

# Alzheimer's and Dementia Care: The Need and Solutions

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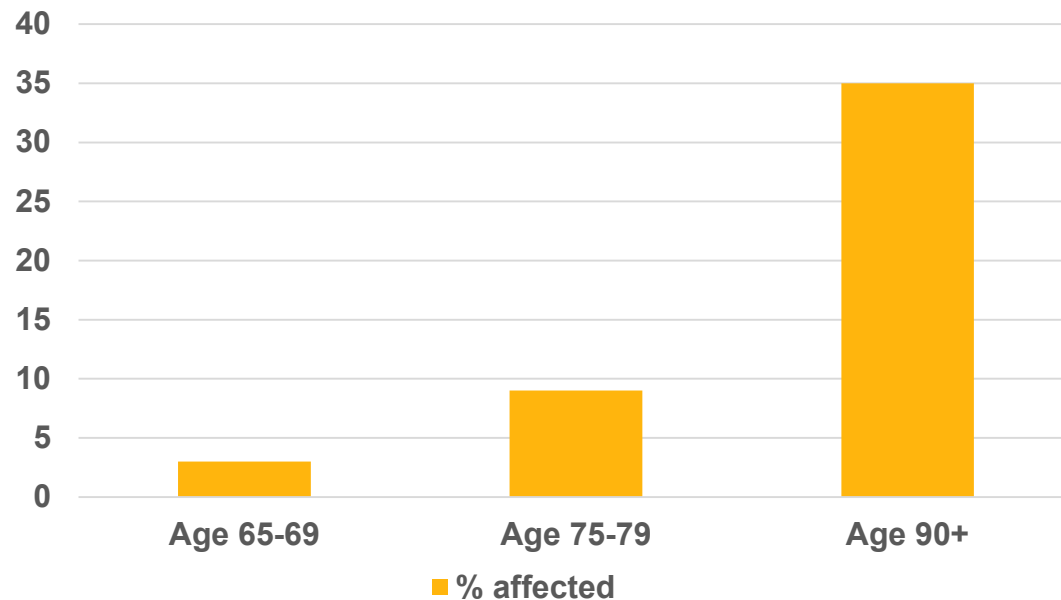
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# What we will cover

- Dementia and Alzheimer's disease
  - Definitions and causes
  - Complications
  - Management
    - Caregiver support
- Comprehensive Dementia Care Management
- The ADC Program
  - Local and National

# The Worst Fear of Aging, and with Good Reason

Prevalence of Dementia



**6.5 million** Americans have Alzheimer's Disease

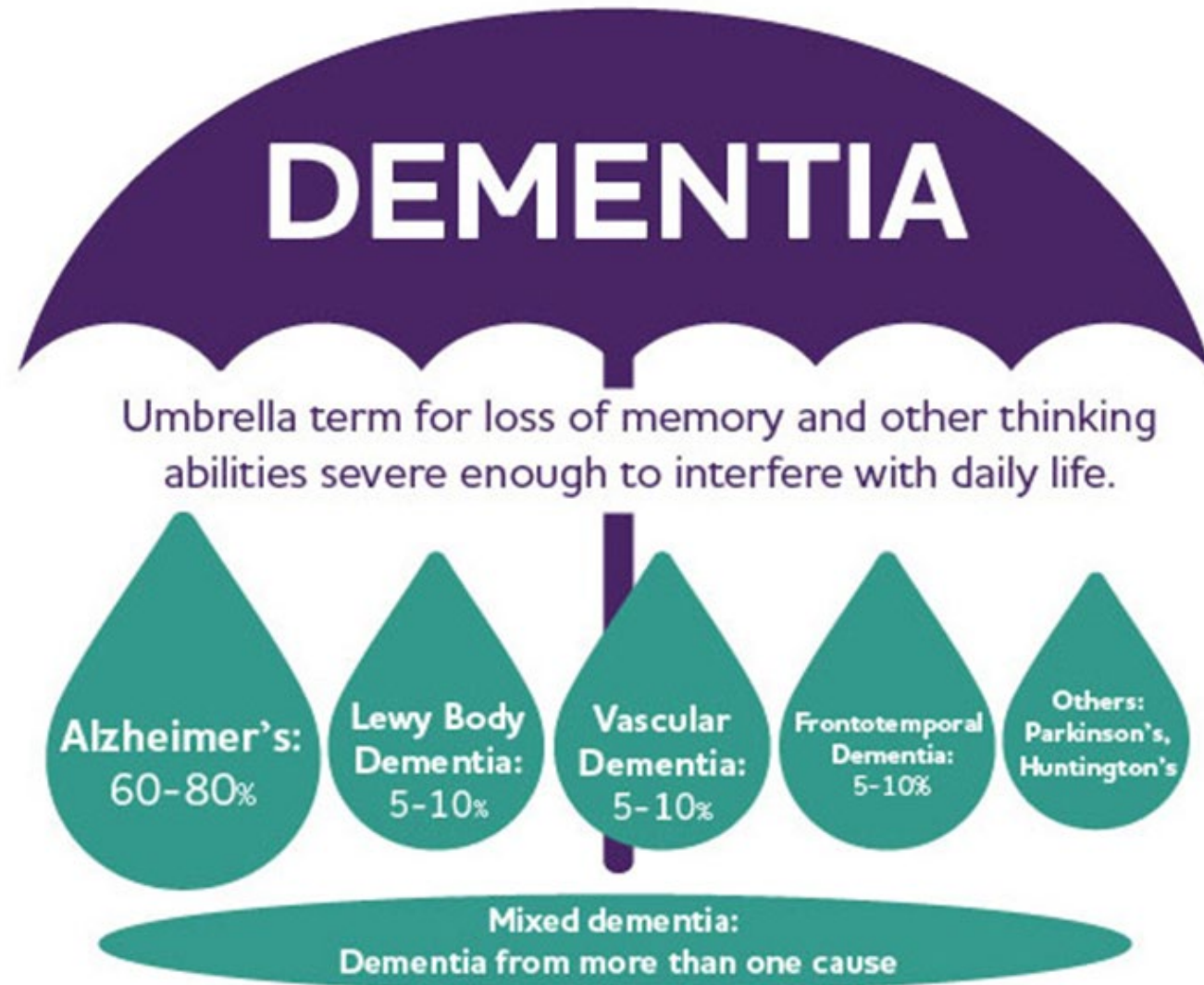
By 2025, it will be **7.2 million**

Higher prevalence in African Americans (OR 1.8) and < high school education (OR 1.6)

# Dementia-2011 NIA Definition

- A chronic acquired decline not explained by delirium or psychiatric disorder in two or more of the following domains:
  - Memory
  - Reasoning and complex tasks
  - Visuospatial
  - Language
  - Personality
- Sufficient to affect daily life

# Diseases Causing Dementia



# Alzheimer's Disease: 2011

- 3 stages
  - Preclinical: normal cognition; defined by changes in biomarkers
  - MCI: impaired cognition, intact function; positive biomarkers; may help determine progression to dementia
  - Dementia: impaired cognition; impaired function; biomarkers may be helpful in excluding AD as cause

# Stages of Dementia

Mild

**Mild: Difficulty with:**

- Social withdrawal
- Mood changes
- ↓ insight & judgement
- Short term memory
- Finances
- Driving
- Medications

Moderate

**Moderate: Difficulty with:**

- Worsening memory
- Repeating questions
- Instrumental ADLs
- Some ADLs
- Getting lost
- Gait and balance
- Disorientation
- Delusions/Agitation

Severe

**Severe: Difficulty with:**

- Remote memory
- Recognizing family
- ↓ verbal output
- Apathy/depression
- ADLs
- Sundowning
- Mobility
- Swallowing

# Alzheimer's Disease Behavioral Symptoms

- NPI-Q symptoms at any point during their disease
  - Apathy 70%
  - Anxiety 68%
  - Irritability 66%
  - Agitation/aggression 64%
  - Dysphoria/depression 62%
  - Sleep/nighttime behaviors 62%
  - Delusions 36%
  - Hallucinations 26%

*JAMA Psychiatry. Published online February 16, 2022.  
doi:10.1001/jamapsychiatry.2021.4363*



# Management

- This is a lifelong disease
  - Play the ball where it lies
    - If disease is early, include person living with dementia
    - If late, rely on family and caregiver
  - Aim for the highest level of independence that works for everyone
- Treat the disease
  - Manage hot-button issues (e.g., driving)
  - Manage other diseases
  - Manage symptoms
  - Advance Care Planning
  - Caregiver support

# Caregiver Support

- Caregivers are the most important resource
- Over 50% of caregivers develop depression
- The more knowledgeable and empowered the caregiver is, the better the care
- Caregiver training/support programs work
  - REACH II (12 individual and 5 telephone support groups over 6 months)
  - NYU CI (2 individual counseling sessions, 4 family counseling sessions, weekly support groups, ad-hoc counseling)
- Alzheimer's Association and other community resources

# Caregiver Support (cont.)

- Barriers and limitations
  - Focus only on the caregiver
  - Tested using traditional research not pragmatic designs
  - Cost (\$2.50-\$5/day for 6 months) and reimbursement
  - Poor integration with health care systems

# Comprehensive Dementia Care

- Focuses on patient and caregiver and includes:
  - Continuous monitoring and assessment
  - Ongoing care plans
  - Psychosocial interventions
    - Aimed at person living with dementia
    - Aimed at caregivers
  - Self-management
  - Medication management (some community-based don't)
  - Treatment of related conditions
  - Coordination of care

*Boustani M, et al. An Alternative Payment Model To Support Widespread Use Of Collaborative Dementia Care Models. Health Aff (Millwood). 2019 Jan;38(1):54-59. PMID: 30615525.*

# New Models of Comprehensive Care for Dementia

- Focus on patient and caregiver
  - **BRI Care Consultation:** by phone at CBOs by SWs, RNs, MFTs
  - **MIND at Home:** in person at home by staff, RNs, geri psychiatrists
  - **The Care Ecosystem:** by phone by staff, APN, SW, Pharmacist
  - **Indiana University Healthy Aging Brain Center:** in-person visits in community by staff, RN, SW, Psychologist, MD
  - **The UCLA Alzheimer's and Dementia Care Program:** in-person NP or PA co-management with PCP
  - **Integrated Memory Care:** NPs providing in-person primary care of PLWD

# How Comprehensive Care Models Differ

- Staffing
- Base of operations
- Scope of services
- Intensity
- Cost
- Efficacy/Effectiveness (pragmatism)
- Potential ROI
- Level of evidence

# Comparison of Some Dementia Care Models

Structure and Process	BRI – CC	Care Ecosystem	MIND	HABC	UCLA ADC	IMCC
Key personnel	Non-licensed, SW, RN, MFT	Non-licensed care navigator, CNS, SW, Pharmacist	Non-licensed staff, RN, MD	Non-licensed staff, MD, SW, RN, Psychologist	NP, PA, SW, non-licensed staff, MD	NP, SW, RN
Key personnel base	CBO or Health system	Health System or Community	Community or Managed Care Organization	Health system	Health system	Health system
Face-to-face visits	No	No	Yes	Yes	Yes	Yes
Access 24/7/365	Optional	No	No	Yes	Yes	Yes
Communication w/ PCP	Mail, fax, phone	Fax, phone	Phone, mail, fax	EHR, phone, mail	EHR, phone	N/A
Order writing	No	No	No	Yes	Yes	Yes
Medication management	No	Yes	No	Yes	Yes	Yes

# Comparison of Some Dementia Care Models (cont.)

Benefits	BRI – CC	Care Ecosystem	MIND	HABC	UCLA ADC	IMCC
High quality of care	N/A	N/A	N/A	Yes	Yes	Yes
Patient benefit	Yes	Yes	Yes	Yes	Yes	Yes
Caregiver benefit	Yes	Yes	Yes	Yes	Yes	Yes
Costs of the program	+++	++	+++	+++	++++	++++
Costs savings, gross	++	++	+++ (Medicaid)	++	++++	++++



# The UCLA Alzheimer's and Dementia Care Program

**Mission:** To partner with families, physicians, and community organizations to:

- maximize person living with dementia function, independence, and dignity,
- while minimizing caregiver strain and burnout.



# The UCLA Alzheimer's and Dementia Care Program

- Began in 2011 with philanthropic funds
  - Planned 250 patients
- Round 1 CMMI Award July 2012—Dec 2015
  - To expand the program to 1,000 patients
- As of April 20, 2023 3767 patients have been enrolled; 787 are currently active, 189 are scheduled to be seen and 55 are waiting to be scheduled

# The Program



Approaches the patient and caregiver as a dyad; both need support

Provides comprehensive care based in the health system that reaches into the community

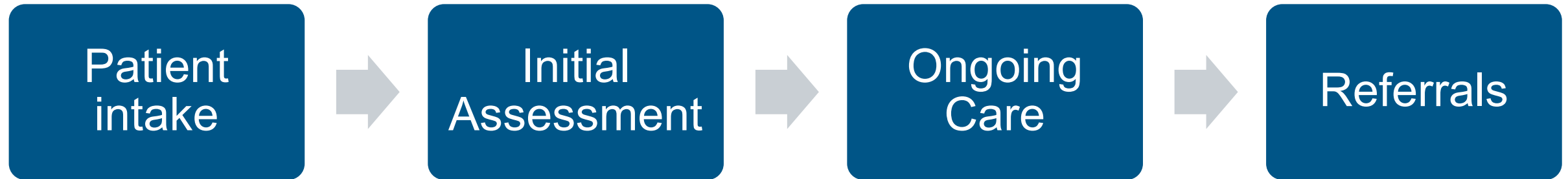


Recognizes that this care is a long journey.



Uses a co-management model with Nurse Practitioner Dementia Care Specialist (DCS) who does not assume primary care of patient

# ADC Process



# The UCLA Alzheimer's and Dementia Care Program

- Works with primary care and specialty physicians to care for patients by
  - Conducting in-person needs assessments
  - Developing and implementing individualized dementia care plans
  - Monitoring response and revising as needed
  - Providing access 24 hours/day, 365 days a year
- Partners with community-based organizations (CBOs) to provide direct services (e.g., adult day care) and caregiver training

# Services Provided by Partner CBOs

- Services for patients:
  - Adult day services
  - Programs for enhancing brain health (for early stage memory loss)
- Services for families/caregivers:
  - Education (workshops, classes, informational sessions, handouts)
  - Counseling and peer-to-peer support
  - Case management
  - Legal and financial counseling
  - Support groups

# Dementia Care Specialist (DCS)

- Advance Practice Provider
  - Nurse Practitioner, Clinical Nurse Specialist (with prescribing authority), Physician Assistant
- Healthcare system-based, outpatient clinic setting
- Dementia Care Co-Management along with the individual's medical team (e.g., Primary Care, Neurologist, Psychiatrist)
- Each DCS follows roughly 250 patients

# DCS Training

- On-line curriculum (GAPNA distribution)
  - 22 on-line modules + 4 asynchronous videos
- Zoom training
  - 1:1 weekly trainings with a DCS expert
    - Brings together information learned in the on-line training to the real world environment
    - Case based scenarios
    - Networking
  - Available office hours each week



# DCS Training vs The Model

- Completion of DCS training (both on-line and one-on-one)
  - Document of Completion
- Completion of skills training alone is not sufficient for implementation of the ADC Program; additional training about the model of care is necessary

# Dementia Care Assistants (DCA)

- Dementia Care Assistants
  - Licensed (RN, SW) or Non-licensed, trained staff
  - Reach out to lower acuity PWD-caregiver dyads
  - Offer resources (i.e. CBO, non-pharm behavioral modifications)
  - Help to schedule appointments
  - Identify dyads in crisis
  - Allow DCSs to work at the top of their license

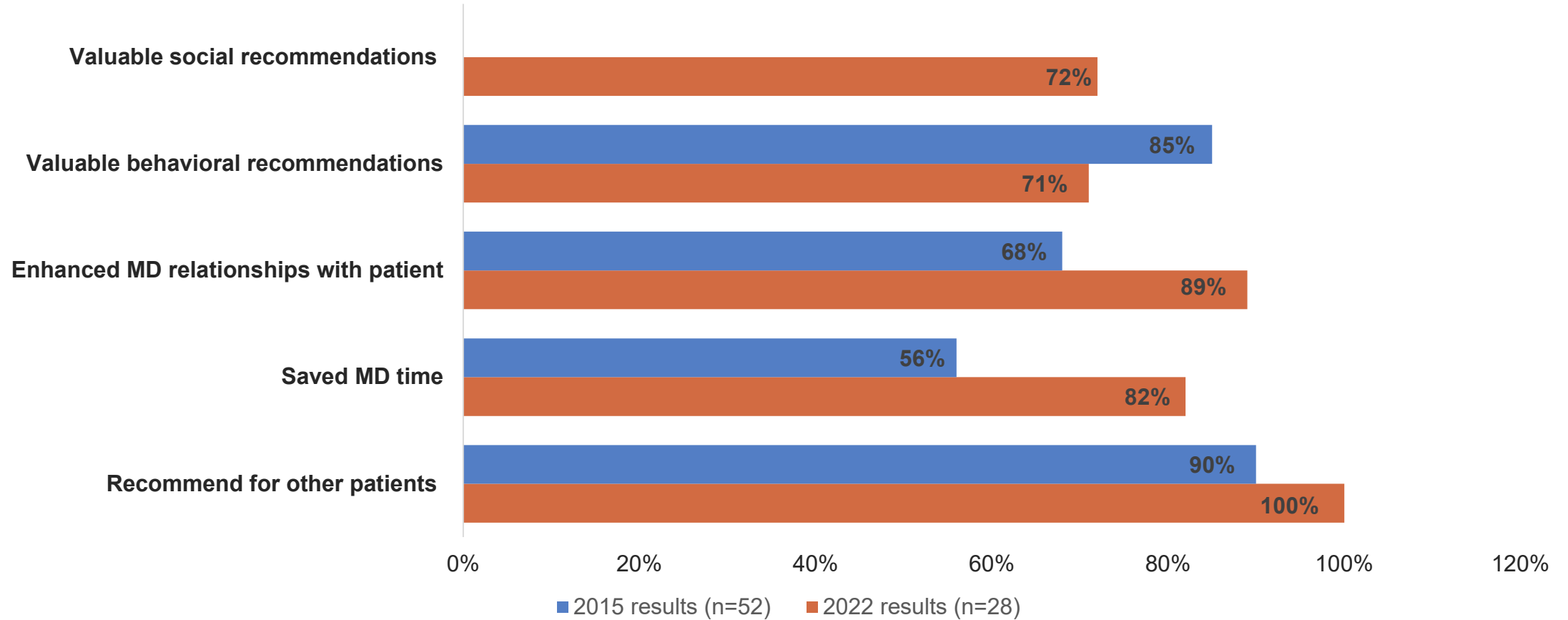
# Comparing Quality Across Different Practice Conditions

<u>Overall Dementia Quality of Care*</u>	<u>QI Pass Rate</u>
Community-based physicians (observational)	18%
Community-based physicians	38%
Community-based physicians & NP	60%
UCLA Alzheimer's and Dementia Care	92%

\*Based on medical record abstraction of first 797 patients using ACOVE-3 and PCPI QIs\*

Jennings LA, et al. J Am Geriatr Soc, Jun 2016. PMID: 27355394

# Physician Satisfaction



# 1 Year Outcomes for patients and Caregivers

	Patient	Caregiver
Cognition (MMSE)	Worse	
Functional status (FAQ)	Worse	
Behavioral symptoms (NPIQ)	Improved	
Distress because of behavioral symptoms (NPIQ)		Improved
Caregiver strain		Improved
Caregiver depression (PHQ9)		Improved

# Utilization and Costs

Type of Care	Impact
Hospitalizations	▼ Down 12%
ED visits	▼ Down 20%*
ICU stays	▼ Down 21%
Hospital days	▼ Down 26%*
Nursing home placement	▼ Down 40%*
Hospice in last 6 months	▲ up 60%*

Total Medicare costs of care:  
 ▼ \$2,404/year \*

\* p<.05

Based on NORC external evaluation of CMMI Award using fee-for-service claims data and UCLA ACO data September 2015- September 2017

# Going National

D-CARE Study (PCORI and NIA)



The John A. Hartford Foundation -  
Supported dissemination

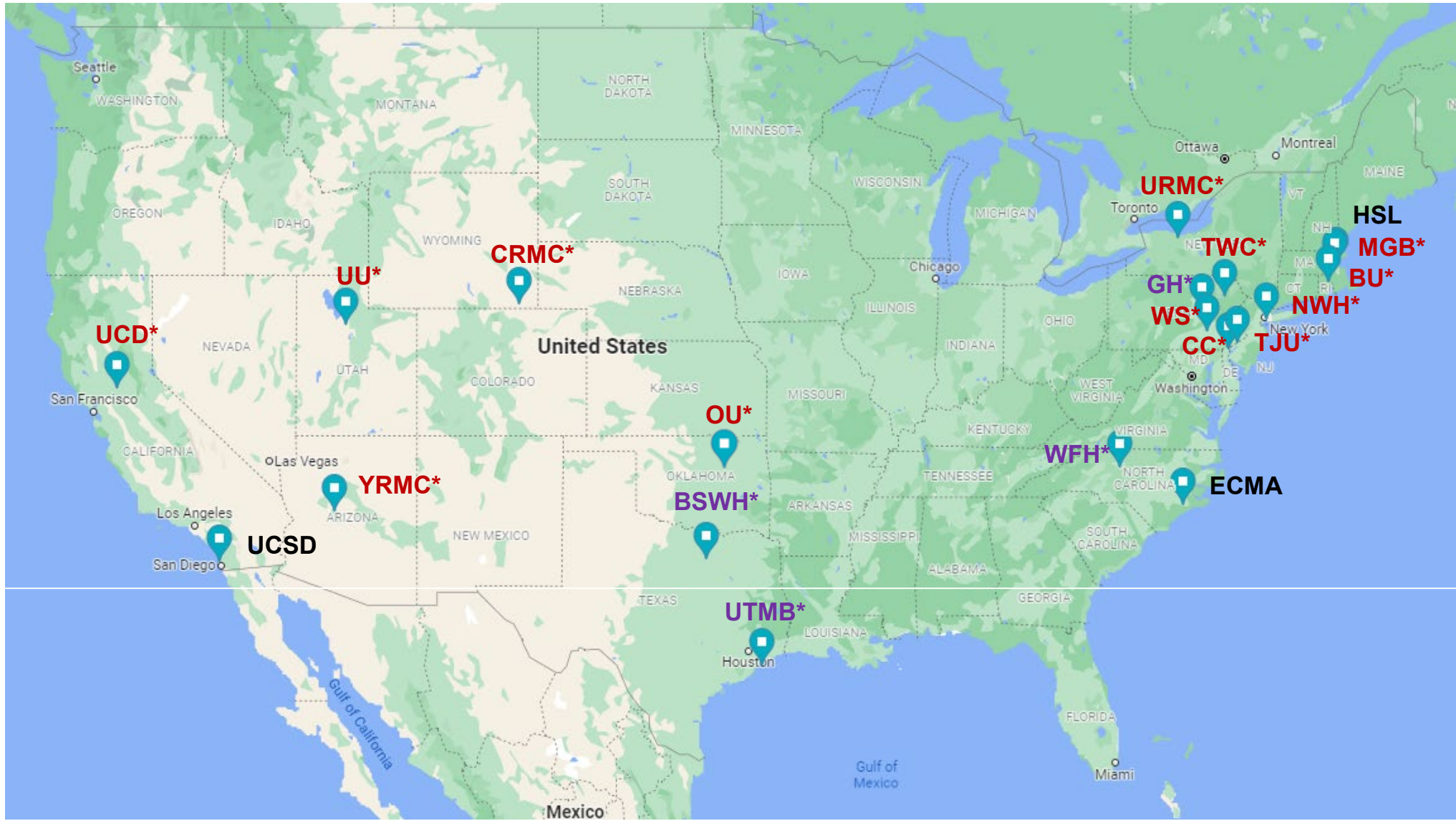


# Spread of the ADC Program 2019-2023

- Partnerships with:
  - Alzheimer's Association
  - American Geriatrics Society
  - Gerontological Advance Practice Nurses Association
- 4 sites as part of a randomized clinical trial, the D-CARE Study
- Dissemination sites supported by The John A. Hartford Foundation grants



# Dissemination Sites



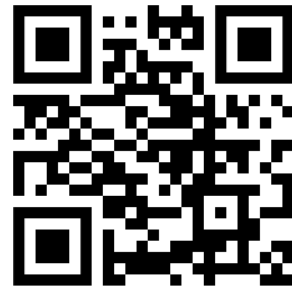
# Lessons Learned in Early ADC Dissemination Efforts

- Identify and nurture a product champion
- The business case is critical
- Training is essential
- Local factors are important
- Be patient
- Don't underestimate the time needed for program implementation

# Q & A Session

For more information about the implementation of the ADC Program, contact [kserrano@mednet.ucla.edu](mailto:kserrano@mednet.ucla.edu)

Visit our website:



[adcprogram.org](http://adcprogram.org)

# Thank you!

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