CBPR to create an intervention in which African American “designers,” who experience persistent disparities in access to health information and technology, selected the technology they wished to engage with to promote access to health information. The literature describing studies that use these three approaches does not include African American older adults with chronic conditions participating in the design of health information interventions that promote technology use.

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