A Relational Research Recruitment and Engagement Intervention for Cognitive Aging Research

Study Protocol and Statistical Analysis Plan

NCT05444244

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4.1. Background/Significance

Alzheimer's disease and related dementias (ADRD) are a major public health priority and remain the only of the top 10 leading causes of death for which there is no cure or disease-modifying treatment. Individuals with ADRD experience progressive and irreversible losses in cognitive functioning that eventually lead to functional impairment and dependence on others to meet their basic needs. In addition to negatively impacting quality of life for those affected by ADRD, the condition also has tremendous societal consequences due to the heavy financial costs of the condition and stress/burden associated with caregiving – most of which are shouldered by informal (i.e. family, unpaid/nonprofessional) caregivers. Estimates of ADRD diagnoses are projected to rise dramatically in the coming decades, highlighting the importance of research aimed at not only better understanding disease risk and protective factors – but also identifying best approaches to supporting people with ADRD and their caregivers.

Our ability to address these needs is currently hampered by what is referred to by national experts and funders as the "Alzheimer's recruitment crisis." There is currently a need to screen 700,000 individuals to recruit 70,000 people to participate in ADRD research studies.[1,2] Studying people with ADRD is challenging for many reasons – including stigma related to the condition, public misconceptions regarding brain health and ADRD, challenges with informed consent, and difficulty identifying study participants as 50% of ADRD is not detected or diagnosed.[3] Many are concerned that advances in ADRD discovery and care will not be made unless we are able to rapidly and effectively recruit, engage and retain more research participants.

Because we now understand that the pathophysiologic changes that contribute to ADRD conditions and late-life cognitive decline occur decades (often beginning around 40 years of age) before clinical symptoms are observable, there is widespread recognition of the need for comprehensive inclusion of both adults and older adults in what is referred to as cognitive aging research which spans the entire pre-clinical to late-stage disease continuum.[4]

In addition to needing to expand the numbers of individuals participating in ADRD research there is pressing need to also expand the representativeness of ADRD research participants. This is particularly important because ADRD disproportionately impacts individuals from historically underrepresented and disadvantaged backgrounds – including racial and ethnic minorities and individuals from low socioeconomic backgrounds.[5,6] These groups also experience significant disparities in ADRD diagnosis, time to diagnosis, response to treatment, and mortality[7,8]—and are at higher risk for many other health conditions that serve as independent ADRD risk factors (i.e. cardiometabolic conditions). Despite these concerning disparities, these groups are significantly underrepresented in ADRD and cognitive aging research.[9] Reasons for low rates of inclusion of these populations in AD research are multifaceted and include stringent inclusion/exclusion criteria of some studies, and mistrust due to discrimination and historical mistreatment of research participants.[10,11] Emerging research suggests that social and economic barriers also serve as major barriers to research participation. Individuals from under-represented backgrounds are disproportionately more likely to experience these barriers including time scarcity challenges due to multiple jobs (lack of free time), lack of respite care or childcare (due to social or financial circumstances), and lack of transportation.[11,12] As the ADRD field as a whole advances rapidly toward a new recently defined biological definition of ADRD to improve prospects for therapeutic targets, there are growing concerns regarding the potential inapplicability of many study findings to non-Caucasian individuals as emerging evidence demonstrates variable biomarker, genetic and risk profiles among minority populations. In short, emerging research suggests that disease mechanisms may vary among diverse racial, ethnic, gender and socio-economic groups. It is further worth noting that ADRD incidence and prevalence are highest among the demographics that are growing at the fastest rate in the US. Consequently, absent more advanced and

successful research recruitment and retention strategies and programs that proactively tackle the fundamental mechanisms of disparities in research participation– local, regional, and national goals to address the many health and societal challenges posed by ADRD are unlikely to be met.

4.2. Study Objectives

The Brain Health Community Registry will identify adults over age 40 and ADRD caregivers that may be interested in receiving information about current or future research opportunities related to brain health and/or caregiving, and will proactively employ strategies to reduce fundamental mechanisms that contribute to disparities in research participation.

Through the Brain Health Community Registry, participants: (1) receive information about research studies they may be eligible to participate in and (2) receive information about relevant resources and services through comprehensive retention strategies (i.e. wraparound services) in an effort to eliminate barriers to research participation that result from unmet needs. The Brain Health Community Registry is not time limited and will remain active indefinitely. The long-term goals of the Registry are to facilitate connections to research opportunities and reduce barriers to research participation through comprehensive retention strategies, and to establish a network of participants and caregivers who may be able to participate in future research studies.

4.3. Methods

ELIGIBILITY

The Brain Health Community Registry will enroll individuals in 3 categories: (1) Caregivers to people with ADRD who are 18 years or older, (2) Adults ages 40 and over interested in brain health and (3) Adults ages 40 and over experiencing changes in memory such as ADRD,

Inclusion Criteria for Caregiver Participants Ages 18+

- English-speaking
- Has had previous or current contact with a person with ADRD at least monthly (can be phone/virtual or in-person contact) and provides unpaid support to the individual which can be health, financial, social, or logistical in nature
- Interested in learning about research opportunities related to aging and brain health, particularly related to care for people living with ADRD

Inclusion Criteria for Participants Ages 40+ Not Experiencing Changes in Memory Interested in Brain Health

- English-speaking
- Interested in learning about research opportunities related to aging, brain health and caregiving

Inclusion Criteria for Participants Ages 40+ Experiencing Changes in Memory Interested in Brain Health

- English-speaking
- Interested in learning about research opportunities related to aging, brain health and caregiving
- If evidence of a lack of decision-making capacity is present, presence and consent from a legally authorized representative (LAR) in addition to assent from the participant with cognitive challenges (further detail regarding informed consent, assent, and LARs is noted in Step 3).

Exclusion Criteria for Caregiver Participants Ages 18+

- Frequency of contact with the person with ADRD is or has been less than monthly
- Nature of contact does not involve providing supports for person with ADRD, or caregiver is paid for supports
- Person they are providing care for is not experiencing any changes in memory
- Under 18 years of age
- Does not speak English

Exclusion Criteria for Participants Ages 40+ Not Experiencing Changes in Memory Interested in Brain Health

- Is not interested in learning about research opportunities related to aging and brain health
- Under than 40 years of age
  Does not speak English

Exclusion Criteria for Participants Ages 40+ Experiencing Changes in Memory Interested in Brain Health

- Is not interested in learning about research opportunities related to aging and brain health
- Under 40 years of age
- Evidence of a lack of decision-making capacity and LAR cannot be found or contacted
- Does not speak English

RECRUITMENT PROCEDURES

Information about the study, eligibility for participation, and how to get involved will be distributed through community organizations' regularly scheduled newsletters (online or print) and/or posted flyers. The study team members will follow organizational guidelines for submission and a pre-written advertisement will be submitted to agencies for publication.

Newspaper, radio and social media advertisements will contain Information about the study, eligibility for details on how interested participants can contact the study team members.

When making first contact with potential participants, study team members will explain the study and assess interest and eligibility based upon the inclusion category the participant best aligns with (e.g. Adult over the age of 40, or Caregiver over the age of 18).

Contact can take place in-person or over the phone, or through a secure online REDCap survey. All formal capacity to consent assessments and contact with LARs will still be done by phone or in person. For caregivers, there will simply be two questions on 1) status as caregiver of someone with a dementia diagnosis, and 2) nature and frequency of contact with the care recipient, in addition to the requirements on age and ability to speak English. Throughout all steps of over the phone and in person interviews, lack of decision-making capacity will be determined by members of the study team with training and prior experience in making formal capacity assessments. For the online survey, participants will be asked if they are experiencing memory changes. If they select yes, they will be asked if these changes affect their daily life. If they select yes to both questions, they will be redirected to complete the remainder of the survey over the phone or in person, so that the research team may complete an accurate formal capacity screen.

CONSENT PROCEDURES

Consistent with best practice for obtaining informed consent, study team members regularly check for questions and understanding of study details throughout the consent process. If

during initial and later contact, a potential participant expresses memory concerns or demonstrates challenges remembering key study details, the study team members will complete a formal capacity assessment. Formal capacity assessment will be triggered by disclosed concerns about memory or cognition, observed challenges following the consent process, and/or demonstrated lack of recollection or comprehension of key study details. In the formal capacity assessment process, study team members first explain the purpose of a formal capacity assessment to interested participants and their family members as a tool to check whether participants can independently and safely weigh benefits and risks of research or whether they may need support from someone they trust. A question gauging presence of concerns about memory or cognition that impact daily life is built into the online eligibility, informed consent & intake tool. If the potential participant indicates they are experiencing changes in memory or cognition that impact daily life, the online process will be stopped and a study team member will contact them for a formal capacity assessment.

Formal capacity assessment will follow the Evaluation to Consent measure – a widely used reliable/valid procedure designed for this purpose that study team members have applied to previous research. The study team member will clearly explain the study and will use the teach-back method to confirm understanding of the Registry procedures. This method utilizes a series of open-ended questions throughout the process to confirm that the participant understands the Registry and their involvement. These questions include:
1. What is the potential risk of your participation?
2. What will happen in this study?
3. What if you don't want to continue the intake interview?
4. What if you experience discomfort during the intake interview?

If the participant demonstrates understanding of the Registry and their voluntary rights and risk regarding participation, and is interested in participating, a study team member will perform informed consent procedures as outlined in this protocol. If the individual is interested in participating but does not demonstrate capacity to consent, the study team member will determine whether a LAR who meets criteria listed below is present, following the order for LARs as outlined. The study team member will enroll the participant by having the LAR provide informed consent on their behalf.

If the individual is interested in participating but does not demonstrate capacity to consent and has no LAR, or the LAR cannot be identified, the study team member will thank them for their time and interest, end the recruitment process, and destroy any identifiable information about the person. In addition, the study team member will provide resources for the interested participant on LARs and ensure they have the study team member’s contact information for any follow-up questions. Persons without decision-making capacity will be as involved in the consent process as possible through evaluation of assent by research team members. A participant's preference not to participate in the study will operate as a veto to their participation, even if their representative consents to the research.

Study team members will make contact with the designated Legally Authorized Representative (LAR) according to the criteria and hierarchy detailed below, in accordance with institutional policy and state law. If the study team members feel it is necessary to deviate from the criteria and hierarchy below they will consult with UW Legal Counsel prior to enrollment.

1) A research power of attorney may consent to a potential participant's participation in research, if the agent’s decision is not inconsistent with the wishes and preferences of the potential participant expressed in the power of attorney instrument.

2) A court-appointed guardian of the person may consent to a ward's participation in research if the court order includes the power to consent to research. NOTE: A guardian of the estate or guardian ad litem cannot provide surrogate consent.
3) A power of attorney for healthcare may consent to a potential participant's participation in research, if the agent's decision is not inconsistent with the wishes and preferences of the potential participant expressed in the power of attorney for health care instrument.
4) If the potential participant has no research power of attorney, guardian, or healthcare power of attorney, then the potential participant's "next of kin" may consent on behalf of the potential participant.

"Next of kin" can provide surrogate consent in the following order: the spouse or registered domestic partner, adult child, parent, adult sibling, grandparent, adult grandchild, or a close friend of the potential participant." The study team members will again confirm the inclusion category the participant best aligns with (e.g. Adult over the age of 40 not experiencing changes in memory, Adult over the age of 40 experiencing changes in memory, or Caregiver over the age of 18) and conduct informed consent with HIPAA authorization. Signatures have been waived for both the informed consent and HIPAA authorization.

Consent procedures will occur before any study procedures, like intake, happen. Consent procedures conducted in person or over the phone will occur in a private location of the person's choice, over the phone or by secure, UW-approved videoconferencing platform (WebEx) in a private location. Consent obtained through the online survey is completed within the secure REDCap survey. The informed consent document within the REDCap survey reminds participants of the importance of protecting personal information and encourages participants to complete the survey in a private location if possible. Participants will receive a copy of the informed consent document for their records, sent to their preferred contact method. The study has a waiver of consent with the IRB. After reviewing the informed consent document, participants will be asked to indicate whether or not they agree to participate in the study.

We will provide potential participants who decline to participate with the option to speak with the research team about their decision not to participate. Individuals who decide not to participate will be given the study team's phone number as well as email address. If the individual reaches out to the study team, the study team will answer any questions and the information given by the individual will be used to better understand perceptions of the registry, barriers to participation in the registry, and potential improvements. Contact information and any other identifiable information given by the participant will be deleted immediately after the individual makes contact with the study team.

INTAKE PROCESS

For participants completing enrollment over the phone or in person: Following informed consent, Registry participants will complete an intake visit. During the intake visit, participants will provide demographic information as well as information necessary for identifying potential research studies participants may be eligible for and successfully engaging retention strategies through identification of potentially relevant resources. Specifically, information pertaining to participant's health, safety, financial, and caregiving situation will be collected. Participants will also be given the opportunity to opt in/out of a semi-annual newsletter or similar informational flyer provided by the Brain Health Community. They may select to have the newsletter sent via e-mail or postal mail. Participants will be informed that deciding whether or not to receive in the newsletter does not impact their participation in the Brain Health Community in any way

For participants completing enrollment online: Following informed consent, participants will be directed to two questionnaires. In these questionnaires, participants will provide demographic information as well as information necessary for identifying potential research studies participants may be eligible for and successfully engaging retention strategies through identification of potentially relevant resources. Specifically, information pertaining to participant's health, safety, financial, and caregiving situation will be collected. Participants will also be given the opportunity to opt in/out of a semi-annual newsletter or similar informational flyer provided by the Brain Health Community. They may select to have the newsletter sent via e-mail or postal mail. Participants will be informed that deciding whether or not to receive the newsletter does not impact their participation in the Brain Health Community in any way.

The intake visit will take 45-90 minutes and can also be completed via phone, in person, or through the secure, online, REDCap survey. It can also be completed just after informed consent or scheduled at a later time, depending on the participant's preference. For participants completing the survey online, they will have an option to save and return later to the survey, allowing them to complete enrollment in multiple sessions if they wish. In-person visits will occur in a private location convenient to the individual, including their home, a private room in a community center or library, or the patient's room in a community-based or acute care facility. Phone calls will take place from a private room
For participants with a LAR, intake meetings will take place with the LAR, or a proxy informant (as the LAR is sometimes court appointed and may not always be the individual with the most detailed, relevant information about the person with dementia) as designated by the LAR. For in person and phone enrollment, prior to meeting the participant, the researcher will ensure they have the necessary materials—including the intake intro script, intake form, and thank-you card with $10. These materials will be in the study binder.

The study team member conducting the intake visit will greet the participant, introducing themselves and thanking them for their time and interest. The study team member will remind participants the purpose of the Registry and that participation is voluntary. The study team member will ask participant if they have any questions. The study team member will explain the purpose of the intake form, answers questions as needed, and provide necessary breaks during completion of intake visit. The intake form will be completed by the study participant with assistance from the study team member as needed.

For online enrollment, all information participants will need to complete enrollment is built in to the secure online REDCap survey. Participants will select how they would like to receive their payment at the end of the survey. The research team's contact information is listed throughout the survey in case participants have any questions, or would prefer to complete enrollment in person or over the phone instead.

RETENTION STRATEGIES
If any potential barriers to participation in the Registry or subsequent research studies are identified during the intake visit (e.g. lack of respite care, lack of reliable transportation, housing or food insecurity concerns), researchers will offer Registry participants (or their LAR) a list of potential resources and services based on their identified unmet needs (includes contact information, eligibility requirements, steps for getting connected). During the intake process, situations may arise where participants (or their LAR) need to gather personal information before being provided with a list of relevant resources. For example, information about insurance eligibility may affect which types of community support groups or respite services would be appropriate resources. In these instances, the researcher will arrange follow up with participants via phone as needed until connection to appropriate resources and services are

made. All contact will be scheduled at a time and frequency desired by and convenient for the participant.

Participants will be offered an additional follow-up call following connection to resources and services. This follow-up call is optional. The purpose of this call is to help identify “real time” barriers the participants encounter and sufficiency of services. Participants who have opted in for the Brain Health Community newsletter will receive periodic information classes or events of interest, information related to brain health, and additional ongoing studies. Some participants may not be interested in engaging in retention activities, as they may feel they do not have unmet needs or would like to use other mechanisms to address their needs. In these situations, participants that are not interested in receiving information and/or support connecting to supports and services can opt out and/or deny with no effect on their participation in the Registry.

ANNUAL UPDATE VISIT

Researchers will contact participants every 12 months following their entry into the Registry. Participants will have the option to complete the annual update via phone, in person at a convenient location of their choosing, or through the secure, online REDCap survey. Prior to meeting the participant, the researcher will ensure they have the necessary materials—including the annual intake intro script, annual intake form, and thank-you card with $5. These materials will be in the study binder.

These visits, calls, or online questionnaires will last approximately 20-30 minutes and will ask participants to: a) update their contact information, b) complete brief annual update interview to identify any significant changes, c) provide feedback on any research studies they participated in that they would like to share with the study team member, d) provide feedback on the usefulness of retention efforts including any resources or services engaged and their utility, and e) share general feedback on the Registry. This information will be used to facilitate continual improvement in cultivating useful resources, processes for engaging referring participants to research studies and the Registry itself. Resource and service needs will be reassessed on a yearly basis or if a participant demonstrates or expresses problems with participating in the Registry or subsequent studies due to unmet needs. Standard study team member procedures for working with a LAR and/or triggering and completing capacity assessment will apply during the annual update visit.

TERMINATING PARTICIPATION

Participation in the Registry and retention strategies is voluntary; participants may choose to terminate their participation at any time by contacting the study team members. Upon receiving a request, the Registry staff will unenroll the participant from the Registry within 3 business days.

If during the Annual Review process study team members cannot reach a participant, they will make attempts to re-contact the participant every two months for up to six months. If the study team is unable to reach the participant within that time frame, the study team will attempt to contact the participants’ alternative contact every two months for up to six months, if participants listed an emergency contact. If no contact is made, the study team will contact the participant and alternative contact (if listed) at one year from the missed annual update and a final contact at two years from the missed annual update. The study team will unenroll the participant from the Registry after two years of no contact with the participant. The study team members will review death records to determine whether the reason for unenrollment is death. It will be the study team member’s responsibility to periodically evaluate and update their participant pools

and manage the data they have collected from unenrolled participants. Prior data from unenrolled participants may be retained indefinitely as indicated in the informed consent to allow the study team members to analyze Registry procedures.

SPECIAL PROCEDURES TO MINIMIZE STUDY RISKS
To minimize risk of stress or burden during intake and annual update procedures, participants will be informed and reminded that they may take a break at any time, and may choose to end any assessment at any time. They may opt out of answering questions that are upsetting. Resources will be provided as needed. Study team members are trained to evaluate participant stress during interviews and assessments, and will address challenges as they occur. The informed consent process will be conducted in a private location. Subsequent contact by the research staff of enrolled participants will be done via telephone calls or conducted in a private location.

USE OF THE REGISTRY
Individuals requesting use of the Registry, for the purposes of recruiting Registry participants into a research study, should demonstrate adequate preparation and training in the conduct of Human Subjects Research and must hold Principal Investigator status, or its equivalent, at an academic, community or health-systems institution. Individuals requesting use of the Registry must provide documentation of their study's Institutional Review Board (IRB) approval along with their IRB-approved protocol and documentation of human subjects training for any study team members who will collaborate on study contacts. This information will be stored by the study team on our Department of Medicine folders.

Any member of the study team that will have direct contact with Registry participants will complete standard HIPAA and Human Subject Research training courses offered through the CITI Program and the UW-Madison Office of Talent Management, or if external to UW-Madison, the equivalent HIPAA and human subjects training. This training must be completed every three years. In order to access the Registry, the study team requires a consultation with the PI or study team designee both before and after the completion of the project. During the meeting researchers can expect feedback on recruitment and stakeholder engagement plans as well as research materials. This will be a chance for researchers to apply the training described above.

SHARING PARTICIPANT EXPERIENCES
As part of the Annual Update, the study team members will solicit feedback from participants regarding research projects in which they enrolled. This feedback will be presented to the PIs of studies using the Registry in an aggregated, de-identified fashion by the study team members once the project has been completed. This feedback will also be part of the general close-out procedure by the study team, which is a meeting between the PI or another member of the study team and the PI of the external research study.

4.4. Statistical Analysis Plan
Participant demographics and characteristics will be summarized for the Brain Health Community Registry enrollment, using frequencies and percentages for categorical variables, and using mean, standard deviation, and quartiles for continuous variables.

The BHC Registry Intervention Arm will be evaluated using qualitative feedback from participants collected at annual reviews. Analyses of qualitative data will not use statistical approaches.

We will conduct descriptive statistics to detail feasibility of the BHC Registry including statistics regarding:

- refusal rate and reason (%, n)
- enrollment rate, stratified by enrollment mechanism (%, n)
- retention rate (%, n)
- attrition rate (%, n)

4.5. Data Protection, Storage, And Sharing

Paper study materials will be stored under double lock and key Paper intake and retention strategy materials will be stored in a locked filing cabinet located within the study team member's locked office. Only persons directly involved in the research evaluation will have access to these materials. This study waives signed informed consent, and therefore paper informed consent documents are not stored.

Electronic data will be stored and accessed on secure servers (REDCap, Department of Medicine secure folders, and SecureBox) During recruitment, contact information for interested participants will be stored securely on the Department of Medicine's instance of REDCap and on the Department of Medicine secure folders. Contact information will be destroyed if a potential participant denies interest, does not meet eligibility criteria, or is lost to follow-up. Data for enrolled participants will also be stored securely on the Department of Medicine's instance of REDCap and the Department of Medicine secure folders and linked to their intake, retention, and annual update data to as the purpose of the Registry is to facilitate matching participants with research opportunities and resources. Contact lists for research studies recruiting through the Registry will be stored on a Department of Medicine secure folder or on a SecureBox folder, specific to that participating study.

All electronic data will be safeguarded through storage on REDCap, SecureBox, and the Department of Medicine secure folders which are hosted on secure servers which are maintained in locked, secure, limited-access server storage rooms. The servers are secured with robust firewalls that are maintained by UW-Madison School of Medicine and Public Health network staff. Access to the servers and REDCap will be restricted to team members with special training on data safety. Access is audited every 6 months, and removed if determined no longer necessary. Computers used to access the servers and REDCap have an additional layer of password protection. Access to identifiable data is restricted to specific study team members, including the project PI and data programmers, by limiting REDCap and folder directory access permissions to just those individuals. REDCap and the server are protected physically by passkey and electronically by the restriction of access to data to only selected project-specific individuals (need-to-know). Access to contact lists for research studies recruiting through the Registry will be restricted to study team members from that research study provided documentation of their IRB approval, their IRB protocol, and each individual's human subjects training. The datasets used for analysis of Brain Health Community Registry accrual, retention, etc. will be deidentified and aggregated. Data will be reported as group data so that no individual could ever be identified.

4.6. References

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