



Economic
Stability



Education



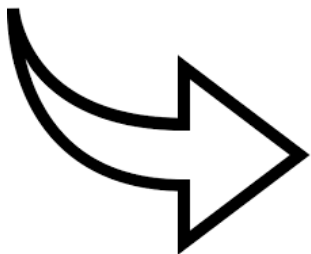
Health &
Healthcare



Neighborhood
& Built
Environment



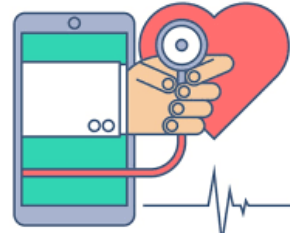
Social &
Community
Context



Social and environmental factors are known to influence **health...**

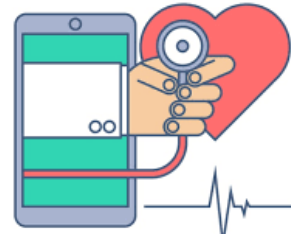
Little work has focused on how these factors influence **capacity to join a research study**

Underrepresented groups are more likely to have **unmet needs** that may serve as **barriers to research participation**



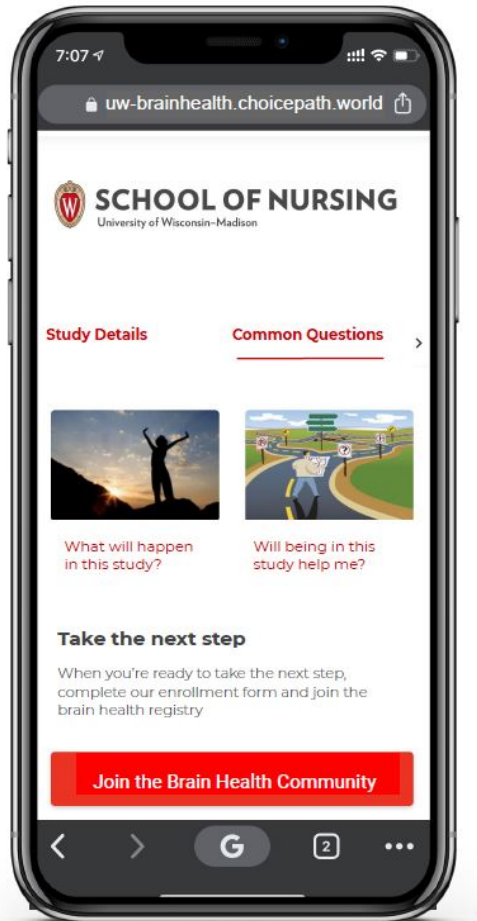
Basic needs such as food, water, housing and health-related needs are important considerations for dementia research accessibility

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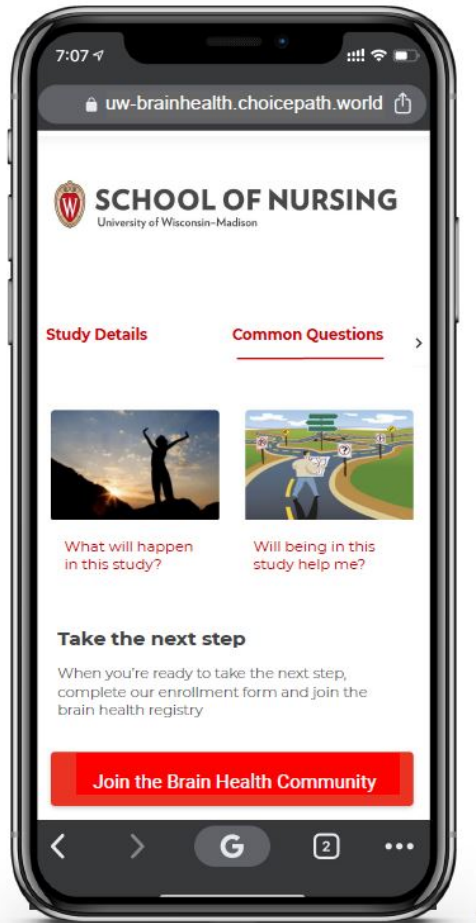


Basic needs such as food, water, housing and health-related needs are important considerations for dementia research accessibility

To address this, we developed the ***Brain Health Community Registry***, which aims to **systematically alleviate barriers to dementia research participation** by proactively connecting participants to care and services to address unmet needs



- Participants are recruited into the registry through public media, social media, community-based, inpatient and outpatient settings



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- Participants interested in learning about research opportunities related to cognitive aging, brain health, or dementia caregiving over age 40 are invited to participate
- Procedures also facilitate inclusion of individuals living with dementia with and without decision-making capacity

The Brain Health Community Registry considers ways that unmet needs contribute to disparities in dementia research participation

Example unmet needs

- **Caregiving Demands**
 - **Transportation**
 - **Mobility Challenges**
 - **Food Insecurity or Insufficiency**
- 

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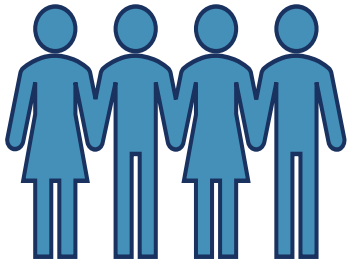
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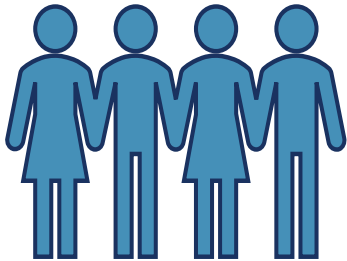
Influence on Capacity to Participate in Research

- **Time Scarcity**
- **More difficulty accessing resources that lead to research opportunities**
- **Reduced capacity to meet demands imposed by research participation**



The registry is guided by the **participant and relationship-oriented research engagement model**

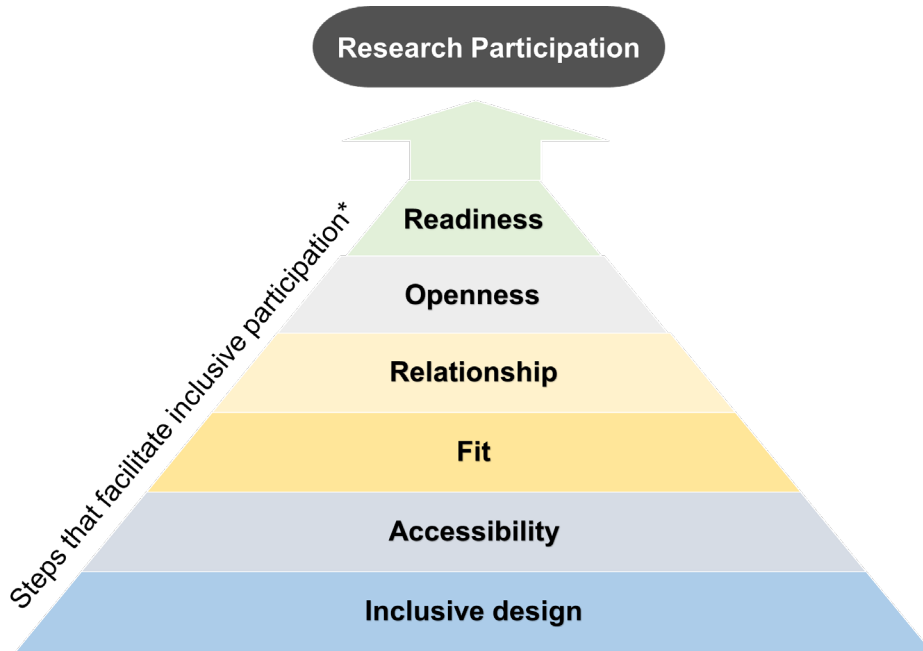
The model views research as a relationship and extends **social determinants** frameworks to our understanding of barriers to **research participation** by centering the priorities, concerns and constraints relevant to research participants from diverse backgrounds



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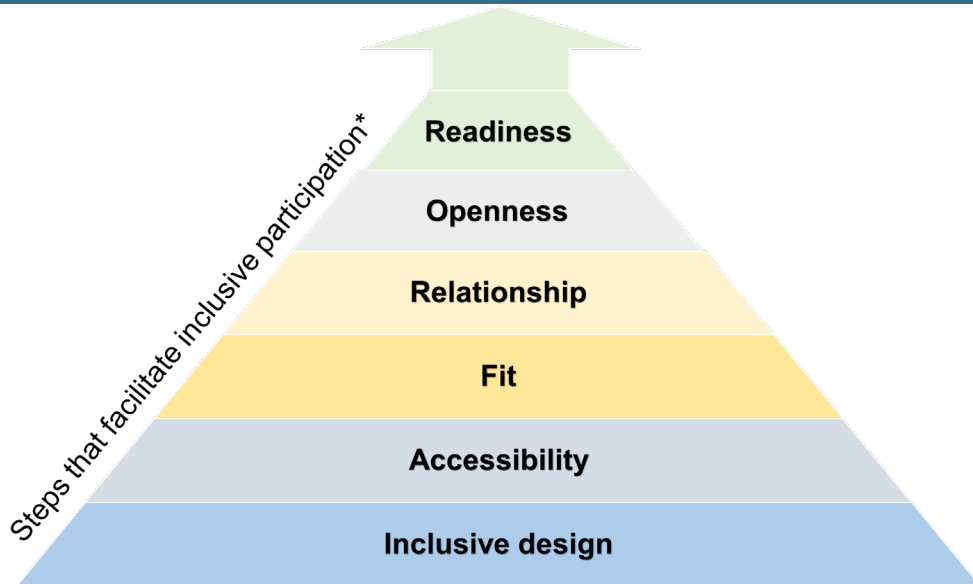
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The model illustrates **foundational requirements** for facilitating **inclusive research participation**

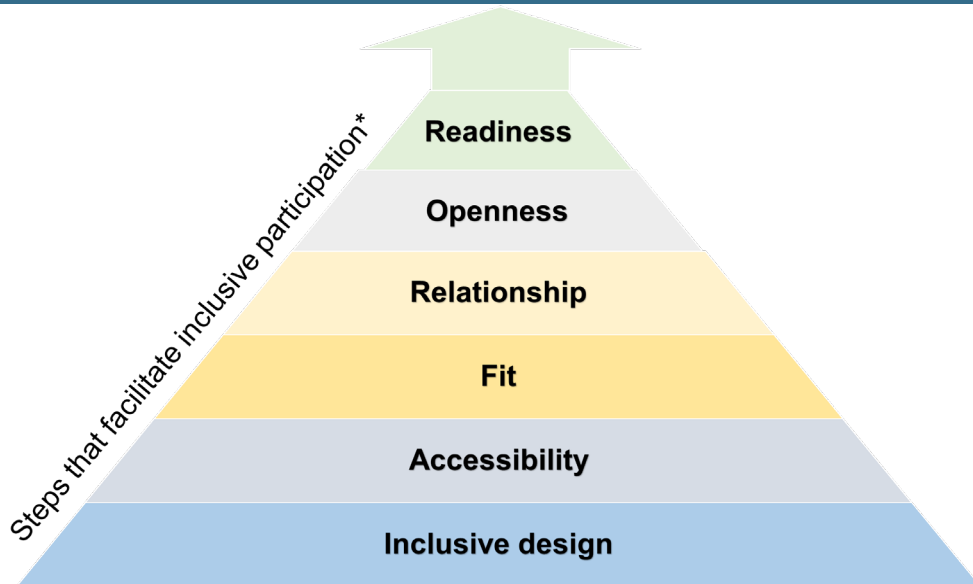


Participant and Relationship-Oriented Research Engagement Model

Steps are not mutually exclusive nor necessarily sequential, and some represent **cyclical and ongoing efforts** to foster participation, such as deliberately **building relationships**, which is understood to require time investment, or **removing barriers** to research participation



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Step 1

The first step in joining the **Brain Health Community Registry** involves conducting a **needs assessment** with the participant across **seven core domains of needs**.



Step 1 - The needs assessment is standardized and addresses these core domains

1. Food Insecurity or Insufficiency Needs

2. Housing and Safety Needs

3. Transportation and Physical Mobility Needs

4. Sensory, Communication, Cognition Needs

5. Health-Related Needs (e.g. Medications)

6. Daily Functional Needs (e.g. Bathing)

7. Caregiving Needs (e.g. Respite Care)

Are there things you'd like to be doing but can't because of trouble with transportation?

Yes

No



Do you use any equipment to help you get around?

Wheelchair

Walker

Cane

Crutches

White Cane

Service Dog

Other

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Step 2 – Resource Matching

The second step involves **research and resource matching** based on the participant's needs assessment. *This step is optional.*

A social worker will identify the participant's **areas of need**, determine if case management services are needed, link the participant's needs to potential resources using a **resource directory**, and create a **personalized resource list** for the participant

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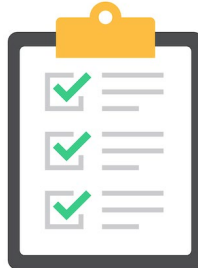
This is a list of kinds of help people may need. Please tell me if you provide this kind of help. (Select all that apply)

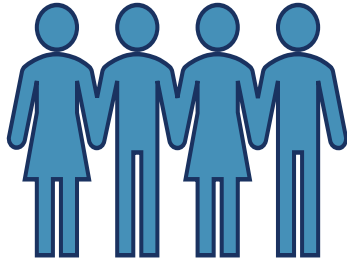
- | | |
|---|---|
| <input type="checkbox"/> Assistance with eating | <input type="checkbox"/> Transportation within the community |
| <input type="checkbox"/> Bathing | <input type="checkbox"/> Shopping for groceries or other essentials |
| <input type="checkbox"/> Using the restroom | |
| <input type="checkbox"/> Dressing | <input type="checkbox"/> Setting up or monitoring medications |
| <input type="checkbox"/> Preparing meals | <input type="checkbox"/> Attending medical appointments |
| <input type="checkbox"/> Housework, such as doing dishes, laundry, or tidying up | <input type="checkbox"/> Arranging or supervising services from an agency, such as nurses or housekeepers |
| <input type="checkbox"/> Managing money, such as paying bills or filling out insurance claims | <input type="checkbox"/> Other:
_____ |

Step 3

The third step involves checking in with participants during an **annual review or earlier if the participant chooses** to update their information and determine efficacy of research and resource matching

We also collect feedback on experiences with studies they are referred to and participate in via the registry





An important concern is determining the need for **case management** and **ongoing follow-up** to ensure **successful connection to resources**



**Partnership with
community
stakeholders,
caregivers and
persons with
dementia** was
essential in shaping
the Brain Health
Community Registry



We spoke to people with dementia and their caregivers to better understand **accessibility challenges** to research



Participants highlighted the role of **positive regard** and relationship with student teams that are “**kind**” “**thoughtful**” “**not forceful**” and “**attuned [to participant’s] feelings**” – among other qualities



Caregivers endorsed **researchers serving as a bridge to resources**, and the ways this could be valuable and useful.

Several shared having had **few resources related to caregiving** and were motivated to participate for this reason



Next Steps include **ongoing evaluation of enrollment/retention** in the registry, **recruitment into other studies**, and **participant appraisal** of experiences with the registry and use of referred services