



Caregiver Intervention Research: Now and into the Future

Laura N. Gitlin Ph.D., FGSA, FANN

Eric Jutkowitz, Ph.D.

Joseph E. Gaugler, PhD.

Presentation to NASEM , Decadal Study

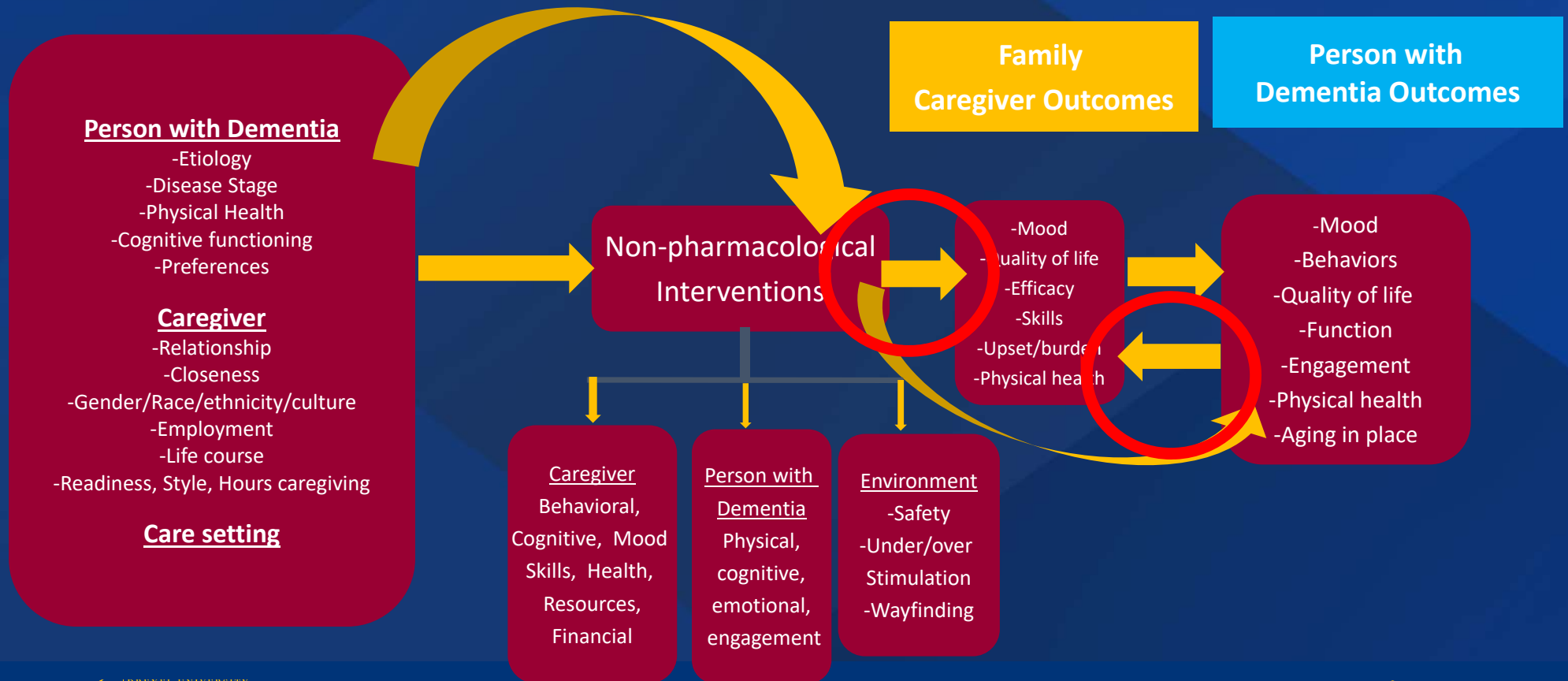
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Objectives

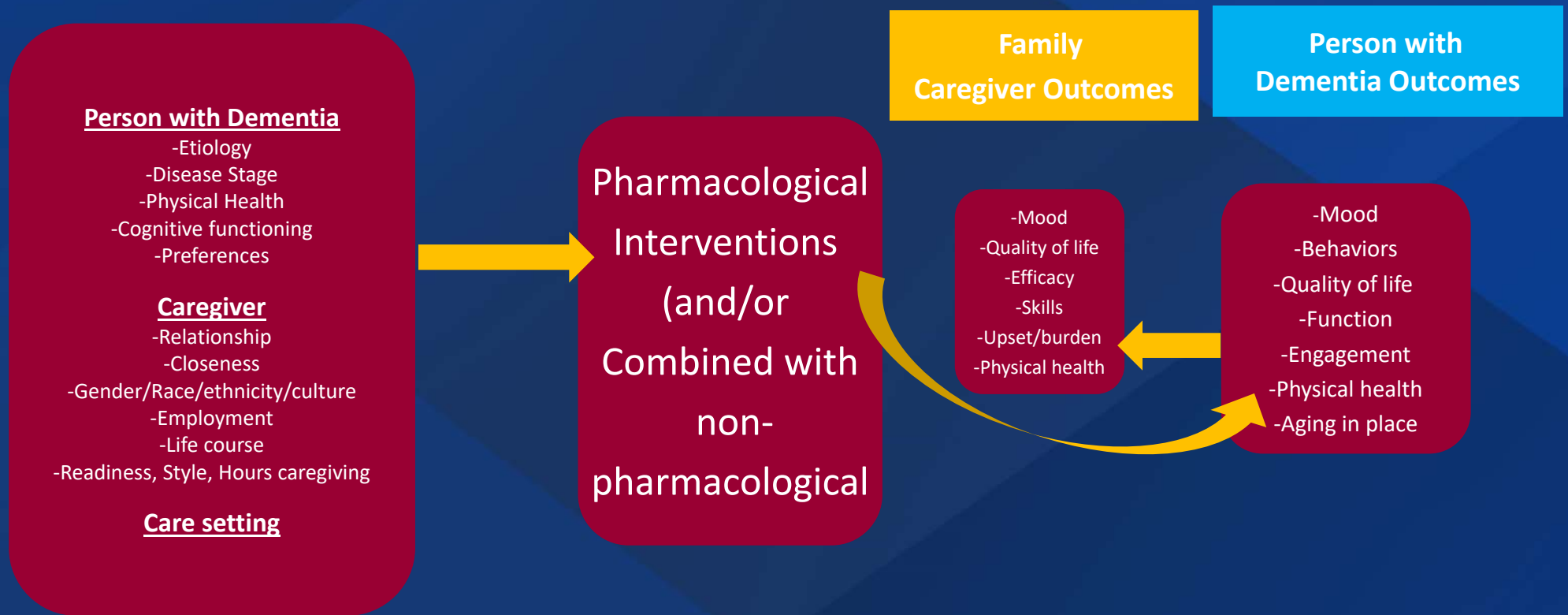
- Key frameworks
- Progress to date
- Emerging recommendations

Key Frameworks

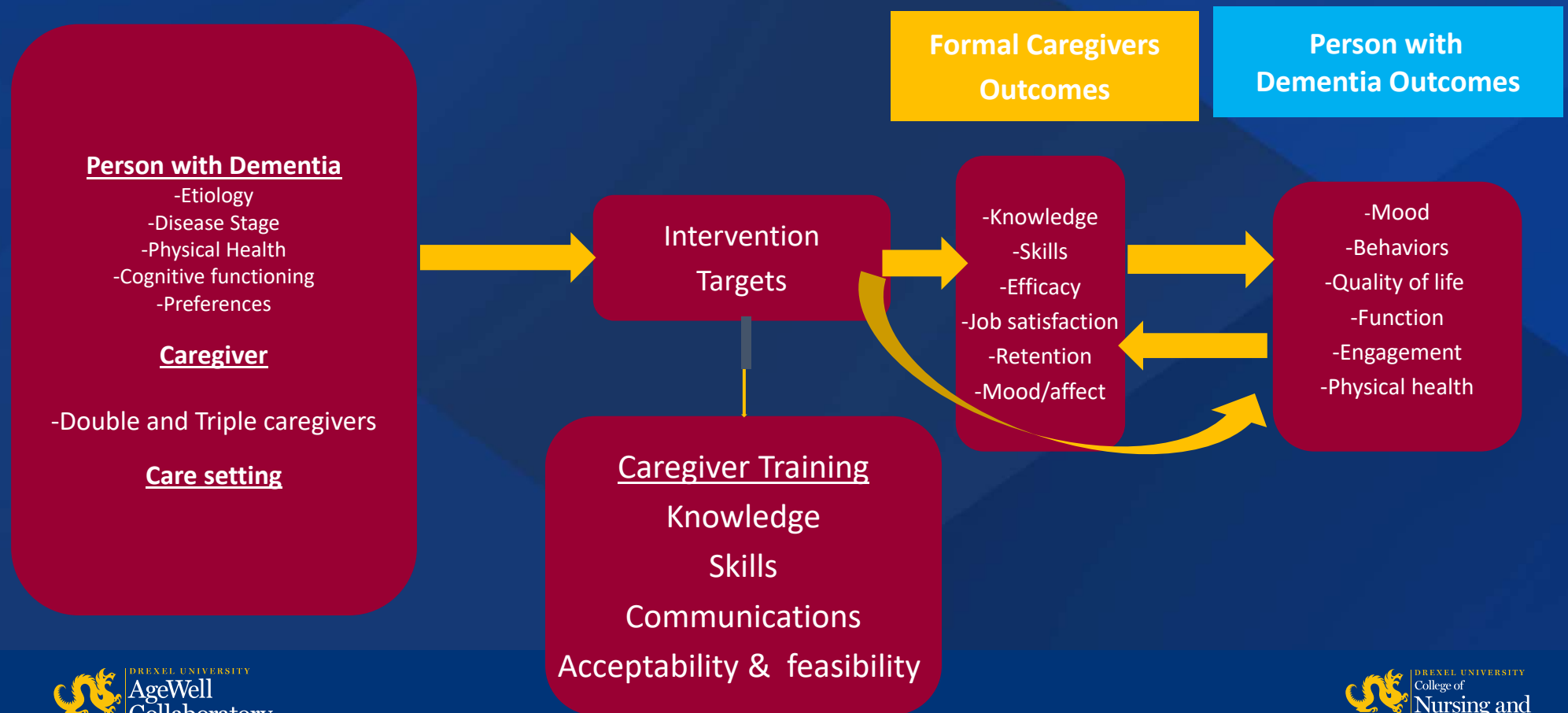
Direct and Indirect Pathways for Nonpharmacological Interventions Supporting Family Caregivers and Persons Living with Dementia



Direct and Indirect Pathways for Supporting Family Caregivers and Persons Living with Dementia



Pathway for Supporting Formal Caregivers



Progress to Date

Categories of Searches

1. Meta analyses and systematic reviews of efficacy trials concerning nonpharmacological intervention effects for:
 - Formal caregivers
 - Family caregivers
2. Meta analyses and systematic reviews concerning impact of dementia drugs on caregivers
3. Individual studies of translation, effectiveness and pragmatic trials
4. Published protocols of trials to understand near future interventions and their outcomes
5. Global perspective
 - Asia
 - Latin America
 - Europe
6. Reports:
 - National research summit recommendations
 - NASEM Family caregiver report

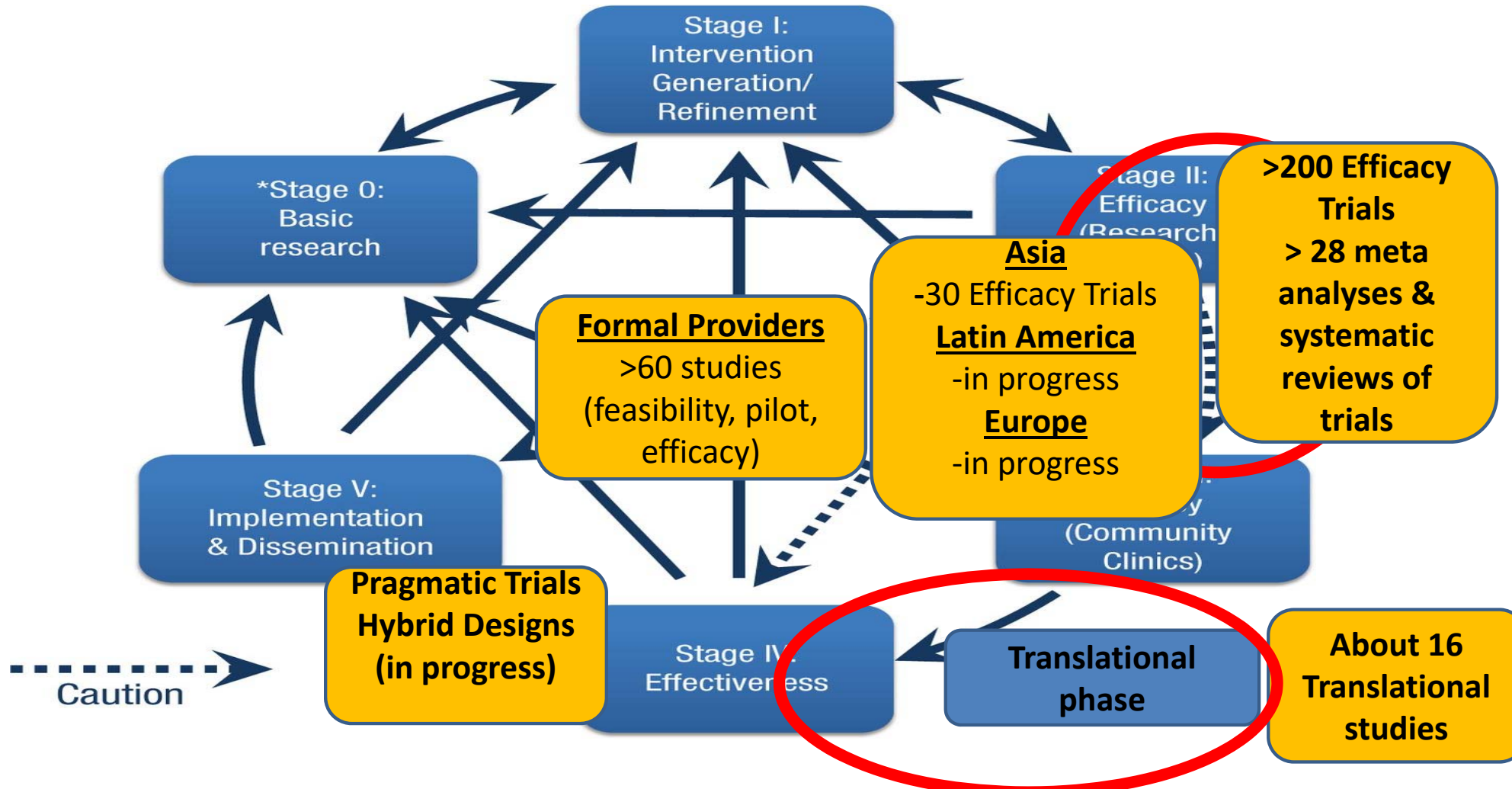


CONSIDERATIONS

- Setting
- Disease stage
- Type of intervention
- Intervention characteristics

Non-pharmacological Interventions for Family Caregivers

Onken et al, (2014) Re-envisioning Clinical Science Unifying the Discipline to Improve the Public Health, Clinical Psychological Science, vo. 2, p. 22-34.



Emerging Recommendations

Emerging Areas for Research Recommendations

Domain	Example
Improve clinical relevance of trials	<ul style="list-style-type: none"> • Examine mechanisms or why interventions have positive effects • Evaluate dose-response relationships and long term effects • Link intervention to disease stage • Evaluate cost and willingness to pay • Determine and report clinical significance
Adequately describe interventions to enable reproducibility, replication, adaptation, widespread adoption	<ul style="list-style-type: none"> • Identify theory base guiding intervention • Describe interventionist characteristics • Detail number of sessions, duration and length of intervention • Describe role of family caregiver in delivering intervention or supporting use of strategies for person with dementia • Describe treatment fidelity plan and adherence rates • Describe type of blinding applied to trial
Examine outcomes of relevance to different stakeholders	<ul style="list-style-type: none"> • Derive consensus in the field as to set of outcome measures for cross-study comparisons • Consider use of objective (performance-based), biological and subjective measures
Enhance study designs	<ul style="list-style-type: none"> • Locate design to stage model • Mediation (mechanisms of action) • Use pragmatic trial designs, hybrid designs and/or mixed methods for effectiveness and implementation • Standardize attention control groups used across studies to address attention, attrition • Examine long-term treatments and treatment effects
Target & tailor to caregiver needs, lived experience, readiness, style, dementia stage, persons needs, and families from different race/ethnic groups	<ul style="list-style-type: none"> • Address broader range of needs and for different stages, preferences, values • Examine dyadic relationships and which types of interventions impact carer and person; • Move beyond isolating primary caregiver and examine informal networks, family decision-making
Engage in implementation science	<ul style="list-style-type: none"> • Move evidence to real world settings using hybrid and pragmatic trial designs • Test implementation strategies for wide scale implementation/dissemination • Examine issues related to sustainability and scalability • Identify barriers to access for race/ethnic groups