

**Tier 3 Pilot Grant Application: Scaling for Greater Impact
Spring 2025 Cover Sheet**

Project Information

Please provide the following information.

Project Title	Bridging the Gap: Addressing Engagement of Dementia Resources and Healthcare in People Living Alone with Early-Stage Cognitive Impairment
Budget Request from Initiative	\$149,952
Budget Match (if applicable)	
Total Project Budget	

Applicant Information

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UW Advisors are campus scholars who may provide guidance on the study with possibilities for future collaborations or data use

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Abstract

This project addresses disparities in access to dementia resources and healthcare among individuals living alone experiencing early-stage cognitive impairment (ECI).¹ Approximately 20% of people with ECI develop dementia each year,² and nearly a quarter of US adults with ECI or dementia live alone,³ which is a likely underestimate due to underdiagnosis.^{4,5} Living alone increases risks of dementia and comorbidity,⁶ underscoring the urgent need for timely engagement and activation of dementia resources and healthcare. Yet, this hard-to-reach population experiences barriers to such resources and remains disproportionately overlooked in statewide dementia prevention efforts.⁷ In collaboration with local community organizations, this project seeks to understand ways to improve the activation and engagement of dementia resources and healthcare among underserved Washingtonians living alone with ECI through three aims: (1) Guided by the Network Episode Model, we conduct a state-wide survey to investigate barriers and facilitators to engagement and activation of dementia resources and healthcare, focusing on the role of informal and formal social networks; (2) We will identify alternative healthcare access facilitators to supplement social network-based facilitators, including individual, technology-based, and community and systemic resources; (3) We will increase public awareness of dementia resources and facilitators through a participatory approach to amplify the voices of Washingtonians living alone and facing risk of dementia. By integrating social, technological, and community-based strategies, this work seeks to bridge gaps in care and empower vulnerable, often overlooked Washingtonians.

Tier 3 Research Plan

Individuals living alone with early-stage cognitive impairment (ECI) are at heightened risk of dementia, comorbidities, limited in-home support, and premature institutionalization, contributing to increased public health burdens. Despite these challenges, this population remains understudied and underserved in healthcare and community support systems. This project, employing a community-driven empowerment approach, identifies barriers and facilitators to engagement and activation of dementia resources (i.e., self-efficacy in dementia care navigation and awareness and utilization of available resources) and healthcare use (i.e., healthcare readiness, receipt of preventative health services, timely healthcare utilization) and implements a participatory program to amplify their voices to drive public awareness and policy change. By engaging directly with at-risk individuals, this initiative seeks to address disparities in access to dementia resources and healthcare by identifying social-network and non-social-network factors that can promote resource accessibility, informing interventions and policies that better support this vulnerable group.

ECI is characterized by deficits in one or more cognitive domain such as memory, executive functioning, language, attention, and processing speed without significant limitations in daily activities,^{8,9} and affects an estimated 22% of midlife and older adults in the U.S.^{10,11} with steady projected increases.¹¹ Up to 20% of individuals with ECI develop dementia over a one-year period,² which is a likely underestimate due to underdiagnosis.^{4,5} ECI, whether neurodegenerative or not, can be worsened when several medical conditions co-occur,^{12–16} including high cholesterol, hypertension, depression, diabetes, and cardiovascular diseases.¹⁷ Delayed or missed engagement in prevention measures or treatment often accelerates progression to dementia by exacerbating modifiable comorbidities,^{13,16} and heightens risks of premature institutionalization,¹⁸ inflating societal costs.^{16,18–21} Even among those without neurodegeneration, disengagement from healthcare allows reversible ECI drivers to exacerbate cognitive deficits over time.^{19,22} Despite the growing prevalence of ECI, this population remains understudied in research²³ and overlooked in clinical practice and public health policies. Without targeted strategies to improve engagement in dementia resources and health services, preventable disability and societal costs will continue to rise.

Those living alone with ECI are of particular concern. Nearly a quarter of US adults with ECI or dementia live alone.³ These individuals experience compounded risks due to increased likelihood of dementia and comorbidity,⁶ social isolation, and inadequate support, underscoring the urgent need for timely dementia resources and healthcare engagement. Living alone often delays a timely diagnosis,^{24,25} particularly for cognitive impairment,^{5,26–29} in part due to the absence of an informal care person who can notice and report concerning symptoms.^{27–29} Without support, coordinating necessary healthcare and managing medications and daily tasks becomes difficult,^{30,31} yet many do not qualify for in-home support benefits.^{31,32} Consequently, individuals living alone with ECI report higher prevalence of unmet daily needs, self-neglect,³³ poorer health, and earlier nursing home transitions.³⁴ Despite these vulnerabilities,

statewide dementia prevention efforts have overlooked this population, focusing on caregiver-supported individuals.³⁵ Our study addresses this disparity by examining multidimensional facilitators that can promote engagement in dementia resources and health services for people living

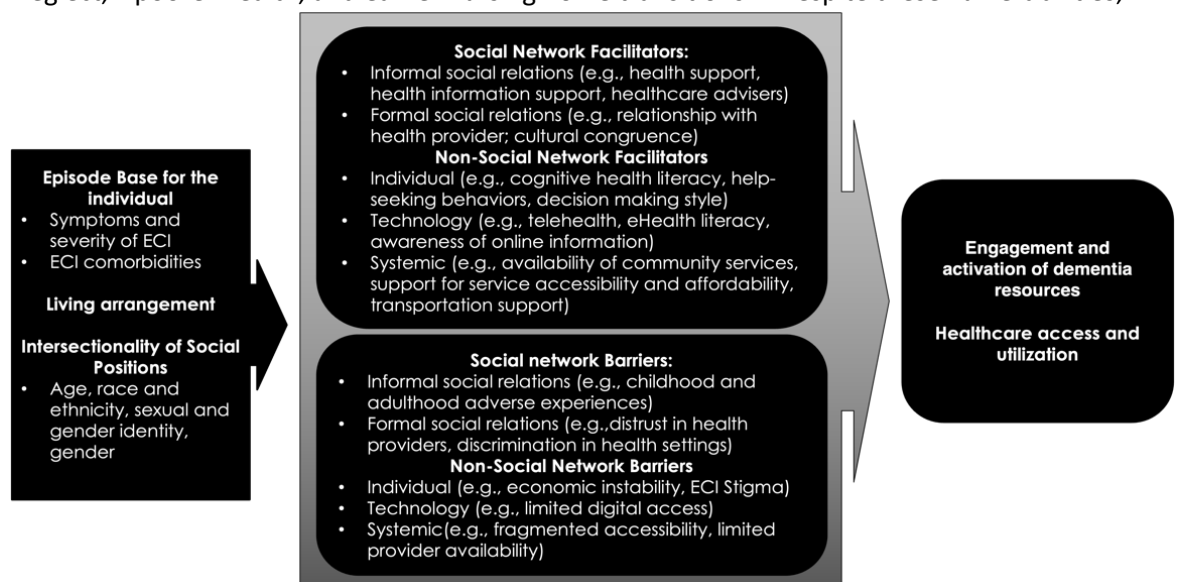


Figure 1. Conceptual Framework (Kim, et al., 2025)

alone with ECI. Our study bridges the gap between current caregiver-focused systems and the growing population aging alone with cognitive impairment.

Understanding ECI in individuals living alone requires a framework that goes beyond medical models and incorporates social networks. Traditional rational choice theories, which emphasize individual decision-making, fail to account for the critical role of social interactions in shaping how people perceive and manage ECI. The conceptual framework explored in this study (Figure 1) is informed by the Network Episode Model (NEM)³⁶ and the empirical findings from the Health Equity and Intersectionality Study funded by UW Royalty Research Fund (PI: Kim). According to the NEM,³⁶ ECI can be conceptualized as a social process, where "episodes" (e.g., ECI symptom flare-ups, diagnosis of ECI-triggering chronic conditions, challenges in daily living) trigger problem-solving behaviors influenced by social ties. The NEM offers a holistic approach by examining how individuals navigate ECI through informal social relations (e.g., confidants' support regarding health information and service navigation) and formal social relations (e.g., relationship with health providers). Importantly, social networks influence whether individuals recognize ECI, seek help, adopt coping strategies, or navigate and access dementia resources and healthcare systems.

Our pilot findings from the Health Equity and Intersectionality Study of adults with disabilities (cognitive disability was the most common in the sample) suggest how social isolation can exacerbate challenges for this population as they lack immediate family or caregivers to help recognize symptoms, access dementia resources, or advocate for care. For those living alone, episodes of cognitive decline (e.g., missed medications, safety risks) often go unaddressed without a robust support system, delaying interventions. The hypothesized framework underscores how weakened social ties lead to fragmented care pathways or crisis-driven responses, resulting in low engagement with dementia resources and healthcare services. Yet, it also identifies opportunities. Community and systemic resources, technology, and individual resources (e.g., health literacy, help-seeking behaviors, deliberative decision making) can compensate for the absence of cohabiting supports, empowering individuals to manage ECI proactively. Unlike static models, this framework underscores dynamic interactions between individuals, networks, and institutions, offering an empowerment-focused lens to support autonomy while addressing individual and system-level barriers. This approach shifts the focus from isolated decision-making to socially embedded strategies, ensuring interventions align with real-world lived experiences of people with ECI.

In collaboration with experts from relevant fields across UW departments, the proposed study will build on these findings to address two identified gaps: 1) how social networks facilitate engagement of dementia resources and healthcare among adults living alone with ECI and 2) for those who lack such social networks, what alternative resources can connect them. The specific aims and methods are as follows:

Specific Aim 1a. Investigate the facilitating role of formal and informal social networks in engagement and activation of dementia resources and healthcare among Washingtonians living alone with ECI while accounting for individual, social, and structural barriers. Aim 1b. Identify alternative healthcare access facilitators to supplement social network-based facilitators, including individual, technology-based, and community and systemic resources.

To achieve Aims 1a and 1b, we will collect data from 500 participants, using purposive sampling to ensure diversity across age, gender, race and ethnicity, and sexual and gender identity. Power analyses were conducted to establish stratified recruitment goals, using conservative estimates based on the smallest sub-samples, which are sexual and gender minorities. With a target of ≥ 75 , we can achieve 80% power at an alpha level of 0.5 based on a series of power analyses using the pilot findings of the Health Equity and Intersectionality Study. Inclusion criteria are as follows. Participants must reside in Washington, live in community settings, and be ≥ 40 years old at enrollment – a critical period when early indicators of dementia, particularly subjective cognitive decline, often emerge and when interventions targeting modifiable risk factors may be most effective in preventing or delaying objective cognitive impairment and dementia.³⁷ They must live alone. To be consistent with the operational definitions used in other studies examining the impact of living arrangement on healthcare access and health outcomes,^{1,38,39} we define living alone as one person occupying a household at the time of study recruitment. While cultural norms may influence the operationalization of living alone,⁴⁰ this standardized definition ensures comparability with prior studies. They must meet validated ECI criteria,⁴¹ including: (1) cognitive decline relative to previous functioning, assessed via self-rated AD8

score ≥ 2 ,⁴² (2) preserved daily functioning assessed via Activities of Daily Living Prevention Instrument score ≤ 30 ,⁴³ and (3) no prior dementia diagnosis (self-reported).

Recruitment: Participants will be recruited from multiple sources using a multifaceted approach, which minimizes biases in relying on samples drawn solely from support groups or health clinics. Strategies include direct referral from community agencies providing aging and health services (e.g., churches, buddy programs and social groups in addition to health clinics and support groups). In addition, study announcements will be distributed through the use of presentations, flyers, newsletters, and a social media campaign. Study staff will facilitate meetings for community agencies that serve older adults, offer presentations on topics of interest to members paired with recruitment, and engage agencies in recruitment efforts. Community partners including DAC and WA Area Agency on Aging will also share study materials, including a user-friendly website, flyers, and social media posts, to amplify visibility. The lead PI and co-investigators have extensive experience in recruitment strategies for hard-to-reach populations, and based upon our previous Health Equity and Intersectionality Study (PI: Kim), IDEA Café study (MPI: Fredriksen-Goldsen, Kim), and WA Wellness with Pride study (PI: Fredriksen-Goldsen), we are confident we can achieve our recruitment goal.

Potential participants who discover the study via the study website or social media campaign will complete an online screener, followed by the main online survey. Individuals who contact the research team by email will be directed to the online screener and subsequent survey. For participants who reach out by phone, researchers will administer the screener and survey via phone interview or provide an online survey link. For all three modes, participants may alternatively request a paper survey, which will be mailed with return envelopes. This multi-modal approach that this study team has experience implementing ensures accessibility and flexibility for diverse participant preferences.

Measures: We measure the status of ECI based on self-report of cognitive decline and MCI or early-stage dementia diagnosis, ECI severity using the self-administered MoCA (MoCA-XpressO),⁴⁴ and ECI comorbidities. For outcome measures, engagement with dementia resources is assessed by self-efficacy in dementia care navigation (the Consumer Access, Appraisal and Application of Services and Information for Dementia scale),⁴⁵ and awareness and utilization of available dementia resources and barriers to utilization by the Dementia Assessment of Service Needs scale⁴⁶ adapted to reflect services in WA. Healthcare use is assessed by measuring healthcare readiness (usual sources of care,⁴⁷ having a personal doctor,⁴⁷ confidence in navigating health care system⁴⁵) and both preventative (regular checkup, flu shot, cognitive test, other CDC-recommended screenings)⁴⁸ and timely healthcare utilization (no delays in getting care).⁴⁹ To evaluate social and non-social facilitators and barriers (as outlined in Figure 1), we adapted measures previously validated among midlife and older adults with disabilities.⁵⁰ The Social Network Roster developed from the Health Equity and Intersectionality Study to assess the role of social networks in navigating and accessing health information and health services will be further adapted to evaluate their role in navigating and accessing dementia resources.⁵⁰ Key social positions analyzed for intersectionality include age, race and ethnicity, sexual and gender identity, gender, and immigration status—all of which have been linked to increased risks related to cognitive impairment^{4,10,51–55} and healthcare access disparities.^{56–59}

Analysis plan. Using Stata MP 17.0 (StataCorp LP, College Station, TX) and Mplus, we will use hierarchical multiple regression to evaluate facilitators of outcome variables. After establishing a baseline model with ECI severity, number of comorbidities, and demographics (Model 1), we will sequentially add social network (Block 2) and non-social (Block 3) factors along with barrier factors to account for them. Final models will test theorized interactions between ECI severity, comorbidities, and demographic factors and key facilitators (Model 4). All continuous predictors will be mean-centered. Significant interactions will be probed using *margins* with follow-up simple-slopes analysis at ± 1 SD of the moderator, analogous to Hayes' PROCESS macro. Model assumptions will be verified through residual analyses (rvfplot, hettest), with heteroskedasticity-robust standard errors applied via the vce (robust) option when needed.

Aim 2. Increase public knowledge about challenges, needs, and enablers for engagement in dementia resources and healthcare services, leveraging a participatory approach to amplify the voices of Washingtonians living alone and facing risk of dementia.

Complementing the survey, this innovative virtual photovoice project will create a space where participants can share lived experiences of cognitive impairment through photography and offer deeper insights into dementia resource engagement and healthcare access while identifying modifiable factors that could enhance engagement. To increase

public awareness, study results will be shared through online platforms, community forums, and policymaker presentations, highlighting actionable strategies to improve healthcare access for people experiencing ECI.

Eighteen participants identified among Aim 1 survey participants and have a stable internet connection, computer, and a device for taking digital photos (phone/tablet/digital camera) will be enrolled and randomly assigned to three Zoom discussion groups (6 per group). We will include \geq six racial/ethnic and \geq six sexual and gender minorities to ensure diverse voices from populations with heightened social isolation^{60–62} and resource barriers,^{56,57} aligning with the empowerment focus of our photovoice method.^{63,64}

We adapted our protocols from a previously validated virtual photovoice project.⁶⁵ Photovoice participants will first meet one-on-one with a photovoice facilitator for a virtual intake interview. The photovoice facilitators, Dr. Souza (co-I) and a doctoral candidate trained by the co-I, will immediately begin the process of building trust in the intake interview.⁶⁶ They will also explain the study requirements and objectives, obtain consent, and assist with any technical issues including downloading Zoom and training in its basic functions.^{66,67} Following the intake interview, participants will be mailed a welcome letter and then will participate in individual virtual orientation meetings. During these orientations, a photovoice facilitator will review the welcome letter, the theme for Session 1, the assignment (See Figure 2) to take three photos aligned with this theme, and will provide explicit instructions regarding uploading photographs. In the first of the three 90-minute group sessions⁶⁶ facilitators will address any technical barriers to participation,⁶⁶ followed by group introductions and setting group norms. Members will then share their individual photographs and the group will discuss common or unique themes across all photographs. The activities for each session are displayed in Figure 2.

Drawing upon established methodologies for analyzing visual data and incorporating polytextual thematic analysis principles,⁶⁸ we will employ the following steps: extracting demographics from participant surveys; examining individual visual and textual narratives; analyzing group discussions to capture collective interpretations; synthesizing individual and collective analyses; collaboratively developing themes with participants while preserving divergent perspectives; validating themes through triangulation with workshop materials; and implementing strategic knowledge dissemination beyond academic publications to engage stakeholders positioned to create meaningful change. Our analysis will deliberately capture the critical consciousness that emerges from group dynamics—not solely analyzing visual data and captions in isolation—to effectively inform experience-based codesign workshops aimed at catalyzing changes in local systems and influencing state policy development. We will track attendance, assignment completion, and participant/facilitator session ratings to assess the project’s feasibility and acceptability.

Online Exhibition. We will co-create an accessible online exhibition of participants photographs and accompanying voluntary, contextual essays. The exhibition will represent the lived experiences of individuals with ECI living alone and serve as an awareness-raising tool for the public, policymakers, and community stakeholders.

Figure 2. Photovoice Session Activities

Session 1 (Week 0): Living with Cognitive Changes	
Focus	What does living with changes in cognitive health look or feel like for you?
Assignment	Take and share photos capturing daily challenges, emotions, or adaptations. And, any daily supports.
Guided Reflection	How do these cognitive changes impact independence, relationships, or routines?
Session 2 (Week 2): Navigating Resources & Healthcare	
Focus	How do you find or access dementia resources and health services?
Assignment	Take and share photos of facilitators (e.g. social networks, community centers, tech tools) or barriers (e.g., transportation, stigma).
Guided Reflection	What works well? What gaps or frustrations exist?
Session 3 (Week 4): Collective Insights & Action	
Focus	What common themes emerge from our experiences? How can we improve resource engagement?
Guided Reflection	Group analysis: Compare photos/stories to identify systemic patterns.
Session 4 (Week 6): Wrap-up	
Focus	Co-create recommendations: Practical solutions (e.g., outreach strategies, policy ideas).
Guided Reflection	Exhibition planning: Select photos + draft captions/narratives for advocacy.

Tier 3 Project Budget (add additional pages if funding is matched by more than three entities)

	Requested from Initiative	Funding Match by: <i>School of Social Work</i>	Funding Match by:	Funding Match by:
Salaries				
Faculty	58,363			
Staff	30,018			
Student	9,874			
Benefits Fringe Benefits Based on Payroll Load Rate In Effect	25,457			
Supplies and Materials Supplies, Equipment Under \$2,000, etc.	3,700			
Equipment Equipment Over \$2,000				
Travel Per Diem Lodging/Meals/Expenses, Air Fare, Mileage, Car Rental	1,500			
Tuition For graduate students				
Other	21,040			
Total Direct Costs	149,952			