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# Exploring Design Recommendations for Promoting Brain Health, ADRD Health Literacy, and Participation in clinical ADRD trials in Older African American/Black Adults

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# Exploring Design Recommendations for Promoting Brain Health, ADRD Health Literacy, and Participation in clinical ADRD trials in Older African American/Black Adults

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Alzheimer's Disease and related dementia (ADRD) is prevalent in one in nine individuals age 65 or above, and it has a 65% higher risk of incidence for African American/Black adults. With an aging population in the United States and persisting healthcare inequities for African American/Black adults, our research aims to explore design requirements of a digital health platform for delivering culturally relevant content that informs African Americans/Black adults (45 years and older) about brain health and participation in clinical ADRD studies. We conducted seven focus groups (n = 44) to collect information on facilitators and barriers to brain health literacy and participation in clinical ADRD research, followed by seven participatory design workshops (n = 44) to collaboratively develop solutions for improving brain health literacy and participation in clinical

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ADRD research. Our findings provide insights into incorporating community into accessible, technological design for reducing brain health disparities for African American/Black adults.

CCS Concepts: • **Human-centered computing → Collaborative and social computing theory, concepts and paradigms**; *Empirical studies in collaborative and social computing*; *Empirical studies in HCI*; • **Social and professional topics → Race and ethnicity**; **Seniors**.

Additional Key Words and Phrases: Community analysis and support, virtual or physical, Information Seeking & Search, Medical and health support, Health - Wellbeing, Older Adults, Empirical study that tells us about people, Participatory Design, Qualitative Methods

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## 1 Introduction

Alzheimer's Disease and related dementias, henceforth referred to as ADRD, is an encompassing term that describes brain disorders that affect individuals' memory, problem solving skills, judgment, changes in mood or behaviors, mental faculties and more [1]. Alzheimer's Disease (AD), however, is the most common cause of dementia [1]. The disease causes plaque and tangle formation that damages neurons, ultimately leading to death [1].

ADRD is primarily a disease of the elderly, and compared to other age ranges, the United States' elderly population will grow the most rapidly from 12% in 2005 to 19% of the total population in 2050 [48]. Therefore, as the nation's population continues to age, it becomes even more crucial to understand how to best prevent and manage ADRD as it impacts not only individuals, but also their families, friends, and communities, in their later stages of life. These challenges are compounded for ethnic minorities, including African American/Black adults, who are estimated to be twice as likely to have AD than White adults [9, 43]. Yet African American/Black adults have delayed diagnoses for AD [9] and are not well-represented in ADRD clinical trials [21].

Older African American/Black adults may be hesitant to enroll in clinical trials because of a "legacy of mistrust" surrounding past research integrity in the United States, legacies of racism and discrimination, mistrust of the healthcare system, and concerns with researchers' methods [21].

Additionally, the online nature of many research registries raises concerns about data management and technology access [9]. However, increasing their participation in clinical ADRD research is crucial to improving the generalizability of findings and achieving more equitable healthcare [21].

Moreover, Kumar et al. highlight the importance of tailoring health messages to align with local cultural practices and knowledge, which can significantly enhance community engagement and information assimilation [33]. They also emphasize that effective health interventions should leverage existing community structures to foster trust and engagement [33].

African Americans often have basic or below-basic health literacy [46], which can contribute to diagnostic challenges. This low health literacy is linked to socioeconomic factors and structural inequalities, such as educational barriers [46], place of residence, income, and parental achievements. However, health literacy is an intervenable factor which if corrected, could conceivably limit health disparities between populations [37, 39]. As health information technology continues to advance, it will be important to incorporate the needs and opinions of older African American/Black adults in designing technology. Individuals with low health literacy can have challenges accessing digital health information, and without incorporating them into future designs, health inequities will only grow [8].

Given these ongoing and emerging challenges, it is essential to engage with African American/Black communities to enhance brain health literacy and clinical ADRD research participation, thereby reducing health disparities. This research aims to explore the technological requirements for delivering culturally relevant content that informs African American/Black adults (45 years and older) about brain health and participation in ADRD clinical studies. This research will contribute to the health research, Computer-Supported Cooperative Work (CSCW), and human-computer interaction (HCI) communities by working towards:

- Understanding older African American/Black adults' socio-technical networks for discussing ADRD and related clinical trial opportunities;
- Exploring design requirements for culturally informed interventions for health literacy and clinical ADRD research participation.

Through these contributions, we aim to enable the reduction of brain health inequities and promote healthy aging and brain health for older African American/Black adults. This research contributes to the HCI community's knowledge of both promoting brain health literacy and clinical ADRD research participation in older African American/Black adults through collaborative design, neither of which have been systematically studied before.

## 2 Related Work

Past research on ADRD has focused on more accurate diagnosis [3], supporting people living with ADRD [51], or assisting caregivers of those living with ADRD [29]. However, this study has a different aim - understanding how to increase brain health literacy and research participation through an informed and collaborative design process for individuals that are not living with ADRD, or those in the pre-trajectory or everyday life phase of elderly care as described by Woll & Bratteteig [54]. Our research contributes to a gap of knowledge in the CSCW community of practicing participatory design with African American/Black adults and understanding socio-technical networks surrounding ADRD, and in the HCI community of designing specifically for brain health literacy and related research participation among older African American/Black adults.

### 2.1 Community-Centric Collaborative Design

Within the HCI community, several scholars have dealt with designing technological intervention collaboratively with vulnerable and under-served populations. For instance, Harrington et al. working with African American communities have provided evidence of the importance of building relationships, trust and creating inviting, culturally sensitive environments in research, as they are crucial for co-creation for health technologies [10, 25, 27, 28]. Creating this relationship based upon mutual trust and collaboration is key when designing with communities who are often neglected and kept at the margins of technological innovation and design [11, 12, 25].

On a very similar line, Lazar et al., whose works focused on design with people diagnosed with dementia, further stress not only the necessity of involving individuals from marginalized groups as active participants in the design process, but also fully acknowledge that even though they are diagnosed with dementia, they still have a say, which must be heard and must impact and shape the development of technology tailored to their own needs and unique experiences [35, 36]. For instance, their conceptualization of the third-hand has been used a way to illustrate the collaboration between the designers and the participants with dementia and as a way to help articulate and materialize the participants' needs without removing its physical and material agency. Hence, building upon Harrington's work [25, 27, 28], they argue that technology development and design for people living with dementia must be built upon the principles of collaboration, but also recognition of each other's agency and standing.

Similarly, Morrissey et al. demonstrate that leveraging community-driven platforms can help create tools that resonate deeply with users, emphasizing the significance of community input at all stages of design as well as inclusive design strategies that account for people with dementia as active users of technology not just their carers [45]. This provides further evidence of the importance of emphasizing designs that are built upon caring relationships rather than a particular user groups. In their case, it results in fostering a caring relationship among people with dementia, their physical and digital communities and their carers. This relationship of mutual care among different stakeholders, who have unique needs and experiences of dementia, generated from meaningful collaboration can contribute to achieve significant social change.

Thus, we could argue that key takeaways for equitable participatory design include avoiding damage-centered research narratives, considering multiple dimensions of accessibility (cultural, economic, societal positioning, literacy), encouraging meaningful conversations, and focusing on participants' storytelling. When discussing health however, they emphasize leveraging community-based design workshops for discussions on community health activism and empowerment, instead of focusing on individuals' stories [26, 36, 45].

Michener et al. examined how academic health centers can better engage with community members through community-engaged research to improve health outcomes [44]. They emphasized that researchers should consider the historical structures that are barriers to entry to research for many community members [44]. To address these barriers, they recommend to first learn in-depth about a community, showing respect, and compensating communities fairly [44]. It is important to include community research partners at all stages of a study [44] to receive their feedback and input, as well as give them the opportunity to learn from the research process.

Our work builds off this collection of literature as a foundation, as engaging with older African American/Black adults requires consideration of the systemic inequalities they have experienced and their experiences with community health research. Only through meaningful involvement of our stakeholders (older African American/Black adults), we may achieve appropriate and usable designs [52]. However, we extend this research domain with specific goals towards brain health and clinical trial participation of older African American/Black adults.

## 2.2 Increasing Health Literacy

There have been several past studies within health research and the HCI community on increasing health literacy and medical information seeking [5, 7, 19, 22, 30]. Without consideration of those with already low digital health literacy, further developments in information technology will only further widen literacy disparities [8]. Additionally, African Americans age 50+ are comfortable with using technology and can leverage their personal devices for health literacy if given the opportunity to do so, as 76% own a smartphone with 96% of African American smartphone users using their device daily [47].

Dong et al. performed a meta-analysis of studies on the effectiveness of digital health literacy (DHL) interventions for older adults, finding significant improvements of health status and health management, especially in interventions that incorporated types of in-person teaching, conceptual frameworks for participants to follow, and were at least four weeks in length [19]. While such work saw positive effects of DHL interventions on older adults' capacity to use information technologies, important unaddressed factors can hinder their potential. For example, factors of aging and disability (e.g. cognitive decline) can compound existing low digital health literacy and challenging medical jargon in online health resources, making it difficult to access and understand medical information [7]. Perhaps most importantly, these works help validate the potential of information technologies, yet do not consider the underlying barriers of historically underrepresented subject groups, in our case, African American/Black adults.

African American/Black communities experience greater barriers to seeking medical information and health literacy, such as limited knowledge, misinformation, mistrust, privacy concerns, fear, and stigma [42]. In a study on barriers to health literacy in African American communities, Muvuka et al. discussed how negative past experiences, structural barriers such as education and discriminatory policies, and health care providers overestimating patient literacy can act as obstacles to achieving higher health literacy [46].

To address these challenges, several initiatives have been proposed to increase health literacy among African Americans and other communities. Evans et al. proposed a game which uses elements of visual novels and strategy games to increase health literacy and self-efficacy for marginalized communities [20]. Goodman, Dias & Stafford have approached this through training the community in research literacy and evidence-based public health, finding benefits not only for enhancing health literacy, but also making minority communities active contributors to research agendas [23]. Gluck et. al's work showcased the promise of leveraging relationships and existing community structures within older African American/Black communities for increasing brain health [22].

The use of Natural Language Processors (NLP) has been explored in the context of health literacy, such as in August et al., where their proposed interactive reading interface provides definitions of unfamiliar terms, key questions and takeaways, and summaries of online health research articles to enhance medical research paper comprehension [5]. While promising as a tool to help users confidently approach research papers, challenges assimilating medical knowledge remain. Users may often encounter unfamiliar terminology, dense text, difficulty knowing what to ask and read, and difficulty relating research findings to personal circumstances [5]. Similar benefits and challenges have been identified with the use of conversational agents (CAs). Kim et al. studied how these factors can affect African Americans. They recognized that CAs can help increase access to reliable health information for remote users [32]. Importantly, cultural challenges remain, as these systems, while highly capable of tackling informational tasks, are yet unable to embody an interactive persona with whom African Americans can relate, and one which they can trust [31, 32].

Past research efforts have also examined ways to improve caregivers' support and health literacy. Online support groups can allow the provision and reception of support from individuals who may not always be well-represented in more public environments [30], which may extend caregivers' support networks. However, these individuals have to navigate complexities of online privacy, advocacy, and education [30]. To improve caregiver health and support, Yuan et al. also studied the use of a conversational robot meant to ask questions and empathize with caregivers of people living with AD [55].

Our research draws from these works, as considering technological design for increasing health literacy in older African American/Black adults requires understanding their comfort with various technologies, as well as considering novel ways to use technologies for health literacy. Our research supplies a novel dimension to this body of literature, as we aim to understand how to increase health literacy, specifically about brain health, through technological intervention.

## 2.3 Encouraging Medical Research Participation

Past work on increasing participation in medical research of African American/Black adults has emphasized the importance of incorporating community and family members into recruitment efforts, as trust of researchers may be decided collectively [14, 24, 34, 49]. Additionally, Gluck et al. highlighted the importance of targeted recruiting for older African American/Black men, as they were successful when becoming involved with and recruiting through church groups [22]. Studies have found that most motivations for research participation are altruistic in nature [18, 38], and that barriers to participation include a lack of trust [14], viewing ADRD symptoms as part of the aging process [18], and lack of technology and digital literacy [4].

When designing technology for participation in research, Anuyah et al. discussed the importance of including support for technical skills and equipment, guarantees of privacy and no harm, and the acknowledgement of participants' personal and social identities as assets in research [4]. These considerations both address barriers to participation for vulnerable populations and empower participants through valuing their unique experiences.

A common technological intervention to encourage medical research participation was the chatbot [15, 38]. Chuan et al.'s chatbot was designed as an eligibility assistant that interacted with participants and categorized research study criteria into questions that either they could answer or those that would require medical consultations [15]. A chatbot studied by Manea et al. was designed to encourage medical research participation by personalizing participation and engagement through storytelling [38]. In both instances, chatbots were advantageous because of their flexibility, accessibility, and interactivity [15, 38].

We identify a gap in this literature of encouraging participation by older African American/Black adults in clinical ADRD trials through technological interventions. By working towards this aim, our research builds off previous work on understanding research motivations of African American/Black adults [18, 38], as well as previous technological interventions for increasing medical research participation [15, 38].

## 3 Methods

### 3.1 Collaborating with Community

Throughout this research, there has been an emphasis on working with African American/Black communities to influence and inform the trajectory of the study. As evidenced by prior studies [27, 44, 52], it is crucial to establish positive relationships with community members and incorporate them as research partners. One of our efforts to achieve this was the formation of a community advisory team, which consisted of older African American/Black adults living in the study region who have personal experiences involving ADRD and the organization of monthly meeting between the researchers the community advisory team.

Before the data collection session, the researchers mainly asked for input concerning the type of activities proposed for the participatory design, looking for valuable feedback and suggestions. For instance, one of insights received concerned the type of activities, indeed the advisory team members suggested the researchers to focus more on activities that would not require high level reading skills and physical mobility, as some participants might have been with low readings skills and low mobility. The researchers then adjusted the activities to take into account the inputs received. After the research events concluded, findings were presented to the community advisory team members for insights from their perspectives. For instance, when discussing the perceived mistrust towards the U.S. health system expressed by our participants, the community advisory team members helped us understand this within a historical and social context of racial inequality and mistreatment of African American/Black citizens and patients. Therefore, any methods and findings described in this study have been shaped by the community advisory team, as advisory team members' experiences with ADRD and as older African American/Black adults helped fill knowledge gaps of the researchers. Additionally, two community engagement specialists organized the community advisory team meetings, as well as engaged with the African American/Black community through attending local events, promoting brain health, and sharing monthly newsletters through email about ongoing research efforts.

## 3.2 Recruitment

After receiving Institutional Review Board (IRB) approval from the researchers' institution, participants were recruited through our community engagement specialists by sharing information about planned focus group sessions and participatory design workshops through digital and print advertisements, seminars run in local churches, and word of mouth.

Given our research aims to understand the needs of older African American/Black adults when seeking and discussing ADRD and related clinical trial opportunities, as well as design requirements for informed health literacy interventions and clinical ADRD research participants before such diagnoses, our goal was to work with older African American/Black adults who had not be diagnosed with ADRD. Thus for recruiting purposes, the two criteria were required: age over 55 and living in the state where the study took place.

Attending participants numbered 44 in total: 17 in region 1 and 27 in region 2. These two regions represent two different geographical areas within the same U.S. state in the Midwest, region 1 is where the capital of the state is located, while region 2 is located at the northeast area of the state, distancing almost 3 hours from the capital, representing a somewhat more peripheral area. Focusing on two geographical regions within the same state allowed us to capture a more representative picture of the needs of the older African American/Black adults living in the state.

Before the planned research events, participants were asked to complete a questionnaire regarding demographics information and their personal experience with ADRD. Tables 1 and 2 describe the list of participants/responses for regions 1 and 2, respectively. Completing the questionnaire was optional, so the table contains all available information with some incomplete responses. The questionnaire asked participants about their age, their gender, their education and their employment, in addition to some questions specific to ADRD. Those were whether the participants had prior family history with ADRD hence, whether they knew of some of their family members being diagnosed with ADRD, and whether they had been a caregiver for a person living with ADRD.

The ages of participants ranged from 48 to 88 years old, with 39 identifying as women and 8 as men. Level of education varied from high school diploma to 34 participants having a college education. Regarding participants' relationships with ADRD, 24 claimed to have some prior family experience with ADRD, while 12 stated that they have been a caregiver for a person living with ADRD.

| P# | Gender | Age | Education | Employment | History of ADRD | ADRD caregiving |
|---|---|---|---|---|---|---|
| 1 | Female | 66 | Associate's degree | Retired | NP | NP |
| 2 | Female | 56 | High school diploma | Full-time | No | No |
| 3 | Male | 61 | High school diploma | Retired | No | No |
| 4 | Female | 56 | Bachelor's degree | Full-time | Yes | No |
| 5 | Female | 57 | High school diploma | Full-time | No | No |
| 6 | Female | 74 | High school diploma | Retired | No | No |
| 7 | Male | 62 | High school diploma | Retired | No | No |
| 8 | Male | 70 | Bachelor's degree | Full-time | Yes | No |
| 9 | Male | 72 | Some college | Retired | Yes | No |
| 10 | Female | 66 | Some college | Retired | No | No |
| 11 | Female | 70 | Some college | Retired | Yes | No |
| 12 | Female | 87 | Elementary and middle school | Retired | No | No |
| 13 | Female | 65 | Bachelor's degree | Full-time | Yes | No |
| 14 | Female | 56 | Bachelor's degree | Full-time | No | Yes |
| 15 | Female | 48 | some college | Full-time | NP | Yes |
| 16 | Female | 66 | Associate's degree | Retired | Yes | Yes |
| 17 | Male | 67 | Some college | Retired | No | No |
| Avg. Age |  | 65 |  |  |  |  |

Table 1. Demographic information of participants attending the session in region 1. NP= not reported

| P# | Gender | Age | Education | Employment | History of ADRD | ADRD caregiving |
|---|---|---|---|---|---|---|
| 18 | Male | 60 | Bachelor's degree | Retired | NP | NP |
| 19 | Male | 60 | Some college | Retired | No | No |
| 20 | Female | 60 | Bachelor's degree | Full-time | NP | No |
| 21 | Female | 63 | Bachelor's degree | Currently seeking opportunities | Yes | No |
| 22 | Female | 69 | Bachelor's degree | Retired | Yes | No |
| 23 | Female | NP | High school | Part-time | No | Yes |
| 24 | Female | 64 | Some college | Part-time | NP | No |
| 25 | Female | 54 | Associate's degree | Full-time | No | No |
| 26 | Female | 47 | Some college | Disabled | No | No |
| 27 | Female | 72 | High school | Retired | No | No |
| 28 | Female | 61 | Master's degree | Currently seeking opportunities | Yes | No |
| 29 | Female | 74 | High school | Retired | NP | NP |
| 30 | Female | 70 | Some high school | Retired | Yes | No |
| 31 | Female | 67 | Associate's Degree | Retired | No | Yes |
| 32 | Female | 73 | Some college | Retired | Yes | Yes |
| 33 | Female | 67 | Ph.D., MD, or higher | Retired | NP | Yes |
| 34 | Female | 57 | Bachelor's degree | Full-time | Yes | Yes |
| 35 | Female | 68 | Bachelor's degree | Retired | Yes | No |
| 36 | Male | 74 | Some college | Retired | No | Yes |
| 37 | Female | 64 | Master's degree | NP | No | No |
| 38 | Female | 61 | Some college | Retired | Yes | Yes |
| 39 | Female | NP | Master's degree | Part-time | NP | No |
| 40 | Female | NP | High school | Retired | Yes | Yes |
| 41 | Female | NP | Associate's degree | Retired | No | Yes |
| 42 | Female | NP | Some college | Retired | No | Yes |
| 43 | Female | NP | High school | Retired | Yes | No |
| 44 | Female | NP | Bachelor's degree | Currently seeking opportunities | NP | No |
| Avg. Age | | 65 | | | | |

Table 2. Demographic information of participants attending the session in region 2. NP= not reported

The questionnaire also provided insights into participants' knowledge level of ADRD and comfort with technology use. Most participants claimed to be at least somewhat familiar with AD (88.23% in region 1, 75.8% in region 2) and dementia (94.1% in region 1, 81.8% in region 2). Cell phones were the most used device to connect to the internet (70.6% in region 1, 69.7% in region 2), with home being the most common location for internet access (88.2% in region 1, 90.1% in region 2). Most participants stated that they would be likely or very likely to use an electronic information platform to learn about ADRD (52.9% in region 1, 60.6% in region 2).

The final section of the questionnaire gathered information on participants' past experiences of and opinions on research. Most participants had never participated in a research study before, though participants expressed moderate levels of trust in research and researchers as a whole. The majority of participants (94.1% in region 1, 72.7% in region 2) stated they would be at least somewhat likely to participate in a clinical trial or research experience about ADRD.

### 3.3 Focus Group Structure

Focus group sessions were conducted in two regions in the Midwest United States. The questions for each session were identical, with one group of sessions being conducted in October and the other in November of 2022. Each focus group session lasted approximately 1.5 hours. Before the start of each focus group session, participants of each region were randomly divided into groups of 5-6 participants, each group with one researcher and note-taker.

Before the beginning of each session, the researcher described the general purpose of the session: learn about the participants' needs and demands concerning a potential tool to help participants learn about brain health and ADRD. Additionally, researchers stressed the importance of understanding and respecting all opinions and participants. The focus groups started with an ice breaker activity that introduced participants to their group. Focus groups were carried out in a semistructured manner, with researchers basing their questions from an outline and monitoring participants' conversations to keep them relevant to the study.

The questions were structured to address four areas: participants' personal experiences with ADRD, their use of tools and information sources to look for ADRD information, their use of tools to evaluate the reliability and trustworthiness information sources and tools, their perception of clinical ADRD trials and related research participation. The goals of these questions were to understand how older African American/Black adults use technology to learn about brain health, as well as learn how they discuss ADRD and related clinical trials with each other.

### 3.4 Participatory Design Workshop Structure

Following the focus group session and a long break with lunch, the same participant groups each completed a participatory design workshop. Each workshop lasted approximately 1.5 hours, which was composed of four design activities. An overview of the whole data collection session can be observed in figure 1.

Participants stayed in their same groups of 5-6 participants from the focus group sessions. The first activity asked participants to create a group persona that summarized the group's needs, goals, obstacles, and tools used when searching for information about ADRD and participating in clinical ADRD research, as highlighted by the prior focus group session. To assist them, participants were given pictures of older African American/Black adults and a printed persona template with five different sections: biography, goals, needs, barriers, and tools. The persona creation activity lasted approximately 15 minutes. This activity aimed to summarize the information gathered during the prior focus group and create a fictional user, who represented the groups' members and could be used as a reference for the following activities.

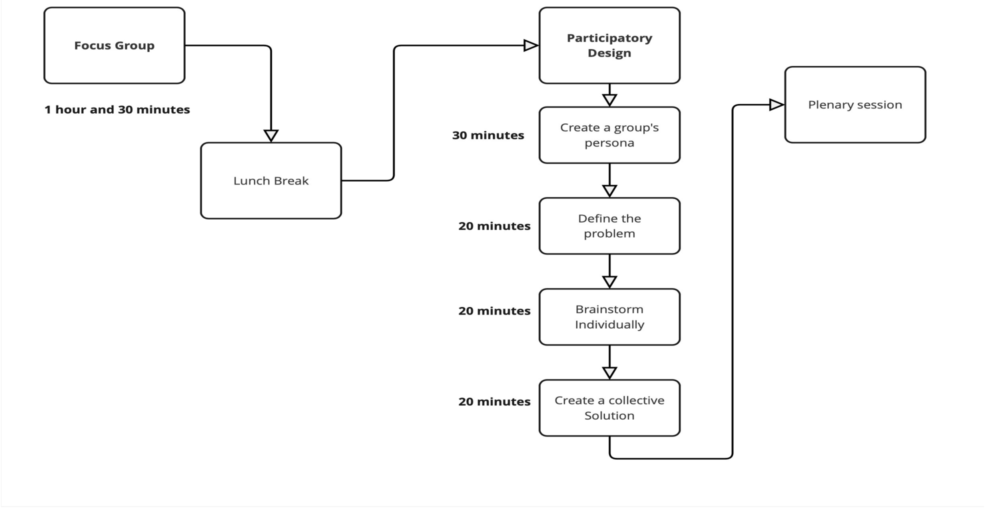


Fig. 1. Chart showing the flow of the activities

The second activity's goal was to construct a concise definition of a problem that participants would attempt to address during the design workshop. Participants were asked to identify a particular challenge relating to their created persona. Participants completed a provided template by stating their persona's name, a challenge their persona might face, and in what way this challenge impacts them. This activity aimed to prepare participants for the following "How Might We" activity and to narrow their following brainstorming activity to one problem.

Referring to their problem statement, participants were asked to visualize possible solutions to their problem through brainstorming. Each participant individually brainstormed for ten minutes, and they were given paper and markers to visualize their ideas. Participants then shared their ideas with the rest of their group, after which each participant voted for their favorite ideas of other group participants. To finish the workshop, each group worked together to create a final, more detailed idea that incorporated the most voted upon ideas. All final ideas were shared with the other workshop groups. By engaging in this participatory design workshop structure, we aimed to collaboratively explore how technology might supplement existing social structures and strategies to learn about brain health and participate in ADRD-related clinical trials.

### 3.5 Post-Workshop Analysis

After the focus group and participatory design workshops were conducted, transcriptions of the participants' and researchers' conversations were made and anonymized for further analysis. Any physical materials made from the workshops, including participants' notes and completed templates were digitized for further analysis. Focus group workshop transcriptions were analyzed by four researchers, beginning with each researcher analyzing one randomly selected transcription for qualitative analysis following Braun & Clarke's guidelines [13]. Transcriptions were qualitatively coded through the online platform Taguette.

Each researcher created their own list of codes based on their analysis of the single focus group transcription and then met to discuss their codes. By the end of this process, 72 codes emerged. The researchers collectively developed a common code-book of 72 codes based on the initial list of codes, which were then used individually by each researcher to code the remaining transcriptions.

The researchers met repeatedly during the coding process to discuss any new codes and how they would fit into the existing themes, or if new themes should be considered. By the end of the process, from those 72 codes, 6 themes emerged, which were grouped into 3 categories. The digital participatory design materials were analyzed by identifying how frequently similar ideas emerged between the separate workshops, and a similar protocol as the focus group sessions' analysis was used to analyze participants' discussion points.

## 4 Results

### 4.1 Focus Group: Results

Across all focus group sessions, findings emerged on the multiplicity of challenges of caring for people living with ADRD, apprehension towards discussing or admitting the onset of ADRD, best practices and challenges of retrieving information on ADRD, and facilitators and barriers to participation in medical research.

*4.1.1 ADRD Caregiving takes a profound emotional, physical and mental toll on the caregiver.* Participants discussed the impact caregiving has on their own lives or those of their friends and family members. First, ADRD has emotional impacts on caregivers as participants perceived it as a "scary" disease because of how ADRD changes people and their ability to carry out what used to be daily tasks. One participant gave an example of how people living with ADRD may still attempt to care for themselves, but there are physical implications of risks of forgetfulness:

> *That's what I'm afraid of for my mother because sometimes she wants to still think that she can do things and she has an electric stove, you know there's no fire, [but] she can leave something on the stove and overcook it and it might catch fire.* P38.

Another level of fear for caregivers is for themselves, as they recognize the challenges that ADRD can bring to an individual and their family. One participant explained that whenever they forget something, they think *"oh damn, I'm already, is it already happening?"* (P3, Region 1). Participants had these concerns about the onset of ADRD, which they recognized could begin at various ages. Many expressed feelings of hopelessness without any real solutions to curing ADRD, which led to further turmoil as caregivers must decide the best course of action for themselves and their loved ones. As one participant explained, ADRD can affect those who even stay active and take preventative measures against it:

> *They worked crossword puzzles. They did a lot of reading and stuff, and they said that, I had heard that, if you do that it may delay it or prevent it. I don't know, but it didn't help them. Those were the two in the family that always did puzzles and read and even did it individually and called each other and got things together. So, what's the deal about it, there's no cure for Alzheimer's. And the medicine only delays it, so what can you do?* P8.

Caregiving becomes more intensive when it alters relationships between family members, as people's children or relatives can become involved with caregiving when someone has ADRD. This furthers the emotional toll upon caregivers, as they want to care for their relatives, and they see how ADRD has changed their loved ones. One participant described how they felt being with their father while he had ADRD:

> *It's just really hard to see my dad in that kind of era. You know, because he's never, he's never, I mean, sometimes I'm glad he forgets. Because you know there was a time when he realized his memory was gone, but now he doesn't really remember a lot of the things that he does, which I'm glad because I think he would just be devastated.* P5.

For the focus group participants that were caregivers, they shared with each other their feelings as caregivers as well as best practices they learned. As one caregiver described, it's even important to just have someone to talk to and empathize with over caregiving challenges:

> *I was stressing myself out. I was eating everything in sight, and the caregiver gets the worst of this. Yes. I mean, my husband, he was just happy. He didn't know what was going on, but caregivers need the care. We need the help and trying to find help for ourselves, I found that difficult sometimes. Because sometimes at two o'clock in the morning, I just needed to talk to someone and to find someone that's going to actually help you. That was an issue.* P24.

Finally, participants described challenges they had within their communities about discussing ADRD in general. Whether friends and family misunderstood ADRD or did not want to admit that their relative might have it, there was an apprehension for discussing it. For caregivers, this can serve as a barrier to receiving much-needed support. One participant described their challenges with discussing AD with their family:

> *I look at all my family members and stuff, and they're just like, I don't really think they really understand and embrace the whole idea of Alzheimer's. That's a disease. That's something that needs special attention, and we don't look at that like that. We just look at it like, 'oh, they're just getting old and yeah, you know, forgetful. Oh, you know because I mean, it is part of aging.'* P5.

This participant's description of their interactions with their family highlights two different reasons for apprehension towards discussing ADRD. People can misunderstand the difference between memory loss associated with natural aging and ADRD, or they might not want to admit to themselves or a peer having something labeled as a disease.

*4.1.2 ADRD related information should be accessible, reliable and actionable for caregivers.* When seeking information about ADRD, participants discussed that they typically look for information that is accessible and accurate. In many cases, accessibility means something that can be read easily and translated into practical facts without unnecessary medical jargon. One participant described their challenges reading about ADRD:

> *And so they would give us something to read, they had such big words. Well what does this mean? What does that mean? So you're trying to read one sentence, you've got to stop, go find a dictionary, look up one word, okay. That means that, then you try to put that in the context, but then in the next sentence it's used a different way then you're going – I think something plain and simple ... People can understand it in more layman's terms than just a whole lot of medical terms.* P10.

When asked about the types of information that people are interested in looking for, participants often focused on caregiving best practices, how to prevent ADRD, how to diagnose ADRD, and community support. For participants that knew someone with ADRD and caregivers, they wanted to learn how to best support their friends and family, as well as themselves. As described prior, caregiving can take many tolls on an individual, so participants expressed interest in finding information on healthy coping strategies. One strategy that arose often was that of community support, whether community centers were providing information or assisting people with finding assistance. Churches were discussed frequently as community hubs, as this participant mentioned:

> *African American community, we don't, especially a disease process like this, we just, we're just about ourselves. We rely on each other, right, you know, and our church, and our loved ones, you know, to provide us with whatever it is that we need.* P5.

Beyond organized community support, participants discussed how their peers with prior experiences with ADRD provided support and information. As a new caregiver, someone could learn from their those who had already learned from caregiving for someone living with ADRD.

However, it often is unclear what kind of information should be searched for. Participants understood AD as a confusing disease because of conflicting sources of information and how it can affect people so differently. Participants might attend education events or read information about ADRD and realize there were things they should have investigated prior, as one participant described:

> *I find it's every time I go to a seminar and looking up on the internet and stuff, I find there's a lot of stuff that I didn't know that's out there. So I'm not going to say there's anything out there that I would like to know, that I can't get because I probably can. And I'm just now learning that these are the things that I do need to know.* P7.

Finding information about ADRD occurred through the following methods: books, computers, phones, television, seminars, organizations, and people. The use of these sources depended upon availability, but more importantly, how trustworthy they were perceived to be. Participants expressed that they often were not sure what information about ADRD were true, and this added to participants' feelings of being overwhelmed by the amount of information available. They spoke of wanting the "right" information, whether that was something that was applicable to their situation or that was accurate and not being advertised for profit. This feeling applied to participants self-searching for information online, in addition to concerns of discording information between multiple doctors and other sources.

Participants trusted information that came from their peers, or people they had long-standing relationships with, and recognizable organizations such as their church, the Alzheimer's Association, or public libraries. Just as participants had support from people with similar experiences to them regarding ADRD, they also trusted them as sources of information. However, this does not mean that people always seek out information from these sources. As one participant explained, information needed to be provided to them:

> *We don't really seek out information like that. Usually, information has to come to us, you know, it has to be close so we can get to it.* P5.

*4.1.3 Transparency, accessibility and acknowledging the past can foster participation in ADRD clinical research.* Researchers discussed with participants how medical research opportunities encourage and discourage participation, and recommendations for clinical ADRD research opportunities in the future. Participants were asked what their initial thoughts were when they heard the phrase "medical research," to which they gave an open range of responses of varying types of interventions (e.g. medication, shots/needles, experiments).

Encouraging factors for medical research participation included researchers showing concern for African American/Black communities, transparent communication, and personal connections/relevance. Participants expressed that as African American/Black adults, they were not well-represented in ADRD medical research. As one participant explained, this is why they thought it was important to find ways to participate:

> *African Americans are always the last ones to volunteer for these things. And that's why we don't have a lot of information to heal. So it's like, if you don't join, you know, and be a part of the solution, then how do you? How do you find out how to cure it? So that's, that's, you know, kind of the, my mindset is, if you don't participate, then how will we find a solution?* P4.

They appreciated it when researchers took time to advance knowledge on ADRD with their communities in mind, to ensure that findings would be relevant for them. Additionally, participants liked when research activities were very descriptive about their procedures and implications. Whether they were being compensated, undergoing some medical intervention, or knowing how research data would be processed, they wanted be aware. The participants appreciated this communication because the well being of themselves, their peers, and future generations could be impacted by the research. When they felt that medical research could bring positive change for someone in their lives, they were more likely to participate, as evidenced by one participant:

> *And what are you going to do with the, with the data, and how's it going to be helpful? You got to explain that. Because, I mean, that's what I was dying to find out, you know, like how is this going to help Dad, and how is this going to help, maybe not Dad, but somebody else 10 years from now or whatever? And I'm happy to be a part of that.* P5.

Discouraging factors included side effects, racial discrimination in the healthcare system, and unethical past research. Participants consistently expressed concerns about side effects, especially long-term effects of experimental drugs. Participants also expressed concerns about discrimination in the healthcare system, such as being mistreated for pain management because doctors told them that Black adults had predispositions for high pain tolerance. In every conversation, unethical past research on African American/Black adults was discussed. Many referenced the U.S. Public Health Service Syphilis Study as Tuskegee. Such facets of medical research make it intimidating for African American/Black adults to participate, as one participant explained:

> *I do understand what you're saying about side effects, and then even one back, you know, for Black people. We all always heard about the Tuskegee syphilis experiment and study and all of that. So I know as a community in general, we're scared to risk it to be the first ones out there for anything.* P3.

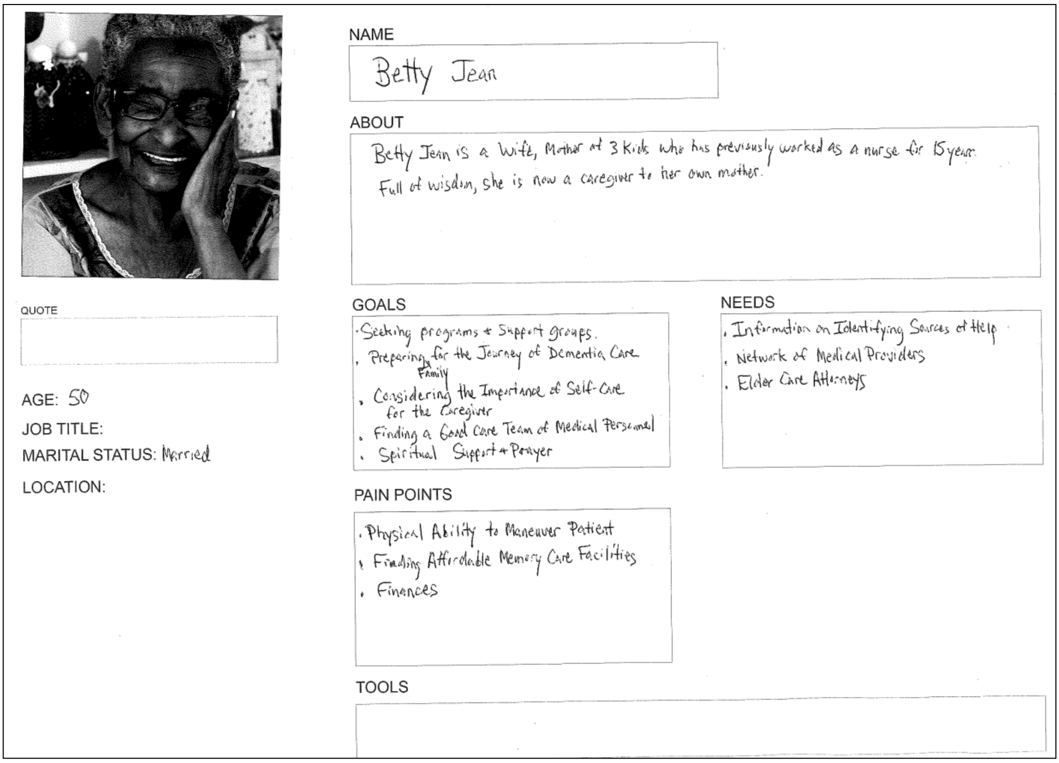
When prompted what recommendations they would give to increase participation of African American/Black communities in ADRD research, participants responded that they would like events to be held in accessible places, making events social, focus on building relationships between researchers and community members, and adequate compensation. Participants expressed a desire for research events to be social in nature, being at physically accessible community centers and churches. They expressed it would be helpful to make medical research a community event, where community leaders/advocates could encourage their peers to participate and help their community. Keeping research social keeps the activities engaging and promotes awareness of ADRD, while also minimizing any apprehension of engaging with ADRD. As one participant summarized, they wanted researchers to be a part of this social experience as well, as it would promote trust and understanding of the research:

> *Go to the community and townhouse meetings, you know, community meetings and like to say it, you know, show up, be present, you know, for to be able to educate and help us understand what the medical research is about and that how important it is for us to be a part of our African American community, to be a part of the research.* P31.

## 4.2 Participatory Design: Results

*4.2.1 Materials Synopsis.* The activities from the participatory design workshops gave participants the opportunity to brainstorm examples of challenges they faced and explore solutions that could work for them. Results of the activities can be divided into three segments: persona creation, problem statements, and group solutions.

When creating a persona, each group collaborated to create a fictional person that represented themselves. Participants filled in information about their persona's name, age, job title, status, location, about section, goals, challenges, needs, and tools they used. The persona creation activity proved to be most challenging out of all the workshop activities. While the other activities involved discussions or brainstorming, which participants potentially had prior experience with, persona creation is a more design-specific act that can be difficult to relate to. To overcome participants' hesitations with persona creation, researchers described the activity as creating a fictional character that would be representation of all of the participants of each group. Researchers prompted the participants to create the fictional character one step at a time, first starting with simple information such as age. Across all groups, the most common characteristics of the personas were that they were a caregiver, someone above 45 years of age, and a family-oriented person. For example, Figure 2 shows a created persona, "Betty Jean."



NAME
Betty Jean

ABOUT
Betty Jean is a Wife, Mother of 3 Kids who has previously worked as a nurse for 15 years.
Full of wisdom, she is now a caregiver to her own mother.

QUOTE

AGE: 50
JOB TITLE:
MARITAL STATUS: Married
LOCATION:

GOALS
- Seeking programs & Support groups.
- Preparing Family for the Journey of Dementia Care
- Considering the Importance of Self-Care for the Caregiver
- Finding a Good Care Team of Medical Personnel
- Spiritual Support & Prayer

NEEDS
- Information on Identifying Sources of Help
- Network of Medical Providers
- Elder Care Attorneys

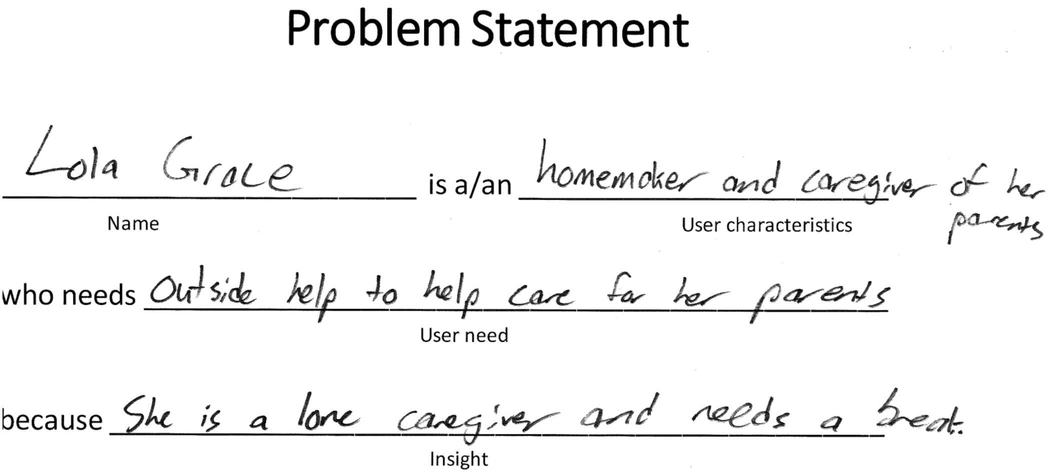
PAIN POINTS
- Physical Ability to Maneuver Patient
- Finding Affordable Memory Care Facilities
- Finances

TOOLS

Fig. 2. One of Region 1's created personas, "Betty Jean."

Each group's problem statement reflected the goals and challenges of each created persona, with participants being asked to focus on one issue. Most commonly, problem statements focused on either obtaining financial/social support outside of the household, educational resources to learn how to prevent and manage ADRD, or tools to assess the reliability of information regarding ADRD. Figure 3 shows the problem statement created for a different persona, "Lola Grace", reflecting the need for external resources and support due to caregiver burnout.

To resolve each group's problem statements, participants brainstormed solutions that could assist their created persona. A variety of solutions were ideated, each of varying modalities. Most commonly, solutions involved interacting with medical professionals or community members via phone, with a mix of digital and physical resources. Participants believed that having accessible repositories of information about ADRD, as well as information on social, transportation, and financial assistance would be helpful. For participating in medical research, participants also believed it would be useful to have repositories of information that described the benefits of participation for participants and their communities. With all these solutions, participants emphasized the importance of community-centric practices and having information accessible in physical places, such as churches and schools. Participants tended to prefer face-to-face interaction and the integration of solutions within their communities. For example, Figure 4 details one group's solution as a physical, local resource center that can provide transportation, information, financial assistance, and more.



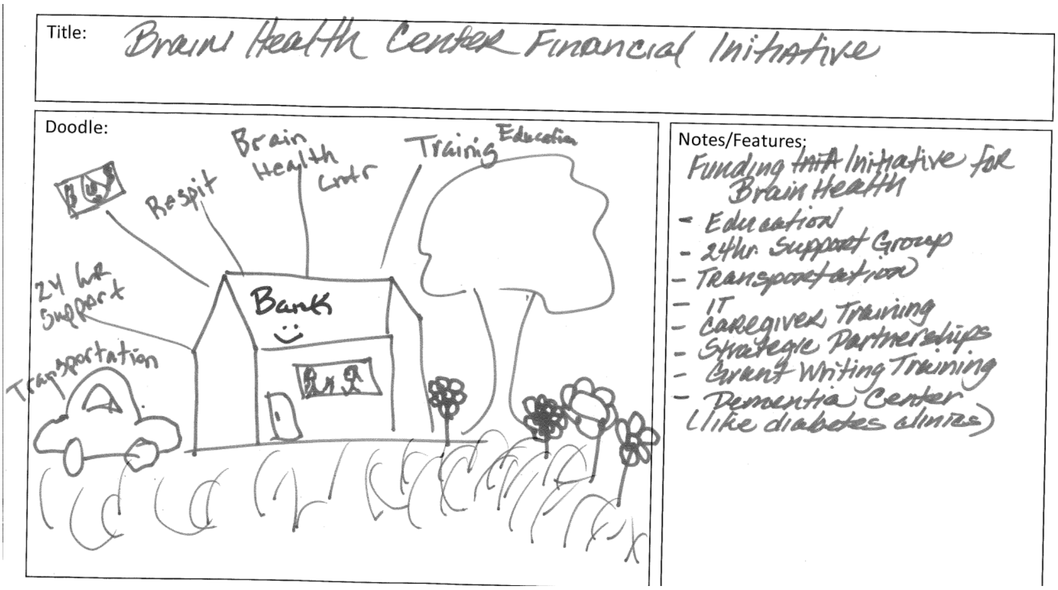
**Problem Statement**

Lola Grace is a/an homemaker and caregiver of her parents
Name — User characteristics

who needs Outside help to help care for her parents
User need

because She is a lone caregiver and needs a break.
Insight

Fig. 3. One of Region 2's group's created problem statement for their persona "Lola Grace."



Title: Brain Health Center Financial Initiative

Doodle:

Notes/Features:
Funding ~~init~~ Initiative for Brain Health
- Education
- 24hr. Support Group
- Transportation
- IT
- Caregiver Training
- Strategic Partnerships
- Grant Writing Training
- Dementia Center (like diabetes clinics)

Fig. 4. One of Region 2's group's solution to the problem statement and persona they created, the "Brain Health Center Financial Initiative."

*4.2.2 Designing Community-Oriented, Caregiver Friendly Solutions.* Given the resulting designs from the participatory design sessions, the importance of designing for caregivers' multitude of challenges and integrating community were highlighted once again. These results align with the discussions that occurred prior during focus group sessions, as caregivers expressed their particular needs, and community was identified as both a trustworthy communication channel and host for new designs. For example, one group ideated a local organization that would host interviews and discussions with local, ADRD professionals to spread education on ADRD and awareness of opportunities for participating in clinical research. These events would be located within places already trusted and used by the community, such as churches, schools, senior living facilities, radio channels, and social media groups.

The different solutions also offered a spectrum of levels of engagement, as some solutions provided more passive sources of information (i.e., newsletters, social media posts), while others would require more intentional participation (i.e., attending events, participating in discussions). This variety is important, as it can allow caregivers and others with time constraints different levels of engagement.

Beyond the emphasis on caregivers and community, the variety of designs showcase older African American/Black adults' comfort level with a variety of technologies, with the caveat that they be tied to local resources. Designs used phone calls, physical buildings, social media campaigns, websites, newsletters, and face-to-face interactions as methods to addressing the problem statements created for each persona. Depending on existing community info-structures, certain technologies may integrate better into local communities than others. For example, it may be beneficial to incorporate trusted social media groups into information dissemination if those groups exist, but creating a group from scratch may be more difficult to garner support for. These aspects of design realistically point to implementations on smart devices or computers, as they have the flexibility of incorporating the different types of engagement, technologies, and existing community structures.

## 5 Discussion

The results obtained through the focus group and the participatory methodology are discussed in this section. Table 3 provides a high level summary of the findings which will be discussed in greater details in the sections below.

| | | | |
|---|---|---|---|
| **The importance of community** | providing trusted information source | validating decisions | fostering collective decision-making process |
| **Balancing the right amount of information** | participants want detailed information | avoiding medical jargon | information's transparency |
| **Implications for design** | integrating community resources | multidimensional accessibility | designing for informal caregivers |

Table 3. Table providing an overview of the key-findings

### 5.1 The importance of community

One of the major findings offered by this research is the crucial role played by communities in both the health information-seeking process and in motivating older African American/Black adults to participate in clinical ADRD research. Community serves as a type of trusted information source (e.g through sharing personal experience with peers or asking for advice/suggestions), as demonstrated by prior work on public health and minority populations describing the collective decision of trust in researchers [14, 24, 34, 49]. Community trust also validates individuals' decisions to trust information from medical specialists and organizations, such as the Alzheimer's Association. While individuals are more likely to align with people that they have long-standing, personal relationships with, the community's faith in a specialist or organization can allow a source to be trustworthy. This collective-decision making process has been observed in prior research on collaborative search and retrieval of information, as community members act as information sources as they share, archive, and consult on ADRD information [53]. However, dependency on community can exacerbate challenges of stigma and misunderstandings surrounding ADRD. As seen in prior research, individuals may dismiss ADRD as normal parts of aging and be apprehensive of something labeled as a disease [6]. Thus, a combined approach is needed, where efforts to increase digital health literacy can help mitigate misinformation and stigma surrounding ADRD, coupled with strong communal ties which can solidify the update of such technologies and increase its adoption and access. This can be seen in the work of Evans et al., by combining gamified information assessment, while simulating community advocacy through game mechanics [20].

This is also attainable in other ways. The importance of well-known community spaces and the desire by participants for research events to be more social is notable, as face-to-face interactions can increase researcher-participant rapport and equal relationships [18, 23], increase digital health literacy intervention success-rates [55], and aligns with past findings of social bonding as a motivation for research participation [41]. Navigating health literacy with the help of the community can be promoted by purposefully designing peer interaction for medical information comprehension, such as dedicated online forums, as evidenced in Rubenstein's work, which enabled informational and emotional types of social support to promote "feedback and camaraderie that interacted together to help in the learning process" (p.3) [50].

The desire to improve their community was also a significant motivator for participating in medical research. While study benefits may only directly impact participants (e.g. through compensation, social bonding), helping future generations of their community was considered just as important, if not more so. These altruistic behaviors have been observed as motivators for research participation in prior work as well [18, 24]. Important prior work by Gluck and colleagues has also proposed a strong emphasis on community value through long-term relationships, the use of local spaces such as churches, gaining information from trusted community leaders, and promoting "ambassadorship" in research participants [22]. These lessons can greatly inform CSCW work, as designing technologies with a community focus is imperative to increase visibility of African American/Black adults in research, through designating "power users" amongst both community leaders and research participants, as advocates to aid in building and maintaining lasting relationships between designers of technology and the community. This can lead to culturally sensitive participatory and co-designs of technologies for education and research of brain health.

### 5.2 Balancing between too much and too little information

Participants desired every piece of information, but they also faced challenges of being overwhelmed by too much or contradictory information. Conflicting information can be challenging when it comes from multiple sources online, or when trusted doctors and professionals are giving varied information that must be parsed through. These challenges align with those of providing medical ADRD information to individuals, as individuals may want as detailed information as possible but also need something that is not littered with medical jargon, as medical terminology can be a barrier to health literacy [5, 7].

Beyond being confused by contradictory information, the amount of available information about ADRD can paralyze individuals and limit their efforts to learn about ADRD. Participants expressed not knowing what to search for, which agrees with past research that discussed individuals not knowing what to read in medical research articles [5]. This leads to, as many participants referenced, waiting for information to be provided to them. However, this brings more challenges because healthcare providers overestimate the health literacy of their African American/Black patients [46].

Relatedly, participants required transparency about research details when considering participation in clinical ADRD research. This design requirement may stem from the historical mistrust of the United States healthcare system and research practices, as documented by prior research [21]. To start working against this mistrust, it must be a requirement for research studies to clearly describe their methods, the backgrounds of the researchers, investigating institutions, and compensation. Most importantly, potential participants need to be aware of the practical implications of how a research study might impact them or their community, as many African American/Black adults have altruistic motivations for participating in research [18, 38].

### 5.3 Technology for ADRD: Implications for Design

Technological design offers the opportunity to build off existing, successful strategies for information-seeking and medical research participation within the African American/Black community, while also addressing many barriers and challenges. Through building off past research with our findings, we recommend the following guidelines for designing technology for increasing brain health literacy and clinical ADRD research participation in African American/Black communities: integrating community resources with technology, multidimensional accessibility, designing for caregivers.

*5.3.1 Integrating community resources with technology.* Participants were comfortable using technology as an information tool, though they also wanted it to be integrated into pre-existing aspects of their community. By leveraging community resources, one challenge of technological accessibility can be addressed, as past research has discussed concerns about community members having unequal access to digital technology [40]. For example, commonly cited resources for participants were local events and seminars for providing ADRD-related information, which might be held in churches, schools, or senior living centers as participants discussed. To support these types of events, digital technologies could record or summarize presentations for future reference, which could assist anyone with time or mobility constraints by providing information in a non-live format. Digital technologies can also help promote these events, leading to overall higher engagement. A variety of technologies can be considered for implementation, such as phone calls, social media, websites, and digital newsletters as found in our participatory design workshops, to be as inclusive of community members' varied technology preferences as possible. These technologies may help with promotion, as well as provide supplemental ways of information retrieval for community members who cannot attend local events. However, the continued use and support of the in-person events would be inclusive of anyone not comfortable with a digital format. The use of physical, established community spaces should also be used for research events, as they greatly benefit research participation and engagement [18, 23, 41, 55].

Considering the reliance on community as information sources for ADRD, technology could also be used to facilitate information diffusion between community members. Past research has examined the benefits and drawbacks of online support spaces for people living with ADRD and caregivers [17, 30]. Considering the discussion of social media groups and online support spaces in our participatory design workshops, as well as the importance of trust among peers discussed in our focus groups, this offers an opportunity to build of existing, relationship-driven info-structures among community members. Online support groups present challenges of privacy control for users, but a designated, online platform for local community members could provide more privacy than typical, public support groups on social media. Additionally, a designated space might encourage individuals to engage in discussions about ADRD and work against stigma of discussing something labeled as a disease. Online, community support would allow knowledge transfer between community members that are not in individuals' immediate social circles, allowing for greater circulation of relevant brain health information and empowering the community's system of collaborative search and retrieval of information [53]. Trusted specialists, such as local doctors, and representatives of trusted organizations, such as the Alzheimer's Association, could also participate in these community spaces to provide more official information about ADRD and negate potential, misinformed conversations about ADRD (i.e., discussing ADRD as a typical part of aging).

*5.3.2 Multidimensional accessibility.* When asked about their intention to participate in medical research, some participants emphasized how the physical location of research study has to be easy to access, hence accessible for all different types of mobility and motor skills. Physical accessibility is just one aspect, among others such as literacy and cultural accessibility. By adopting this perspective on technology, any technological design has be accessible for African American/Black adults of varying levels of familiarity with technology, motor skills, and health literacy.

Conversational agents (such as chat-bots and voice assistants) could be particularly suited for this population and accessibility. Previous research has identified voice assistants to be useful for users presenting low [16] and limited eye vision [2]. Relatedly, chatbots have been described as flexible, interactive, and accessible for encouraging research participation [15, 38]. Hence, conversational agents, designed to provide ADRD information and potential clinical ADRD research opportunities, could represent an effective tool for assisting African American/Black adults in increasing brain health literacy and research participation. Such tools could also concisely summarize clinical ADRD research goals and methodology for users, providing individuals with the transparency of research they desire.

A notable challenge that emerged from our discussions with participants about learning about ADRD was medical terminology as a barrier to knowledge. Coupled with confusion on what information to search for and being over or underwhelmed by information, this can make knowledge about ADRD largely inaccessible. However, natural language processing systems offer a way to simplify medical terminology, recommend relevant information, and automatically summarize important information for individuals [5]. This technology could provide individuals with usable information that satisfies their desire to be well-informed of medical information, while providing the correct granularity of detail, and the practical implications of participating in clinical ADRD research studies. Paired with the personalization and flexibility possible through conversational agents, natural language processing systems could prove beneficial for empowering brain health in older African American/Black adults. These technologies could also recommend potential action items for users, empowering individuals to learn more, participate in research, or change behaviors to benefit their brain health. Past research has shown that providing such resources to act upon are beneficial in health technology interventions [40].

*5.3.3 Designing for caregivers.* Many participants described the difficulties of caregiving for someone living with ADRD. They stressed how caregiving for loved ones can be time consuming, while also being physically, mentally, and emotionally exhausting. Considering the importance of caregivers in relation to ADRD and their added constraints, it is important to be intentional in designing for them as potential users of technologies. Knowing their constraints, any technology for caregivers must be easily usable and time efficient. Caregivers' interactions must be brief and informative with technology, so that even while caring for someone with ADRD, they have access to helpful information. Special care must be taken when using technology to recruit caregivers for participation in clinical ADRD research trials, as their time and attention is extremely limited. Technology could allow for greater participation from caregivers however, as online participation or contributing to research asynchronously would allow for them to contribute without taking them away from their obligations as a caregiver.

Given the emotional toll on caregivers, any technological intervention designed for this population should also include opportunities for emotional support and assistance. This could be achieved by creating online communities for ADRD caregivers, or by relying on pre-existing support groups run in the community. Technology could facilitate the diffusion of pre-existing, local support groups or create such an online, local platform for community members, as suggested prior. Previous research has supported the use of such online platforms for caregivers but has emphasized the need for in-person training and involving caregivers in the design process [17]. When community-oriented, in-person support may not be available, smart devices may also be used to answer questions and provide emotional support to caregivers, as done by Yuan et al. using a conversational robot [55]. Given the range of technological ideas offered by our participants in our participatory design workshops, as well as their comfort with using cell phones, the implementation of these technologies can vary to match caregivers' unique circumstances. For example, having a conversational agent on a smart phone would benefit potentially more isolated caregivers, while leveraging local resources can be beneficial to those that have them available. Still, online groups may offer support to all, regardless of local resources.

## 6 Conclusion

To address brain health inequities among older African American/Black adults, our research took a first step in engaging this community in promoting their brain health and increasing ADRD-related clinical trial participation through technology. After learning from seven focus groups and participatory design sessions with older African American/Black adults, our research emphasizes the importance of incorporating community into design for older African American/Black adults, as community members facilitate trust and information exchange regarding ADRD. To address barriers to brain health literacy and clinical ADRD research participation, we recommend designing for technology that builds off pre-existing, successful systems within communities, being mindful of different types of accessibility, and designing for the constraints of caregivers for people living with ADRD. Specific technological designs that could be tested in the future for promoting brain health information and clinical ADRD research participation in older African American/Black adults include an online, locally based information-exchange and support platform for ADRD and the use of conversational agents to synthesize ADRD information and provide recommendations for users. Our findings provide novel insights for the HCI community on engaging with older African American/Black adults for promoting brain health and participation in clinical ADRD research, as well as understanding social and technological strategies among older African American/Black adults concerning ADRD.

### 6.1 Limitations and Future Work

The results derived from this study are subject to certain limitations. Using only group activities, such as focus group and workshops, can lead to some participants limiting their interactions and contributions to the discussion. Future work could attempt to address this limitation by pairing individual interviews with group workshops. Additionally, concerning the sample, we can observe that there were few male participants. These could be explained as women tend to live longer than men and being diagnosed more with ADRD compared to their men counterpart, however given that the goal of this study is to increase brain literacy and encourage ADRD clinical trials participation before any diagnosis of ADRD and create an culturally informed intervention ad hoc for this issue, a more gender diverse sample could improve the generalizability of our findings. Hence, Future research could overcome this limitation by placing a greater emphasis on more gender-diverse recruitment.

### 6.2 Acknowledgments

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