



Decision-Making in Dementia Care

Astoria Ho

South King County Provider's Network Meeting

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→ Hello!



- Astoria Ho
- Research Coordinator for Decision-Making in Alzheimer's Research **(DMAR)** (NIA #R01 AGo66957)
 - Anne M. Turner, MD, MLIS, MPH, Principal Investigator
- Health Promotion Research Center at University of Washington

→ Background

- Nearly 7 million individuals in the US have Alzheimer's Disease and Related Dementias
- There is no curative treatment for dementia, management involves supportive care and treatment of symptoms
- Many people with Alzheimer's Disease and Related Dementias receive care at home
- 11 million unpaid caregivers spend about 32 hours/week providing care
- As dementia progresses, more decisions about care needs are made



→ Problem Statement

Persons with dementia are often left out of decisions regarding their care, especially as their disease progresses.

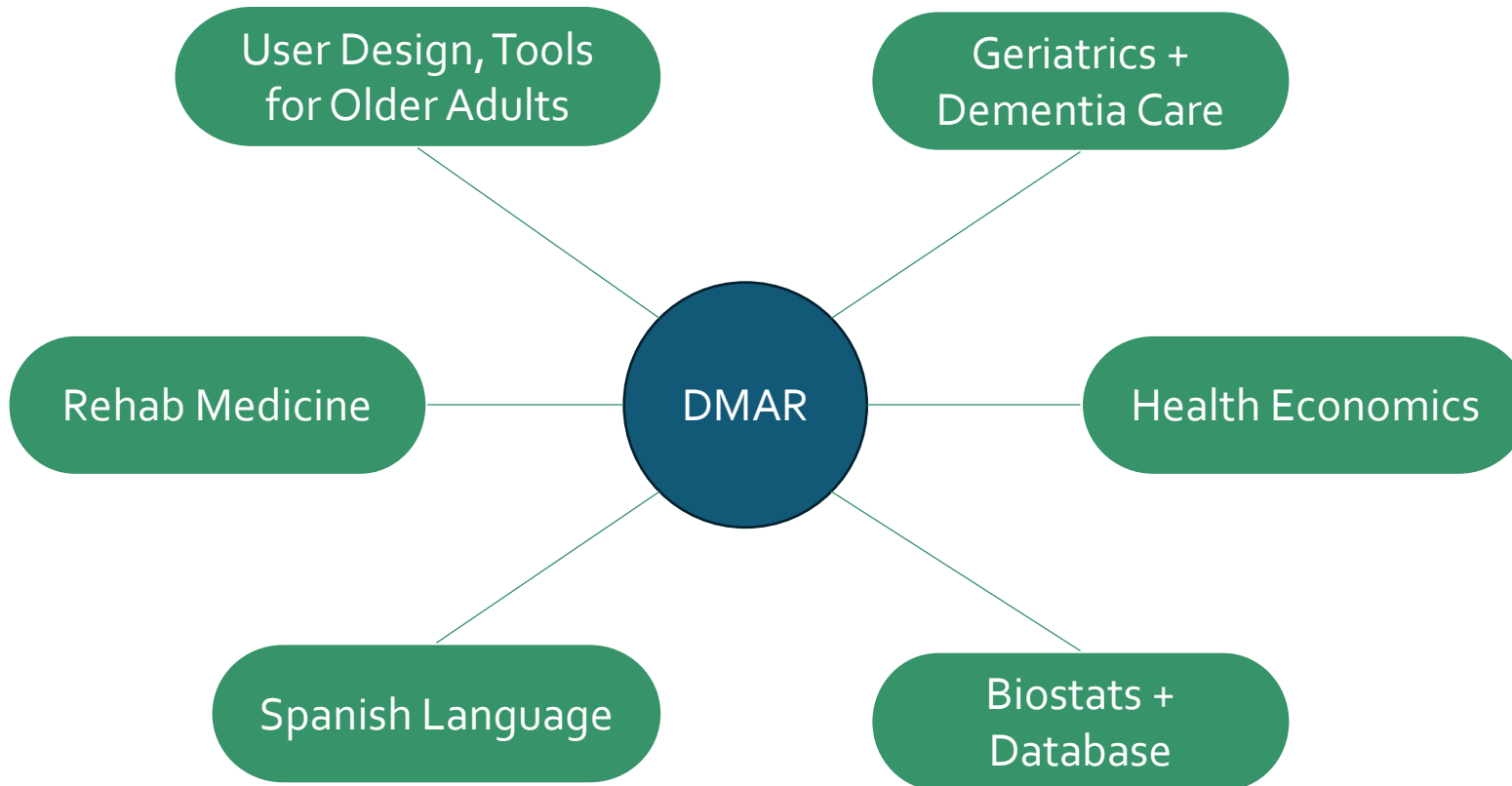
We currently lack ways to measure and track preferences of persons with dementia.

Decision-Making in Alzheimer's Research's (DMAR) Goal

Keep older adults with dementia involved in decision-making through development of a preference elicitation tool to identify and track preferences related to transitions in care.



DMAR's Multidisciplinary Team

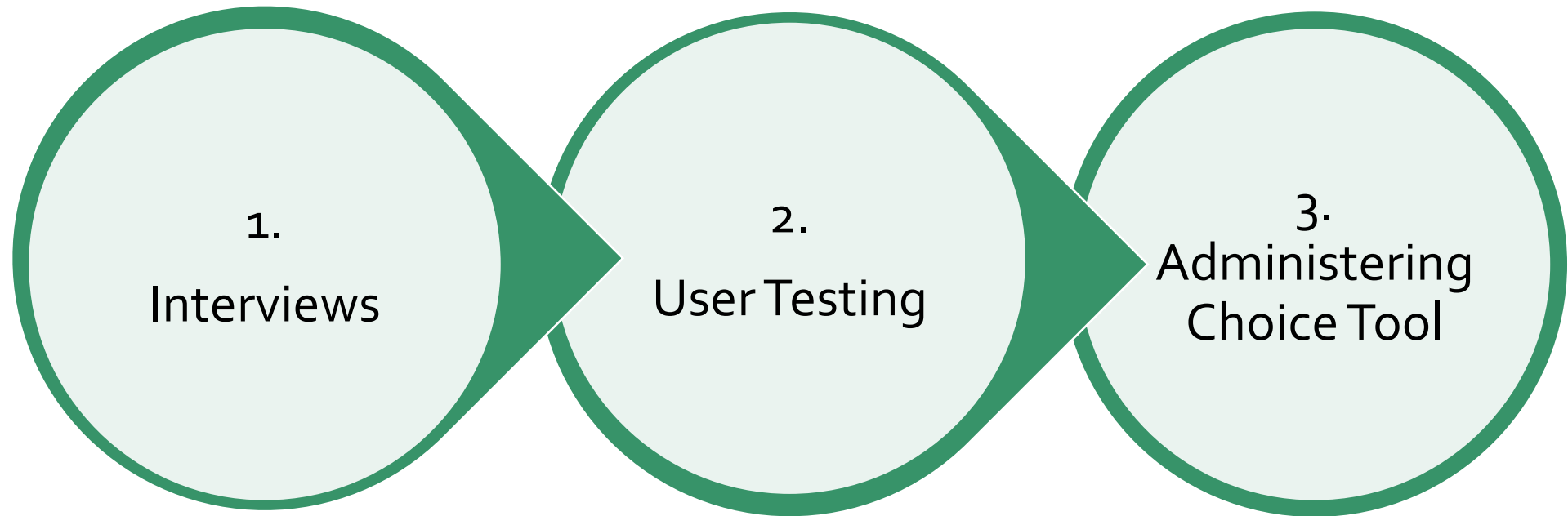


→ Person-Centered Decision-Making

- Research that focuses on individuals and what matters to them
- Putting people at the center of decisions
- Respecting individual needs and preferences



Engaging People with Dementia

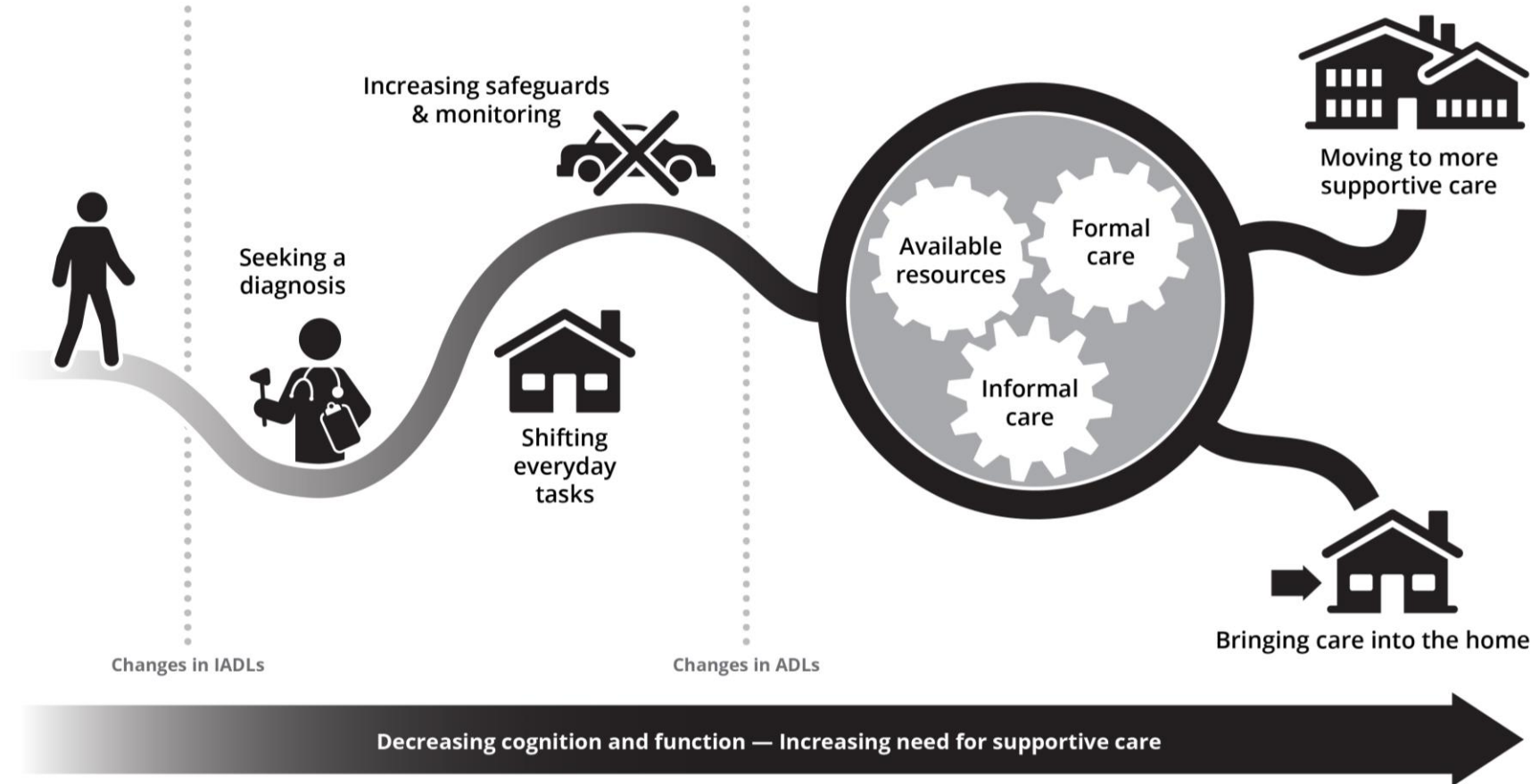


Interviews

- What **decisions** are made related to supportive care and transitions in care in the context of memory loss?
- What **factors** are considered when making these decisions?



Interviews: Decision-Making Path



Interviews



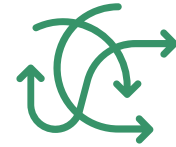
Desire to Maintain their Life

"It looks to me like we're on a path, or a road, and we haven't come to that bridge yet, so I haven't really thought about it that much." (person with memory loss #113)



The Importance of Home

"I'm happy where I'm at, and I have lots of good friends, so why would I want to move?"
(informal caregiver #113, quoting spouse)



Unknowns and Uncertainties

"It's almost impossible to plan adequately because, again, you just don't know what you're planning for."
(informal caregiver #137)



Resource Constraints

"...so many times some of our caregivers don't have the money to really afford to put their loved one in an Alzheimer's facility..."
(medical professional, #117)

Interviews: Key Takeaways

- Older adults and caregivers strong prefer to stay at home
- Caregivers experience tensions
 - Cultural norms vs caregiver burden
 - Autonomy vs safety
- Need for more resources and information
- **Most PWD had difficulty imagining or thinking about their future**

**How can we engage people
with dementia to share their
preferences on care?**

Using a Discrete Choice Tool

The goal of the choice tool is to tease out **preferences** by asking about hypothetical scenarios.

Example conjoint choice task



<https://conjointly.com>



→ Adapting the Discrete Choice Tool

1. Picking relevant **attributes** around complex care decisions
2. Simplifying the tool to be **useful and accessible** for older adults with varying levels of dementia

Selecting Attributes

Round 1: Initial Attributes

Level of ADRD
Caregiver burden
Autonomy
Safety
Financial resources
Social network/ family dynamics
Information
Culture
Values
Attitudes
Dyadic relationship

Round 2: Attribute Refinement

Level of ADRD → Problems with memory and function
Autonomy / Independence → Changes to support safety
Safety → Changes to support safety
Caregiver burden → Hours of paid in- home care
Finances → Hours of paid in-home care

Round 3: Final Attributes

Problems with memory and function
Changes to support safety
Hours of paid in-home care

Final Attributes



Problems with
memory and
function

Level of ADRD



Changes to support
safety

Environment,
Monitoring



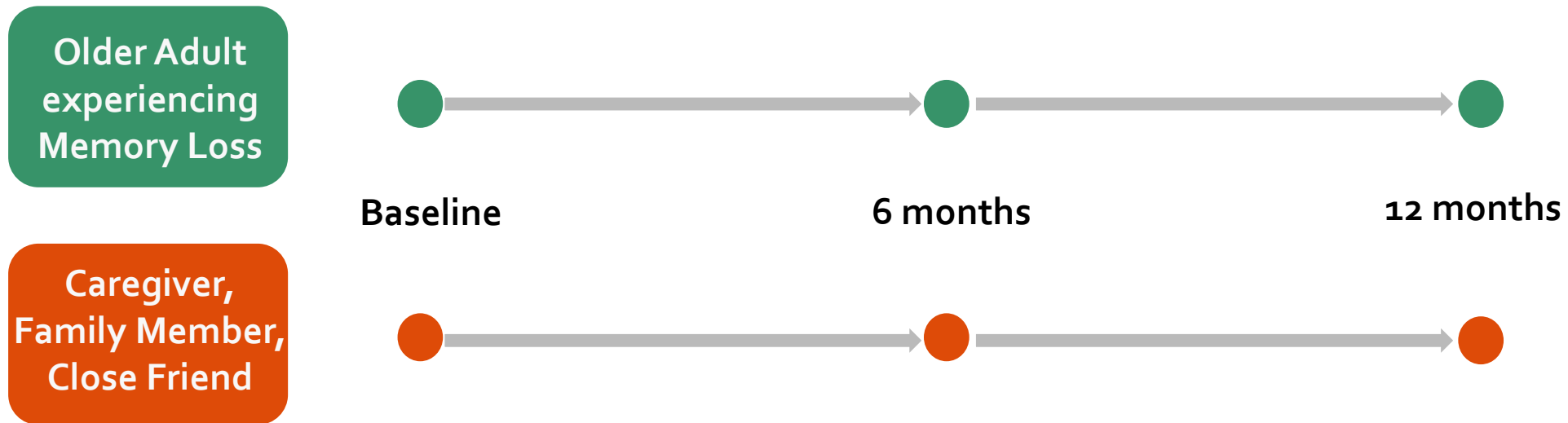
Hours of paid
in-home care

Caregiver Burden,
Finances

Administering DMAR's Choice Tool

We are engaging with about 130 dyads in a longitudinal study

- Person with memory loss
- Informal caregivers (family or close friends)



→ Administering DMAR's Choice Tool

- What are their preferences?
- How might preferences change over time?
- How do preferences differ between persons with memory loss and caregivers?

→ Longitudinal Study: Findings

- What we've heard from participants so far:

"It's a fantastic exercise...I can't predict what my future's going to be... but you've given me some choices that allow me to say, 'Yeah, ok, let's choose this choice'" (person with dementia, #2128)

"I did not enjoy it. It's definitely an opportunity to consider the future and evaluate what I might need." (person with dementia, #2084)

Community Partners



→ Potential Impact

- Exploratory tool can serve as a starting point to initiate care conversations earlier
- Encouraging collaborative care planning between caregivers, providers, and PWD that include and respect PWD's preferences

- ▶ **As a provider, what stands out to you when people need to make decisions about care?**
 - ▶ **How can research reach and involve with older adults who have diverse backgrounds?**
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- **Contact me: astoriah@uw.edu**
 - **Learn more at: dmar-study.com**
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Anne M. Turner, MD, MLIS, MPH,
Principal Investigator
National Institute on Aging (NIA)
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*The content is solely the responsibility of
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Thank you!