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## A Qualitative Examination of Knowledge, Experiences, and Considerations of PET Brain Scan Participation among Older Black and Latino Adults

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### Abstract

**Background:** Biological biomarkers yielded from positron emission tomography (PET) brain scans serve as a pathway to understanding Alzheimer's disease pathology. PET brain scan data remain limited for populations traditionally under-included in aging research.

**Objective:** The purpose of this qualitative study was to examine participant-identified barriers to PET brain scan consent and characterize participant-informed elements of educational materials needed to facilitate PET brain scan participation among older Black and Latino adults.

**Methods:** Participants (N=31) were older adults (mean age=71 years) who self-identified as either non-Latino Black (n=15) or Latino (n=16). Each participant took part in a one-time,

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**Institutional Review Board:** The current study and the two parent cohort studies, Clinical Core and Latino Core, were approved by Institutional Review Boards at Rush University Medical Center. All participants signed an informed consent document for each study.

in-depth individual interview. Researchers analyzed data guided by a Grounded Theory Approach with both Open Coding and Constant Comparative Coding.

**Results:** Four overarching themes emerged across all participants: 1) knowledge limitations; 2) requirements for consent; 3) motivators for participation; and 4) social networks. Within the four themes, there were differences based on participant ethnoracial group. For example, for Theme Three, older Black adults indicated that they would expect compensation for PET brain scan participation. Conversely, older Latinos stated that they would appreciate, but not anticipate, a financial incentive. All participants stressed the importance of written educational materials with subsequent verbal discussions with study staff.

**Conclusion:** Findings inform the development and implementation of scientifically-relevant and culturally-cognizant engagement approaches, educational materials, and recruitment strategies to increase PET brain scan participation by diverse older adults.

### Keywords

Older adults; PET brain scan; qualitative interviews; recruitment science; study design

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### Introduction

Biological biomarkers yielded from positron emission tomography (PET) brain scans represent in vivo assessments of Alzheimer's disease (AD) and serve as a pathway to understanding AD pathology in living persons [1]. However, PET brain scan data remain limited for persons traditionally under-represented and under-included in aging research, especially older Black and Latino adults [2]. As some risk factors for AD differ across race and ethnicity (e.g., the documented weaker effect of APOEε4 on AD for Black adults compared to non-Latino Whites), insufficient PET brain scan data severely inhibit the field's understanding of AD pathogenesis for these populations as well as possible treatment considerations [3-5]. Furthermore, the benefits of scientific advancements or knowledge associated with PET brain scan data will remain elusive to sizeable portions of national (i.e., those in the United States of America) and global populations [6-10]. Voluntary consent represents the first step to obtaining PET brain scan data. As such, diverse perspectives are needed to identify barriers and elements of effective and culturally compatible educational materials associated with PET brain scan to facilitate participation by older Black and Latino adults [9,11,12].

Previous studies have set forth well-documented barriers faced by older Black and Latino adults regarding participation in aging research, broadly, and specifically for brain-related biomarker research, such as agreeing to brain donation and subsequent brain autopsy [6,10,13-21]. Barriers to aging research can stem from skepticism or a lack of trust in research and study protocols possibly enacting logistical (e.g., transportation, scheduling, number and length of visits) and/or linguistic challenges. Conversely, altruism and perceived benefit of research to loved ones and future generations often serve as motivating factors for participation in studies [22-25]. These barriers to and facilitators of aging and brain-related biomarker research may differ or compound in relation to PET brain scans, potentially due to PET protocols being more complex or invasive. To our knowledge, previous research

has not examined potential barriers or elements of effective and culturally compatible educational materials precisely associated with PET brain scan consent and participation among these under-represented and at-risk groups. Without a clear understanding of diverse perspectives in relation to PET brain scan, we may not fully facilitate participation by various demographic groups [9-12,26-30].

We seek to offer PET brain scan at the Rush Alzheimer's Disease Center (referred to as "the RADC" going forward) as part of our research portfolio. To do so, we first examined participant-identified barriers and characterized participant-informed elements of effective and culturally compatible educational materials pertaining to PET brain scan consent and participation among older Black and Latino adults. Here, participant-identified barriers refer to impediments explicitly set forth by participants; and participant-informed elements denote informational content, delivery modality, and messenger of the information, all derived from participant responses to questions posed during the study. We leveraged qualitative in-depth individual interviews with older Black and Latino adults who currently participate in research to gather participant perspectives on barriers and elements of effective and culturally compatible educational materials about PET brain scan. Qualitative approaches, such as in-depth individual interviews, provide insight into *why* people perceive, believe, and behave in a particular manner in relation to a specific topic or issue, which quantitative approaches are unable to fully deliver [31]. Overall, study results can inform subsequent engagement approaches, educational materials, and recruitment strategies to facilitate consent to PET brain scan participation by racially and ethnically diverse older adults and markedly extend the field regarding equity in AD and aging.

## Methods

### Participants

Participants were recruited from one of two ongoing longitudinal studies of cognitive aging in community-dwelling older adults at the RADC. One cohort study exclusively consists of older Black adults and the other solely recruits older Latinos. Both community-based cohort studies are located within the Chicago metropolitan area, with all participants tested annually within their residences, except during the height of the novel coronavirus pandemic. All participants are free of known dementia at baseline, as previously described [15,32]. All participants report their race (e.g., African American/Black) and ethnicity (i.e., Hispanic: yes or no) based on categories from the 1990 United States Census Bureau as well as their gender (i.e., male or female), date of birth, years of education, and income [33]. Annual income is measured using the Show-Card Method from the Established Populations for Epidemiologic Studies of the Elderly, in which participants are asked to select 1 of 10 levels of total annual family income [34].

Eligible persons for the current study were 1) 60 years of age or older; 2) free of dementia; 3) self-identified as either non-Latino Black or Latino; and 4) proficient in English (i.e., the ability to speak, read, and write in English language). Persons were considered proficient in English if they either tested in English as part of their cohort study participation or self-reported proficiency in English and expressed comfortability with conversing in a qualitative interview conducted only in English; thus Spanish-speaking Latinos were excluded from

the study. Participants were then selected using random purposeful sampling, a method where persons are selected based on being knowledgeable or opinionated about the issue of interest, especially with limited availability of resources, to explore typical or average cases [35]. The execution of random purposeful sampling was a collaboration between current and cohort study staff to select older adults to be contacted about the current study. Hence, study staff identified eligible persons based on study criteria and used a variety of direct outreach approaches (i.e., telephone calls, letters, and discussion during cohort study visits) for recruitment into the current study [36]. Guided by a qualitative sampling algorithm, we planned for 10-15 older Black adults and 10-15 older Latinos to take part in in-depth individual interviews, with the total number of participants ranging between 20-30 older adults [37,38]. From a pool of 308 eligible persons (238 Black adults and 70 Latinos), 156 persons (88 Black adults and 68 Latinos) were identified using random purposeful sampling, 92 persons (33 Black adults and 59 Latinos) were contacted regarding their potential interest in study participation, 36 persons (19 Black adults and 17 Latinos) were subsequently scheduled and confirmed, with 31 (15 Black adults and 16 Latinos) taking part in interviews. Of the 92 persons who were contacted regarding their potential interest in study participation, 56 were *not* scheduled or confirmed due to: 1) a person's lack of interest in the current study; 2) study staff being unable to reach the person during requested follow-up phone calls; and 3) scheduling conflicts for the person (e.g., planned surgery). Furthermore, once we reached our planned sample size, we ceased to contact persons for study participation. An Institutional Review Board at Rush University Medical Center approved the current study. Informed consent was obtained from all participants included in the study.

### Interview Guide

Each participant took part in a one-time, in-depth individual interview that allowed for the systematic and subjective examination of sensitive and novel topics and their meaning(s) to the participant [39]. Prior to conducting in-depth individual interviews, an Interview Guide was developed to systematically gather participant perspectives regarding potential barriers and possible elements of needed educational materials associated with PET brain scan consent and participation [39,40]. In qualitative research, an Interview Guide consists of topics and related questions that structure and facilitate high-fidelity qualitative discussions [39,40]. The current Interview Guide was developed for specific use with demographically diverse older adults (e.g., belonging to various racial, ethnic, socioeconomic, and geographic groups) pertaining to PET brain scan and by reviewing previous literature, community-based engagement and experience with demographically diverse older adults, and in collaboration with Investigators at the RADC who have expertise in cognitive aging and neuroimaging among demographically diverse older adults. The Interview Guide set forth six topics, all in the context of PET brain scan for research, including: baseline knowledge, needed information, cursory participation decision, trusted source(s) of information, potential give back(s) for participation, and open space to discuss potential barriers and possible elements of educational materials either not included in previous literature or unknown to researchers.

Notably, responses to all questions provided insight into participant-informed elements needed for effective and culturally compatible educational materials, particularly focused

on required information and how to deliver such material (i.e., modality and by whom). However, Question 4 (i.e., “What would you need to know before agreeing to PET brain scan for research?”) was designed specifically to gather such data. Another sample question from the Interview Guide included, “Before agreeing to PET brain scan for research, would you need to talk to anyone? [IF SO] Who?” See Table 1 for the full Interview Guide, complete with Interviewer instructions. In-depth individual interviews were semi-structured; hence, the Interview Guide provided topics and related questions to be posed and addressed by all participants, but participants shaped the flow of discussion.

### **In-Depth Individual Interview Procedures**

Prior to each interview, study staff called participants as a reminder of the date and time of interviews and mailed an informational sheet regarding the study via the United States Postal Service. At the beginning of each interview, study staff explained the study purpose and what comprised participation, orally led participants through Informed Consent, and initiated the use of audio-recorders. All participants provided verbal consent prior to the activation of audio-recorders. All interviews occurred remotely, either via WebEx or telephone, and lasted an average of 15 minutes. After the completion of each interview, each participant was given a \$25 Visa gift card as a token of appreciation. The Visa gift card was mailed to all participants using the United States Postal Service.

All audio-recordings were uploaded to a secure server at the RADC behind the Rush University Medical Center firewall. Audio-recordings were then electronically transferred to a medical transcription agency. Transcription included the de-identification of participants and the deletion of any names and other protected health information. Across all interviews, 3 trained study staff members served as interviewers (1 person for all older Black adults and 2 people for older Latinos – 1 interviewer conducted 2 interviews with older Latinos and the other interviewer conducted 14 interviews with older Latinos). CMG (the first author) trained all study staff who served as interviewers.

### **Analyses**

All audio-recordings were transcribed, and transcripts served as primary data and the basis for data analyses. To ensure inter-rater agreement, CMG and two trained study staff members conducted all data analyses guided by an inductive Grounded Theory Approach that consisted of two phases [41,42]. For the first phase, data were analyzed across all in-depth individual interviews or, more specifically, across both racial and ethnic identifications of participants using Open Coding (i.e., data-driven coding that does not begin with preconceptions) [43]. The first phase entailed five steps [36,44,45]. First, analysts read each transcript to become familiar with the data. Second, analysts identified key passages within each transcript. Third, analysts developed and assigned 33 codes to key passages. Fourth, analysts identified 17 subthemes from the codes. Finally, four overarching themes were created from the subthemes. At each step, analysts discussed and reached consensus. Overall, themes addressed barriers and elements of educational materials associated with PET brain scan consent and participation across all participants – both older Black and Latino adults.

For the second phase, racial and ethnic identifications of participants served as the unit of stratification and data were analyzed using Constant Comparative Coding (i.e., contrasting the meaning of a code between groups of people or different environments to discover the dimensionality of a code) [43]. The five analytic steps from the first phase were performed; however, analysts focused on divergent and unique aspects for each group. Specifically, results from phase two highlighted differences and distinctive aspects of each theme from the first phase for older Black and Latino adults, separately

## Results

### Participant Characteristics

All participants (N=31) were free of dementia (median MMSE score=28), English proficient, and self-identified as either non-Latino Black (n=15) or Latino (n=16). Of the 16 participants who identified as Latino, 7 participants were second generation (i.e., the person as well as one or both parents were born in the United States of America), 2 participants were first generation (i.e., the person was born in the United States of America but both parents were born in other countries), and 7 participants immigrated to the United States of America. The total group was 74% women, with a mean age of 71 years, a median income range of \$30,000-\$34,999, and 14 mean years of education. Additional demographic characteristics for older Black and Latino adults, respectively, are shown in Table 2.

### Phase One: Themes Across All Older Black and Latino Participants

Four themes arose across all in-depth individual interviews: 1) knowledge limitations; 2) requirements for consent; 3) motivators for participation; and 4) social networks. Each theme builds upon one another with Theme One serving as the foundation for understanding PET brain scan from the participant perspective; Theme Two addressing participant needs for a fuller, more informed understanding of PET brain scan; Theme Three highlighting explicit facilitators of potential participation; and the key role of others in PET brain scan for research decision making in Theme Four. As is common in qualitative research, these themes interconnect with each other. We discuss each overarching theme below.

**Theme One: Knowledge Limitations**—Participants expressed having a lack of information about PET brain scan and faced challenges with recalling the information that they did have. They oftentimes talked about PET brain scan in conjunction with other imaging modalities, including magnetic resonance imaging (MRI) and computerized tomography (CT/CAT) scan, and procedures involving the brain, such as brain donation and brain transplant. Much of their current information about PET scan, in general, was gleaned from their lived experiences (e.g., having a PET scan for a personal health issue), members of their social networks (e.g., a family member diagnosed with cancer), and the RADC's study staff during outreach and recruitment efforts.

**Theme Two: Requirements for Consent**—This theme illuminates necessary elements of educational materials needed to facilitate PET brain scan consent among older Black and Latino adults. Participants emphasized their need to know and understand three main aspects of a PET brain scan prior to consent: 1) its purpose; 2) the process; and 3) anticipated

outcomes. First, participants requested information about PET brain scan as a procedure. Participants specifically wanted to know how PET brain scans related to aging and brain health, and how the scans will align with and further the RADC goals. Secondly, participants wanted to understand the process of PET brain scan, primarily what occurs before (e.g., how a person may need to prepare for the procedure), during (i.e., what takes place in the scanner and what a person can expect), and after (e.g., what a person needs to do or may experience upon completion of the scan). Overall, participants did not know what to expect concerning the process of obtaining the PET brain scan. They desired information related to potential side effects and any associated risks to assess the safety of the scan for them, especially in consideration of their comorbidities and health concerns. Lastly, participants inquired about the outcomes of PET brain scan for research. In part, participants wondered what researchers, overall and at the RADC, will learn from PET brain scans. Furthermore, participants expressed a keen interest in receiving and understanding their own PET brain scan results.

**Theme Three: Motivators for Participation**—There were several motivating factors that may facilitate PET brain scan participation among older Blacks and Latino adults. Specifically, participants expected to receive their PET brain scan results as part of their participation, which served as the primary motivator. They strongly desired to receive their scan results to understand their brain health, particularly whether they have any “damage” or “disease.” Notably, they did not perceive the receipt of their scan results as an incentive or “give back” for their potential participation in PET brain scan for research.

These older adults also provided personal stories of experiencing their loved ones (i.e., immediate and extended family members and close friends) live with Alzheimer’s disease and related dementias (ADRD) and their hope to avoid dementia at all costs. Relatedly, they expressed their altruistic focus on the futures of their families, communities, and the broader society in terms of not experiencing ADRD. Their lived experiences and altruism served as key motivators for potential PET brain scan participation as they desperately wanted to address ADRD in the lives of their families and beyond. They regarded research participation as a way for them to contribute to addressing ADRD. Indeed, participants noted that their previous and current research experiences have fostered their favorable views on research and their comfortability with potentially taking part in PET brain scan, especially at the RADC. However, participants indicated that their willingness to participate in PET brain scan for research largely depended upon their understanding of the purpose and process of PET brain scan (see Theme Two). Financial incentives were less prominently discussed but were still a motivator. Participants viewed financial incentives as an aspect of participation that they would appreciate; however, they either anticipated a financial incentive for their participation (older Black adults) or viewed financial incentives as an appreciated gesture but secondary to receiving their scan results (older Latinos).

**Theme Four: Social Networks**—Older Black and Latino adults looked to four distinct groups within their social networks to inform their perspectives on taking part in PET brain scan for research –loved ones, peers, personal doctors, and the RADC’s study staff. These older adults planned to seek advice from and discuss their potential participation with their

loved ones, especially those who were medical professionals. They also wanted to speak with someone, preferably another older adult, who had already taken part in a PET brain scan. Participants wanted to discuss a peer's lived experience with PET brain scan and to seek reassurance from that peer. As these older adults were keen to understand the purpose, process, and outcomes of PET brain scan, they intended to seek more information and guidance from their personal doctors as to what a PET brain scan entails and whether it would be safe for them to participate, especially considering any comorbidities and health concerns. Furthermore, these older adults stated that if they were to have a PET brain scan, they intended to share and discuss their brain scan results with their loved ones and personal doctors. Participants also expressed their intent to look to the RADC's study staff, particularly a medical doctor affiliated with the study, for more information and to answer any questions related to PET brain scan. These older adults saw study staff as persons with expertise, including about the participant experience.

**Participant-Informed Elements of Effective and Culturally Compatible Educational Materials**—Across the four overarching themes, participants provided insight into necessary elements (i.e., information to be included in educational materials as well as delivery modality(-ies) of information and by whom) of effective and culturally compatible educational materials specifically related to PET brain scan (see Table 3). Theme One indicated the need to develop and deliver educational materials regarding PET brain scan as participants noted limited existent knowledge. Most prominently, Theme Two set forth three core pieces of information to be provided and discussed with older adults and their loved ones regarding PET brain scan: 1) its purpose, especially related to aging research; 2) the process of a PET brain scan; and 3) anticipated outcomes of PET brain scan. These three pieces of information must be addressed within educational materials prior to and in facilitation of PET brain scan consent. Furthermore, participants anticipated the receipt of their PET brain scan results as an outcome (see Theme Three). Participants planned to discuss educational materials and their anticipated PET brain scan results with members of their social networks, including loved ones, healthcare providers, and study staff (see Theme Four). Participants indicated that they would like to receive written educational materials so that they may read and reflect on the information, and to serve as a point of reference for themselves and for sharing and discussing with members of their social networks. Participants also stated that they would like to have subsequent one-on-one verbal conversations with members of their social networks, particularly their healthcare providers and study staff, especially a study-affiliated medical doctor, so that they may pose any questions regarding PET brain scan.

### **Phase Two: Differences and Unique Aspects Regarding Each Theme for Older Black and Latino Adults**

While each overarching theme emerged across all participants, differences within each theme existed for older Black and Latino adults, respectively (see Table 4). Furthermore, older Black and Latino adults noted unique aspects related to each theme. Below, we discuss differences and unique aspects related to the overarching themes.



## Differences Related to Each Theme for Older Black and Latino Adults

**Theme One: Knowledge Limitations:** Across all participants, scant knowledge existed about PET brain scan, with confusion between PET brain scan and other brain-related imaging and procedures. Notably, older Latinos primarily mistook PET brain scan with other studies at the RADDC that utilize MRI capabilities. Older Black adults spoke about PET brain scan in the context of or in relation to brain donation and brain-related surgery.

**Theme Two: Requirements for Consent:** All participants indicated the need to understand the purpose, process, and outcomes of PET brain scan for research. Overall, older Latinos were interested in understanding the general purpose of PET brain scan and its role at the RADDC, but not necessarily receiving in-depth details. Conversely, older Black adults desired specifics, including information about PET scan equipment, to see a simulated or live PET brain scan with a volunteer, hear a presentation about PET brain scan, and speak with others, including their peers who have undergone a PET brain scan.

**Theme Three: Motivators for Participation:** One area of divergence among older Black adults and older Latinos pertained to financial incentives associated with participation in PET brain scan for research. While older Latinos expressed that a financial incentive would be appreciated, they did not expect such a gesture. However, older Black adults did expect to be compensated for their time dedicated to research participation. Older Black adults spoke of research as a “sacrifice” on their behalf and referred to research as a reciprocal act. Older Black adults also noted that receiving a financial incentive in relation to research participation is customary. Notably, financial incentives associated with research participation was secondary to the receipt of PET brain scan results for both older Black and Latino adults.

**Theme Four: Social Networks:** All participants valued input from members of their social networks, from loved ones to their healthcare providers. Older Black adults emphasized speaking with their peers, especially older adults who have taken part in a PET brain scan, to discuss their lived experiences with the scan and for reassurance. Older Latinos underscored their desire to speak with personal healthcare providers for more information, especially in relation to their comorbidities and health concerns.

## Unique Aspects Related to Overarching Themes for Older Black and Latino Adults

**Older Black Adults:** Older Black participants spoke of two unique topics in relation to the four overarching themes: 1) fear; and 2) trust in research. Older Black participants discussed fear associated with PET brain scan that stemmed from two sources. First, participants associated PET brain scan with brain donation and brain surgery. More specifically, when participants spoke about treating potential issues with their brains revealed via PET brain scan results, they invoked feelings of fear and hesitancy, especially addressing any potential brain issues through brain donation or brain surgery. Second, older Black adults spoke of fear related to potential long-term risks associated with PET brain scan. These two sources of fear are particularly contextualized within overarching Theme One: Knowledge

Limitations and overarching Theme Three: Motivators for Participation, primarily receiving PET brain scan results.

However, older Black participants also believed it was particularly important for members of Black communities to take part in research. Participants expressed a trust in research, overall, and espoused its value to address issues in aging, particularly ADRD. Notably, participants' trust in research was anchored in their study-related experiences at the RADC and their familiarity with related investigators and staff. While all participants expressed that they needed more information regarding PET brain scans (Theme Two: Requirements for Consent), older Black participants remained open to learning more about scanning due to their trust in research, especially at the RADC. One participant explained,

“Um, I trust science and research. I know there's some bad actors out there and some things being done that are not right at times but, as a whole, I trust just science and research... .. And, uh, all hard work like this has somewhere down the line where it actually helps people, so that's-that's why I don't question that people working to, uh, you know, to basically find out what happens when we age which is a good thing.”

**Older Latinos:** Older Latino participants centered their loved ones throughout the process of PET brain scan, with loved ones playing a salient role across all overarching themes. For instance, loved ones served as sources of existing information about PET brain scan (Theme One: Knowledge Limitations). Older Latino participants also aimed to receive information about the purpose, process, and outcomes of PET brain scan (Theme Two: Requirements for Consent), in part, to share and discuss with their loved ones. Furthermore, participants remained open to participation in PET brain scan (Theme Three: Motivators for Participation) partly due to the possibility of sharing their PET brain scan results with loved ones, especially to help their family in the future. Overall, loved ones played a salient role in the social networks (Theme Four: Social Networks) of older Latinos, including decision making about participation in PET brain scan. One participant noted,

“Well, I—yes, I want to say that, um, I'm always eager to participate in a study that I know is not going to hurt me, you know, and only because my mother had Alzheimer's, you know, she's about this age, at my age now. And it's just something I want to keep up with... .. But, you know, you have to have a reason to do these things also. So maybe some of it would be because I'm participating in this study, and-and I've had a family member that's had it and died of it, you know. And so that's my whole reason. I don't expect to have any gifts. I'm not doing it for any benefit money-wise or anything. I'm doing it just for my own knowledge, and for my family, you know, so they're aware, too.”

## Discussion

This qualitative study assessed participant-identified barriers to PET brain scan consent and identified participant-informed elements of materials needed to facilitate PET brain scan participation among older Black and Latino adults. Across all participants, four overarching themes emerged: Theme One- knowledge limitations, Theme Two- requirements for

consent, Theme Three- motivators of participation, and Theme Four- social networks. Participants also provided insight into necessary elements of effective and culturally compatible educational materials specific to PET brain scan. Notably, within Theme Two, we discovered three core pieces of information regarding PET brain scan to be provided and discussed with older adults and their loved ones regarding PET brain scan prior to consent: 1) the purpose of PET brain scan, especially related to aging research; 2) the process of a PET brain scan; and 3) anticipated outcomes of PET brain scan. Participants expressed the desire to receive written educational materials followed by verbal discussions of the content with members of their social networks. While each theme and the core pieces of educational materials emerged for both demographic subgroups, differences within each theme existed for older Black and Latino adults, separately, as well as each group noted unique aspects related to the themes. Specifically, older Black adults spoke of fear related to PET brain scan and espoused trust in research and the need for research participation by other Black persons, while older Latinos centered their loved ones throughout the four overarching themes. The current study suggests that knowledge limitations may serve as a barrier to PET brain scan participation among older Black and Latino adults. However, the use of educational materials that highlight the purpose, process, and outcomes of PET brain scan; providing and discussing PET brain scan results; and the inclusion of members of social networks may serve as facilitators for PET brain scan participation among older Black and Latino adults. These study results have important implications regarding potential targets for more focused interventions to facilitate decision making for invasive research protocols among demographically diverse older adults.

Previous studies have outlined both barriers and facilitators to participation in aging research as well as brain-related biomarker studies by demographically diverse older adults [25,28,46-50]. Well-documented barriers include a lack of trust in research among older Black and Latino adults, logistical challenges such as transportation, and linguistic incompatibility of study protocols and materials [12,28,51-53]. Alternatively, noted facilitators consist of altruism and perceived benefit of research to loved ones and future generations [24,53-55]. We postulate that barriers to and facilitators of PET brain imaging differ and expound upon those related to aging and brain-related biomarker research due to more invasive PET protocols that take place with living persons. To our knowledge, prior studies have not assessed barriers and identified elements of effective and culturally compatible educational materials specific to PET brain scan consent and participation as indicated by demographically diverse older adults.

However, the current study builds upon previous research, including registry and brain-related biomarker studies, by focusing on perspectives of older Black and Latino adults specifically related to PET brain scan [6,13-21,24,26,36,55]. For example, previous research has advocated for the continued inclusion of loved ones in older Black and Latino adults' decisions to participate in aging research, especially studies that may be considered more invasive such as brain-related biomarker research [15,24,26,54]. Here, the concept of social networks is expanded to not only include loved ones but also peers, healthcare providers, and PET brain scan study staff, especially study-related medical doctors. Older Black and Latino adults emphasized the important roles of social network members in relation to PET brain scan participation, including serving as sources of knowledge, persons to share

PET-related information with, and as motivators of PET brain scan participation. Specific to each racial and ethnic group, older Black adults highlight the central role of peers, while older Latinos center their loved ones. Overall, current study findings suggest that researchers must include various members of social networks when aiming to engage with, recruit, and sustain participation in PET brain scan research among older Black and Latino adults. Failure to include these key social network members may result in the continued under-representation and under-inclusion of older Black and Latino adults in PET brain scan research.

Current study findings also suggest that social network members serve as a critical source of PET-related knowledge for older Black and Latino adults. However, similar to previous aging research findings, current study results indicate that older Black and Latino adults face limitations in their knowledge regarding biomarker- and other study-related procedures [19,24,56]. More specifically, older Black adults spoke about PET brain scan as being similar to brain donation or brain surgery, while older Latinos mistook PET brain scan with MRI. Notably, 60-75% of older Black and Latino adults in the current research also take part in ancillary studies in the parent cohorts, including MRI studies and brain autopsy; hence, this may result in misidentifying procedures. However, knowledge-related limitations may serve as a barrier to engaging with, recruiting, and sustaining participation in PET brain scan research among older Black and Latino adults.

The potential barrier of knowledge limitations may be addressed through effective and culturally compatible educational materials. Participant-informed educational materials can provide information about PET brain scan, encourage possible participation in PET brain scan, and facilitate related discussions between older Black and Latino adults with members of their social networks. Educational materials related to PET brain scan must include three participant-informed elements: 1) the purpose of PET brain scan, particularly in relation to aging research; 2) the process of PET brain scan, including steps taken before, during, and after scanning; and 3) the expected outcomes of PET brain scan in relation to aging research and the participant. Older Black and Latino adults specify the need for written materials for them to review, reflect on, and serve as a foundation for verbal discussions and related questions with members of their social networks, including their healthcare providers and study-related staff, especially study medical doctors. Furthermore, educational materials may include a definition of PET brain scan – rather, what it is and is not. In sum, current study findings suggest that researchers who are looking to engage with, recruit, and sustain participation among older Black and Latino adults should include educational materials that address the purpose, process, and outcomes of PET brain scan to be delivered in written form followed by verbal discussions with older adults and their social network members.

The study also extends previous aging research findings regarding motivators of participation [24,25, 47,51,54,55,57]. More specifically, researchers have discussed financial incentives in relation to participant-centered and equity-based aging research participation [55,58-60]. Here, older Black adults refer to financial incentives as customary for research participation as the relationship between researcher and participant is deemed reciprocal, while older Latinos express that financial incentives are an appreciated gesture. However, regardless of race or ethnicity, financial incentives are less prominent compared to the

receipt of PET brain scan results. More specifically, financial incentives for PET brain scan participation serve as a distant second to the primary motivator of PET brain scan participation among older Black and Latino adults – the receipt of a person’s PET brain scan results. Older Black and Latino adults spoke of their strong motivation to take part in PET brain scan research so that they may receive their scan results to understand their brain health, discuss with members of their social networks, and to plan for their future and that of their loved ones. The receipt of PET brain scan results also supports participants’ altruistic motivations, which are largely rooted in their lived experiences and desire to help their loved ones, communities, and broader society. Yet, they did not view the receipt of their scan results as an incentive or “give back” for their research participation but rather as an expected part of research participation. Hence, current study findings strongly suggest that researchers who plan to engage with, recruit, and sustain participation in PET brain scan research among older Black and Latino adults should provide, interpret, and discuss scan results as a routine component of their study.

Study findings also indicate unique perspectives held by older Black and Latino adults, separately, in relation to PET brain scan research. Older Latinos emphasized the need to include their loved ones in the PET brain research process – from knowledge acquisition, knowledge sharing, and sources of motivation. We suggest that researchers focusing on PET brain scan participation among older Latinos meaningfully include the loved ones of older Latinos throughout the process of PET brain scan research. Furthermore, older Black adults spoke about fear associated with PET brain scan research. Although they strongly desire to receive their PET brain scan results, they also expressed fear of learning about brain-related disease or health issues that may require treatment via brain donation or brain surgery, which they greatly aim to avoid. For older Black adults, fear associated with PET brain scan may serve as a barrier to participation. Hence, it remains important that PET-related educational materials and engagement efforts geared towards older Black adults explicitly note and address this possible fear. Conversely, older Black adults also expressed their trust in research, overall, and championed the need for more research participation by Black persons. Older Black adults noted their particular trust in research conducted at the RADC and by RADC-affiliated investigators. While previous studies have widely documented mistrust of research among Black adults as a barrier to research, we suggest that researchers looking to engage, recruit, and sustain participation in PET brain scan research among older Blacks first build honest and bidirectional relationships with prospective Black adults.

Overall, researchers are continuously and actively engaged in increasing PET brain scan participation among under-included and under-studied demographic populations, including older Black and Latino adults. However, a dearth of diversity in PET brain scans persists. Current study findings elucidate that while older Black and Latino adults face barriers to participation, including knowledge limitations and fear associated with PET brain scans, they can also inform elements of educational materials (i.e., purpose, process, and outcomes of PET brain scan) that may facilitate participation. Furthermore, providing PET brain scan results to older adults and including members of their social networks throughout the research process may support participation in PET brain scan research among these communities. Hence, participant-centered engagement, recruitment, and sustainability approaches and related educational materials are required for older Black and Latino adults

and members of their social networks regarding PET brain scan participation. With such information, researchers may effectively address potential barriers, facilitate increased rates, and further develop educational materials related to PET brain scan participation among demographically diverse older adults. As such, we have begun to implement these qualitative evidence-based strategies. Since implementing results from the current qualitative study, we have recruited, enrolled, and completed 11 PET brain scans with older Black (n=6) and Latino (n=5) adults. Currently, we are creating templates for educational materials that will be piloted in a larger sample and discussed in future manuscripts.

## Study Limitations

The study has several limitations. One limitation concerns the low participation rate among older Black and Latino men. Future research may implement strategies, such as outreach efforts exclusively focused on engaging with and recruiting older Black and Latino men, to understand their perspectives regarding PET brain scan. A second limitation pertains to the exclusive recruitment of older Latinos who were English-proficient. Future research should explore perspectives about PET brain scan among older Latinos who prefer conversing in Spanish or Portuguese, as well as older persons from other racial/ethnic populations. A third limitation relates to current study findings potentially not being generalizable to older Black adults across the United States of America as older Black adults in the current study tended to have a higher median income level and more mean years of education. A fourth limitation is that all current study participants were enrolled in an ongoing longitudinal aging study. Older Black and Latino adults not already engaged with research may have differing perspectives related to PET brain scan. Furthermore, perspectives of older Black and Latino adults highlighted in the current study, including suggested methods and materials of outreach and engagement, may be of utility for other demographically diverse older adults and their families regarding PET brain scan. However, methods and materials should be tailored as necessary for specific populations, particularly as it remains unclear whether or how current study findings vary by intersecting demographic characteristics (e.g., socioeconomic status or geographic location).

This study also has several strengths, including a well-characterized sample of community-dwelling older Black and Latino adults. We used an established qualitative sampling algorithm; developed an Interview Guide for specific use with demographically diverse older adults based on previous literature, community-based engagement, and experience; and in collaboration with RADC investigators with expertise in cognitive aging and neuroimaging; and executed high-fidelity qualitative data analyses.

## Conclusion

Current study findings provide the foundation for understanding diverse participant perspectives regarding PET brain scan for research. The current study also sets forth participant-informed next steps and related recommendations to guide researchers and others with designing and implementing culturally compatible engagement strategies and educational tools with the purpose of increasing participation in PET brain scan for clinical ADRD research among demographically diverse older adults.

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**Table 1.****In-depth Individual Interview Guide, Including Guidance for Interviewers.**


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Aim of the interview:

Identify: 1) **barriers and potential motivators of PET brain scan** and 2) **education needed**

Interview questions breakdown:

- 1 **Baseline Knowledge** – Question 1 and Question 2
  - 2 **Cursory Decision Regarding PET Brain Scan** – Question 3
  - 3 **Information Needed Regarding PET brain scan** – Question 4
  - 4 **From Whom or Trusted Source of Information**– Question 5
  - 5 **Potential Give Back** – Question 6
  - 6 **Iterative Understandings** – Question(s) To Be Developed During Iterative Process\*
  - 7 **Last Thoughts on PET Brain Scan**– Question 7
  - 8 **END and THANK YOU!**– Question 8
- 

\* Note: As standard for qualitative research, including in-depth individual interviews, the process is iterative; meaning, researchers may add questions during the interviewing process as new understandings of PET brain scan are illuminated by participants.

\*\* Color Coding: **Prompt and Further Prompt** in Yellow, **If Yes** in Green, **If No** in Blue, **Follow-Up** in Purple, and **NOTE** in grey to ease learning of the Guide and ease finding your spot, if needed.

In-Depth Individual Interview Guide

1. Have you heard of PET brain scan?
  - a. **Prompt:** Has anyone ever mentioned PET brain scan to you?
  - b. **IF YES:** Please tell me what you have heard about PET brain scan.
    - i. **Prompt:** Please tell me what you know about PET brain scan.
  - c. **IF NO:** That is okay. Can you tell me what you think PET brain scan means?
    - i. **Prompt:** No problem. Please tell me your best guess about PET brain scan.
2. Have you ever participated in or been asked to participate in a PET brain scan?
  - a. **Prompt:** Have you ever had a PET brain scan or asked to have a PET brain scan?
  - b. **IF YES:** Please tell me about your experience.
    - i. **Prompt:** Please tell me more.
    - ii. **Key Things to Note:** When recounting their experience, the person will likely provide the following details. If they do not, please be sure to ask and record.
      1. Why (the person was asked to participate in a PET brain scan).
      2. Did the person take part in the PET brain scan? Why or Why Not?
      3. When (the person was asked to participate in a PET brain scan).
      4. Who (asked the person to participate in a PET brain scan)?
      5. How (the PET brain scan went for the person if they took part in the PET brain scan – a good/bad experience and why).
  - c. **IF NO:** Thank you. (And Move to The Next Question).
    - i. **Prompt:** No problem. (And Move to The Next Question).
3. Please think about everything you know/have heard about PET brain scan. What would you say if you were offered a PET brain scan as part of research at the Rush Alzheimer's Disease Center?

- a. **Prompt:** If you were offered a PET brain scan as part of research at the Rush Alzheimer's Disease Center, what would you say?
- b. **Prompt:** Thinking about what you have heard (or know) about PET brain scan, would you consider having a PET brain scan as part of research at the Rush Alzheimer's Disease Center?
- c. **Follow-Up:** Why? (or, Why Not?)
4. What would you need to know before agreeing to PET brain scan for research?
- a. **Prompt:** What information would you need before taking part in PET brain scan for research?
- b. **Prompt:** What information would you need when considering/to consider PET brain scan for research?
- c. **Follow-Up:** How would you like to receive this information?
- d. **Follow-Up Prompt:** What is the best way to get this information to you? (Potential Options for Further Prompting: Written materials, pamphlet, video, verbally?)
5. Before agreeing to PET brain scan for research, would you need to talk to anyone before agreeing to PET brain scan for research? [IF SO] Who?
- a. **Prompt:** To consider PET brain scan for research, who would you need to speak with?
- b. **Prompt:** Would you need to talk with or consult with someone before considering a PET brain scan for research? [IF SO] Who?
- c. **Further Prompt:** For example, would you need to speak to a doctor at the Rush Alzheimer's Disease Center, a Study Coordinator like Theresa Jenkins/Elizabeth Montalvo, another doctor, or family member(s) before agreeing to PET brain scan?
- d. **Follow-Up:**
- i. [IF A PERSON (S) IS SPECIFIED]: Why?
- ii. [IF NO ONE IS SPECIFIED]: Please tell me why you would not need to speak with anyone? (OR) Why not?
- e. Follow-Up Prompt: Please tell me more.
6. If you were to agree to PET brain scan for research, would you like to receive something in return? [IF SO] What?
- a. **Prompt:** If you agreed to PET brain scan for research, would you like something given back to you? [IF SO] What?
- b. **Prompt:** Would you like to receive something in return if you took part in PET brain scan for research? [IF SO] What?
- c. **Further Prompt:** For example, would you like to receive a Visa gift card, cash, a copy of your PET brain scan, or anything else if you agreed to PET brain scan for research?
- d. **Follow-Up:**
- i. [IF A GIVE BACK(S) IS SPECIFIED]: Why?
- ii. [IF NO GIVE BACK IS SPECIFIED]: Please tell me why you would not like to receive something in return? (OR) Why not?
7. Do you have any other thoughts about PET brain scan for research?
- a. **Prompt:** Is there anything else you would like to share with me about PET brain scan for research?
- b. **Prompt:** Anything else that you would like to share with me?
8. END. THANK YOU!!!

**Table 2.**

Participant Characteristics for the Full Sample and By Racial/Ethnic Group.

	<b>Number of Participants</b>	<b>Women (%)</b>	<b>Income (Median)</b>	<b>Age (Mean)</b>	<b>Years of Education (Mean)</b>	<b>MMSE</b>
<b>Older Black Adults</b>	15	80.0%	\$30,000 - \$34,999	70.3 years	14.6 years	28.0
<b>Older Latinos</b>	16	68.8%	\$30,000 - \$34,999	71.6 years	13.9 years	27.5
<b>Total Sample</b>	31	74.2%	\$30,000 - \$34,999	71.0 years	14.3 years	28.0

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**Table 3.**

Participant-Informed Elements of Educational Materials, Recommendations for Delivery of Information, and Other Considerations to Facilitate PET Brain Scan Participation among Older Black and Latino Adults.

PARTICIPANT-INFORMED ELEMENTS OF EDUCATIONAL MATERIALS				
Definition	Purpose	Process	Outcomes	Side Effects and Risks
<ul style="list-style-type: none"> <li>What is/is not a PET brain scan</li> </ul>	<ul style="list-style-type: none"> <li>How PET brain scans relate to aging and brain health</li> <li>How PET brain scans align with and further ADRD research goals as well as institutional goals</li> <li>Potential meaning and use of PET brain scan for self, loved ones, and broader society</li> </ul>	<ul style="list-style-type: none"> <li>Before (e.g., how a person may need to prepare for the procedure)</li> <li>During (i.e., what takes place in the scanner and what a person can expect)</li> <li>After (e.g., what a person needs to do or may experience upon completion of the scan)</li> </ul>	<ul style="list-style-type: none"> <li>What researchers, in the field and at the affiliated institution, will learn from PET brain scans</li> <li>PET brain scan results</li> </ul>	<ul style="list-style-type: none"> <li>Particularly related to comorbidities and other health concerns</li> </ul>

  

RECOMMENDATIONS FOR INFORMATION DELIVERY		
Create and deliver written materials emphasizing participant-informed elements	Follow delivery of written materials with verbal discussions	Information Infusion
<ul style="list-style-type: none"> <li>For potential participants to read and reflect upon</li> <li>For potential participants to have as a reference for themselves and to share with others</li> </ul>	<ul style="list-style-type: none"> <li>To facilitate conversations with potential participants, their loved ones, and study staff</li> </ul>	<ul style="list-style-type: none"> <li>Strike a balance between too much or too little information provided to potential participants and their loved ones</li> </ul>

  

OTHER CONSIDERATIONS			
Multiple languages for all materials, correspondences, and conversations	Provide and discuss PET brain scan results with participants and their loved ones	Role and use of financial incentives	Involvement of social network members – who and when – in the PET brain scan process

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**Table 4.**

Phase Two: Example Quotes Denoting Differences within each Overarching Theme for Older Black and Latino Adults.

	<b>Older Black Adults</b>	<b>Older Latinos</b>
<b>Theme One: Knowledge Limitations</b>	“No, because I don’t know if I wanna know. You know, if I’m not having any problems, and at my age, I don’t think I wanna know, uh, that something is getting ready to happen, and you can’t do nothing about it. Like, you know, I wouldn’t wanna have brain surgery at my age, so, uh—”	“Well, I’m under the impression that it’s a whole-body scan. Um, but nobody—I never really questioned it. I have, um, a relative that has cancer.”
<b>Theme Two: Requirements for Consent</b>	“I would have to know, uh, what—I would have to know more about what a PET scan is, and-and I would have to know what-what it does. And I would have to know what, um, what was the out—what would be the outcome, what are the risks, are there any risks in terms of your health, um, regarding taking the, um, brain PET scan. Um, and what are your goals, or why are you taking it. I mean, why would you be taking it. I would like to know that.”	“Well, not only—you know, I would like to know the immediate, you know, risk factors in terms of if it’s found- what contrast, if it’s the same kind of contrast that’s used with a CT scan. And, you know, um, I would wanna know if, you know, in the—if people, who have had brain PET scans, have had any ill after it. You know? Any bad side effects after completion of the-the brain scan.”
<b>Theme Three: Motivators for Participation</b>	“Yeah, I’d like to know. Um, there are things that I—that bothers me that I would like to know that once that PET scan is done that it would, uh, help me better understand my own brain. Or if there was something that might be lurkin’ somewhere in the brain that might be going to happen to me in the future, uh, I would like to, say, get ahead of it possibly with this scan.”	“I don’t—no, I don’t need-I-I don’t need anything in return. I mean, just as a study of, you know, to help, uh, the future.”
<b>Theme Four: Social Networks</b>	“I would, hopefully, be able to speak to somebody’s in the medical field, one, or certainly if there’s someone who’s also had a—who have had this, um, PET, uh, uh, PET scan, uh, what did they think about it, um. And I guess I would like to—I would have to do some research on my own. I would like to kn—I would like to know more about the PET scan itself.”	“I’m always eager to participate in a study that I know is not going to hurt me, you know, and only because my mother had Alzheimer’s, you know, she’s about this age, at my age now. And it’s just something I want to keep up with, and if I could do it for free, that would be great because you know how Medicare is nowadays.”