UCSF Weill Institute for Neurosciences

Memory and Aging Center

The Care Ecosystem: Navigating Patients and Families through Stages of Care

Southern CA Alzheimer's Disease Research Conference

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It took nearly 4 years for us to get a diagnosis.

The doctor told us it was Alzheimer's, that there was nothing he could do, and to come back in a year. We were first devastated, then angry. I also have diabetes, and I got medication, education and care management for that. Now I have a fatal brain disease, and I got 'diagnose and adios.'

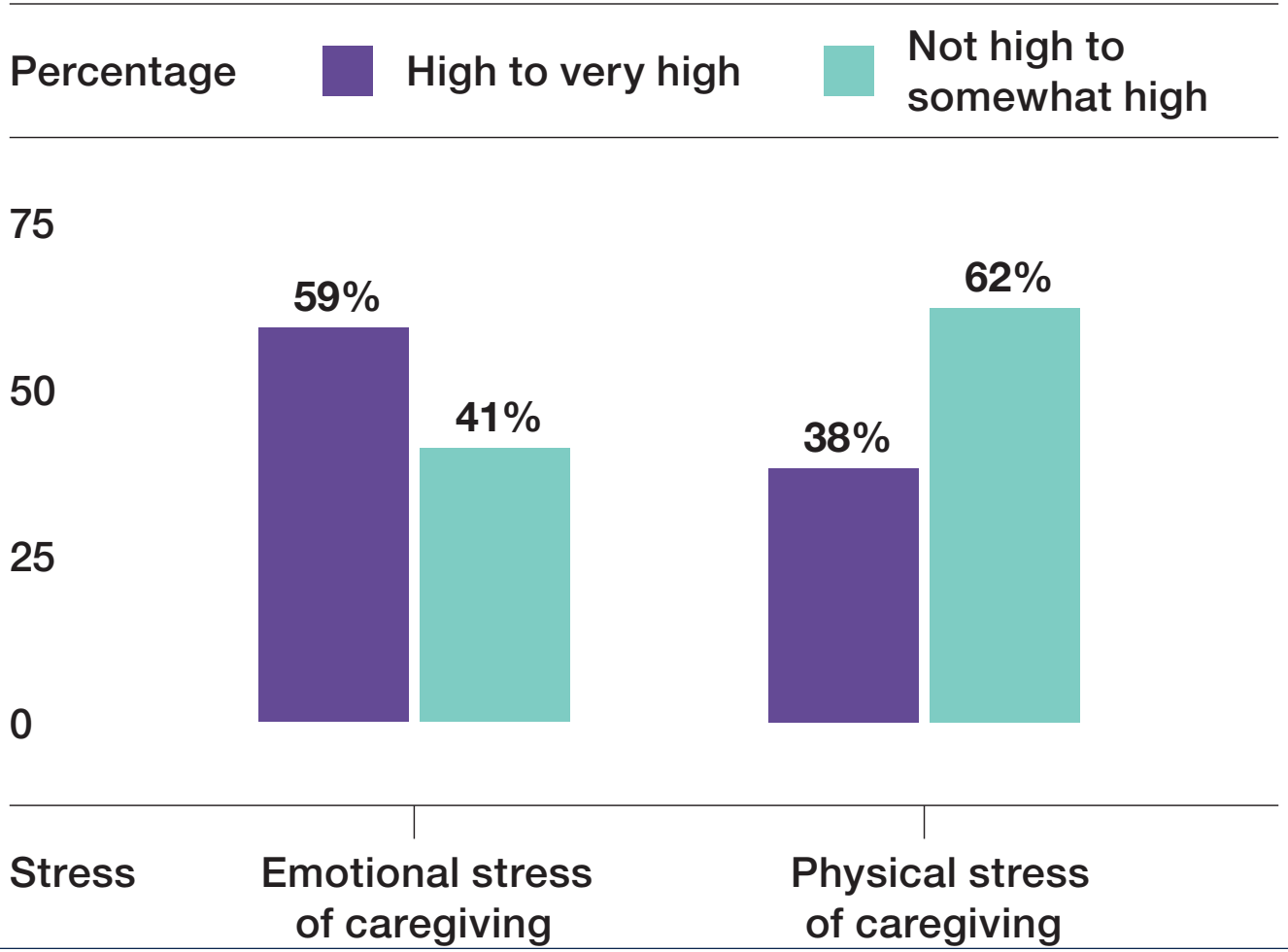
We have to do better.

-Julie, a person living with early-stage AD

Dementia care is too often crisis-oriented and fragmented

- Frequent emergency department visits and hospitalizations (Hunt, Coombs, et al., 2018; Zhu, Cosentino et al., 2015)
- Multiple care transitions (Callahan, Tu, et al., 2015)
- Inappropriate and potentially harmful medication use (Maust, Kim, et al., 2015)
- Aggressive end of life care that is often inconsistent with the patient's values (Mitchell, Teno, Kiely et al., 2009)
- Informal caregivers shoulder substantial burdens with minimal support from our patient-centric healthcare models
  - When caregivers are depressed, PWLD use the ED more (Guterman, Allen, et al., 2019)
- The COVID-19 pandemic has disproportionately disrupted the lives of people living with dementia and their caregivers (Ibáñez, Pina-Escudero et al., 2021)

Dementia Caregivers Report High Emotional and Physical Stress Due to Caregiving



Alzheimer's Association Facts and Figures 2019

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The Care Ecosystem Model

The Care Team Navigator (CTN) is at the Center

Who is a Care Team Navigator or "CTN"?

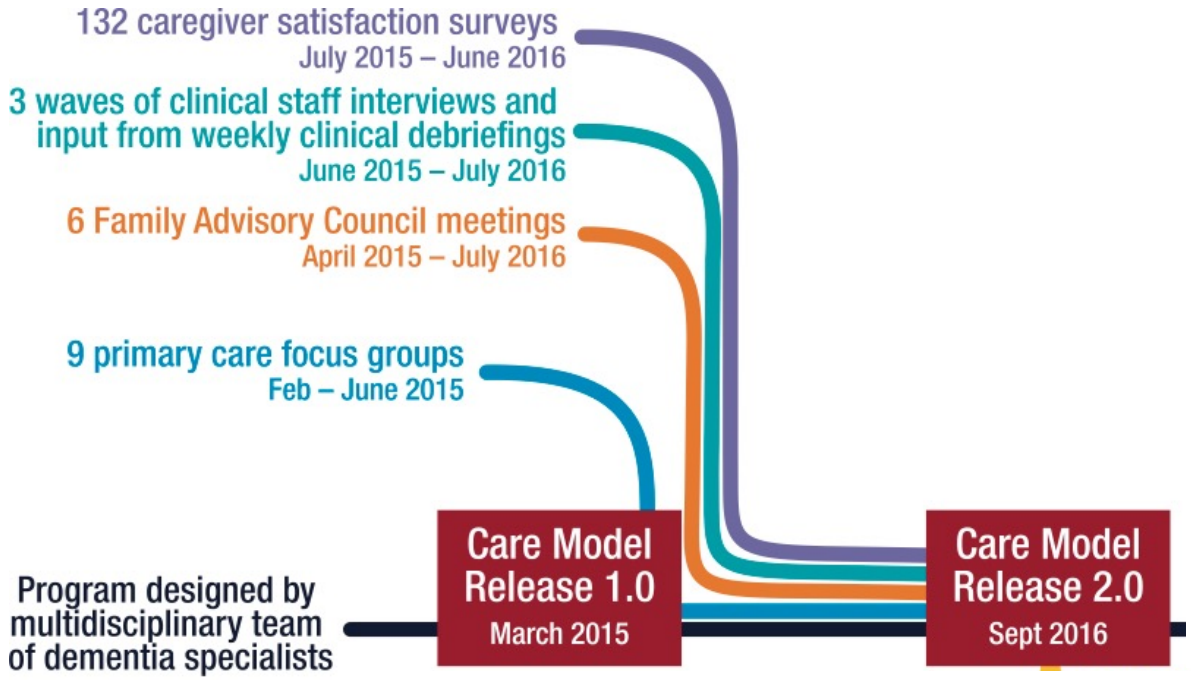
- A friendly, empathic, and organized person who loves working with people
- Health care background not required
- CTN is trained, supervised, and supported by a clinical team
- CTN provides telephone-based care coordination, education, and support

Care Ecosystem
Navigating Patients and Families Through Stages of Care

Care Modules

Care Ecosystem
Navigating Patients and Families Through Stages of Care

Agile Development of the Care Model



Possin et al., 2017, PLOS Medicine

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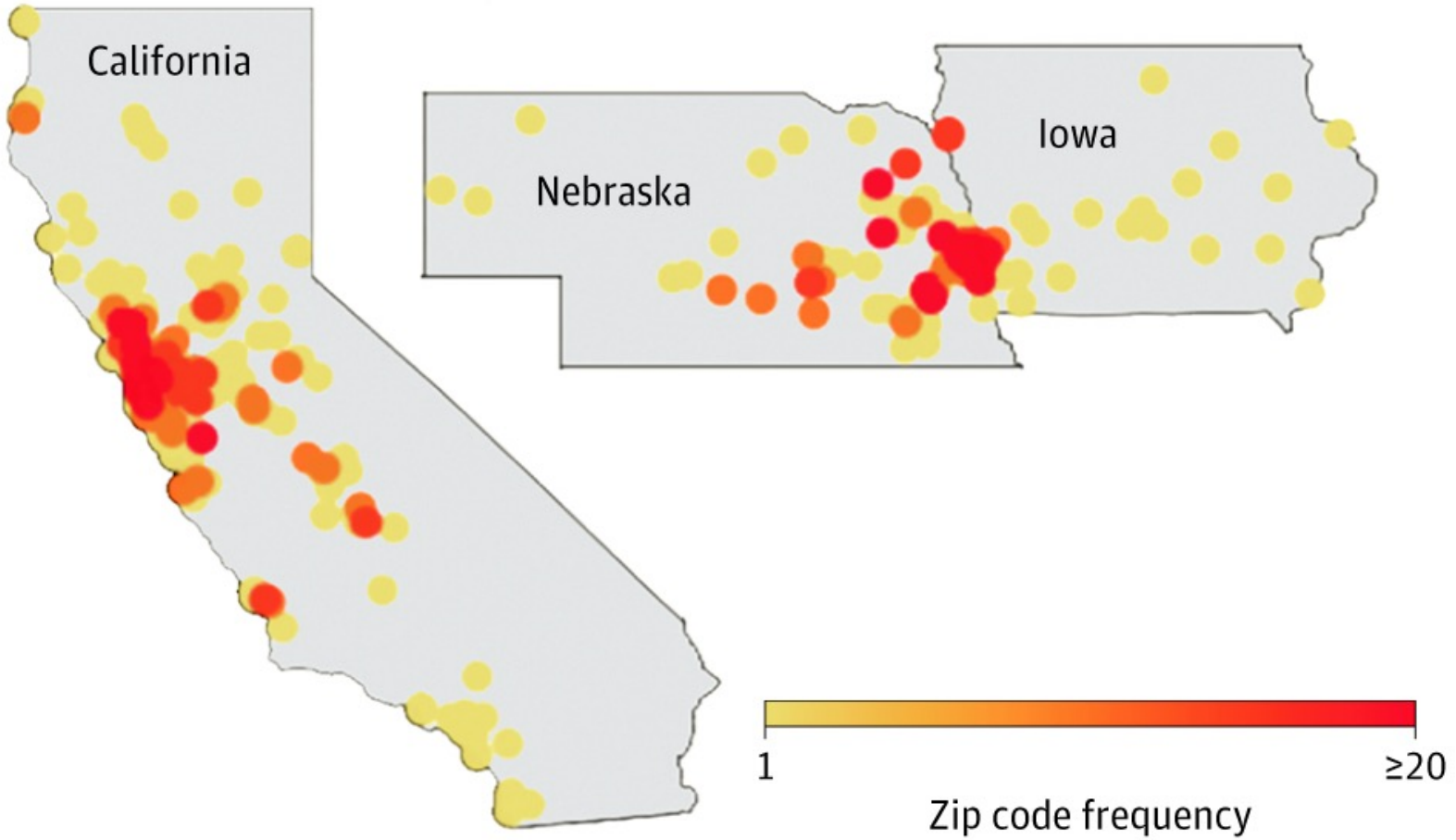
Randomized Trial: Locations of patients enrolled



Possin et al., JAMA Internal Medicine, 2019

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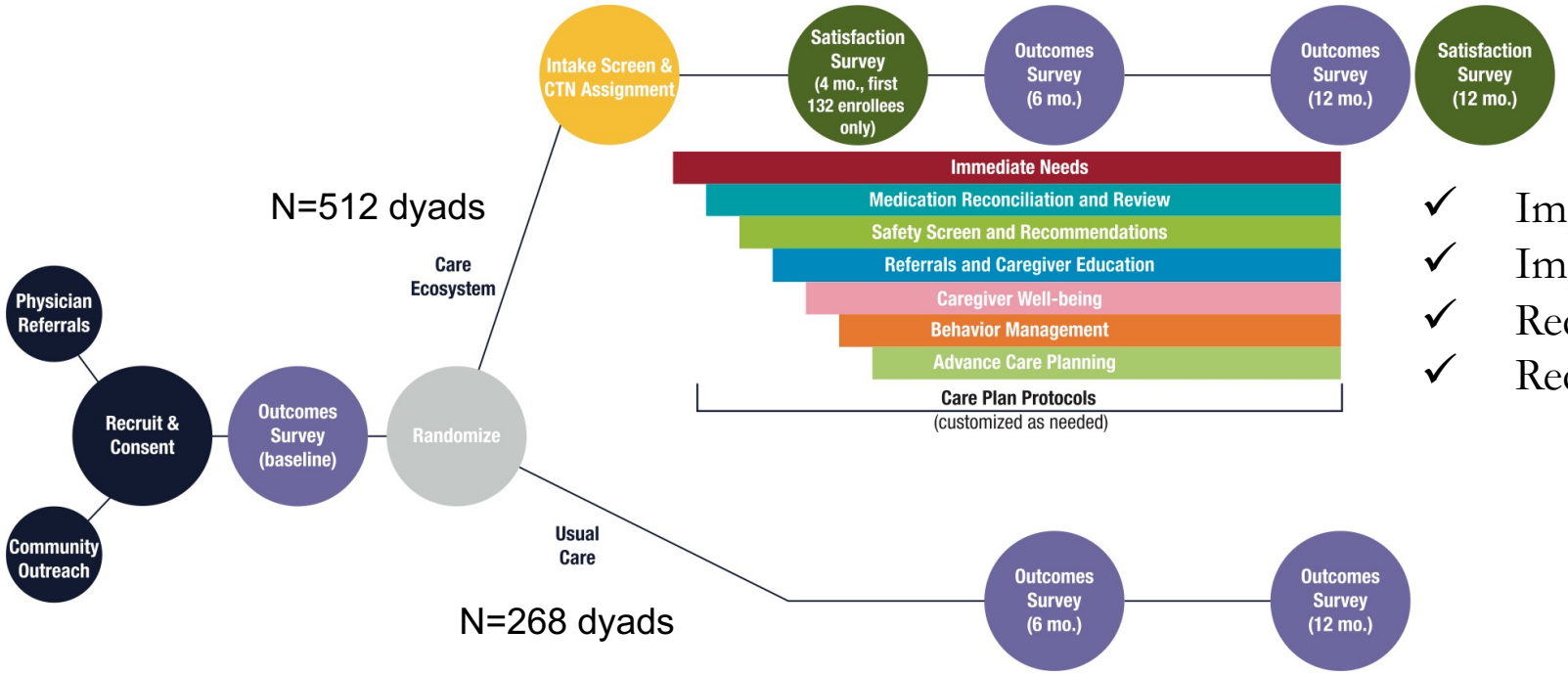
Randomized Trial: Design & Results



- ✓ Improved caregiver well-being
- ✓ Improved patient quality of life
- ✓ Reduced emergency room visits
- ✓ Reduced potentially inappropriate medication use

In press, Kirby Lee and Amy Liu

Possin et al., JAMA Internal Medicine, 2019

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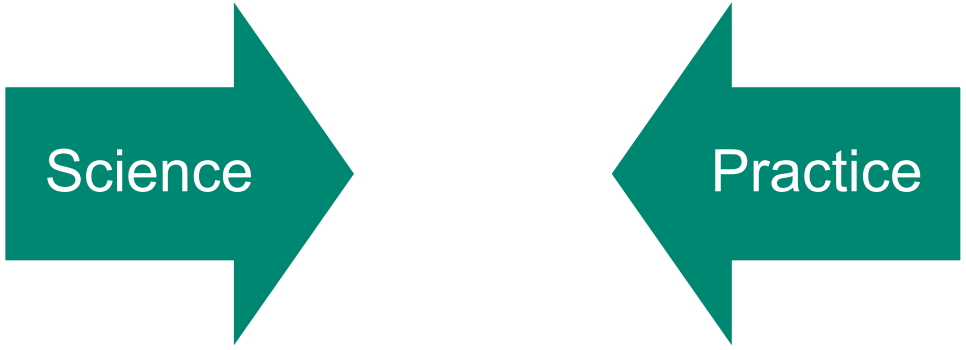
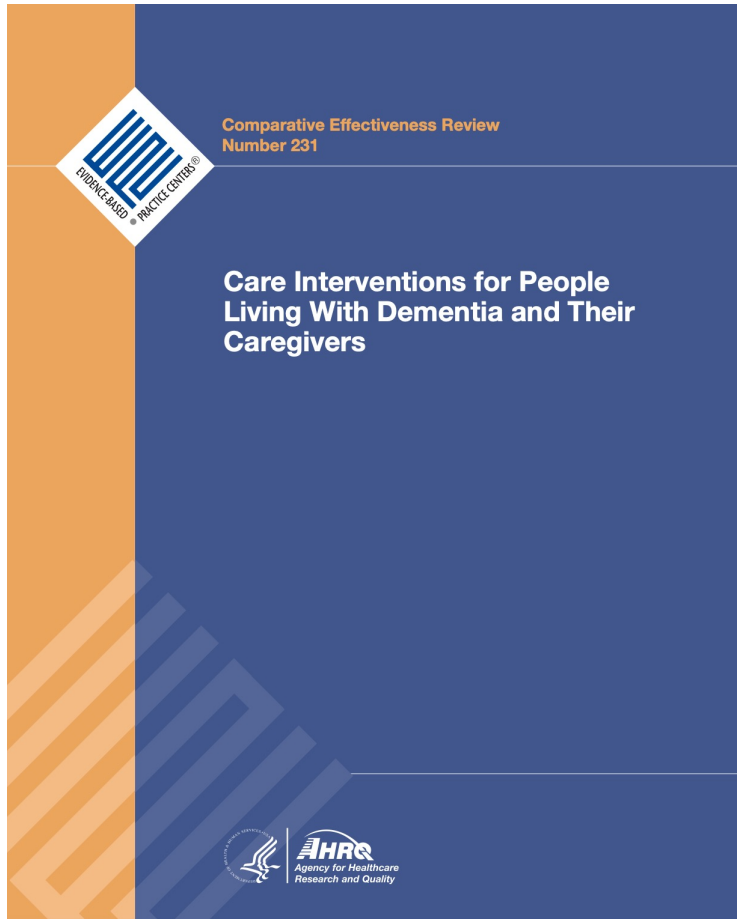
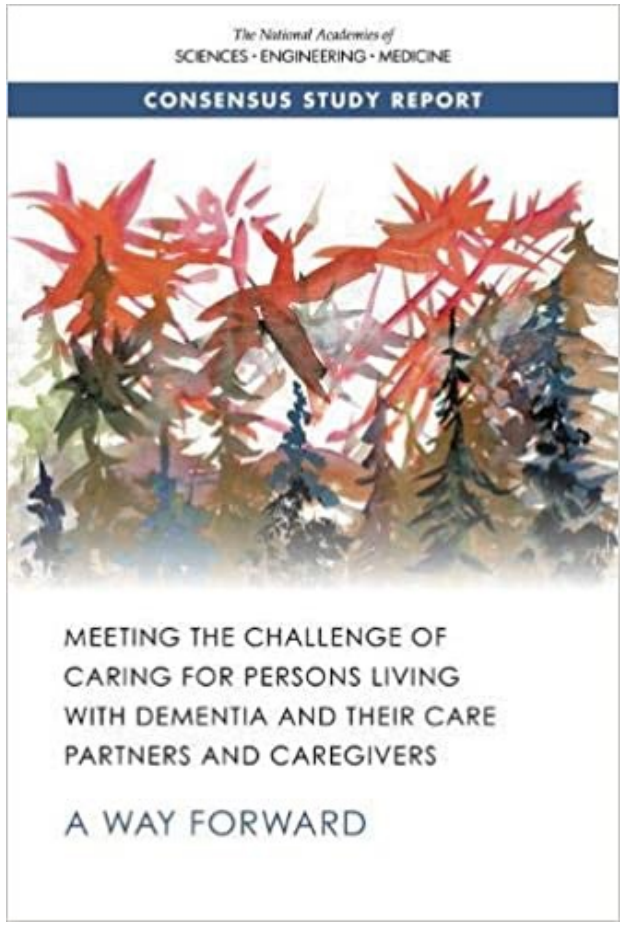
Scientists have a critical role in bridging the science-practice gap

- Scientists too often expect that the implementation and dissemination of their interventions will be taken up by other parties, which is often not the case (Callahan, Bateman, et al., 2018)
- As scientists, we need to understand the barriers to the dissemination of effective dementia care, and trial implementation methods to bridge the gap. (Boustani, Unützer, Leykum, 2021; National Academies of Sciences, Engineering, and Medicine Report, 2021)



The AHRQ's systematic review, and the National Academies of Science's consensus study report, summarize the evidence on effective dementia care models

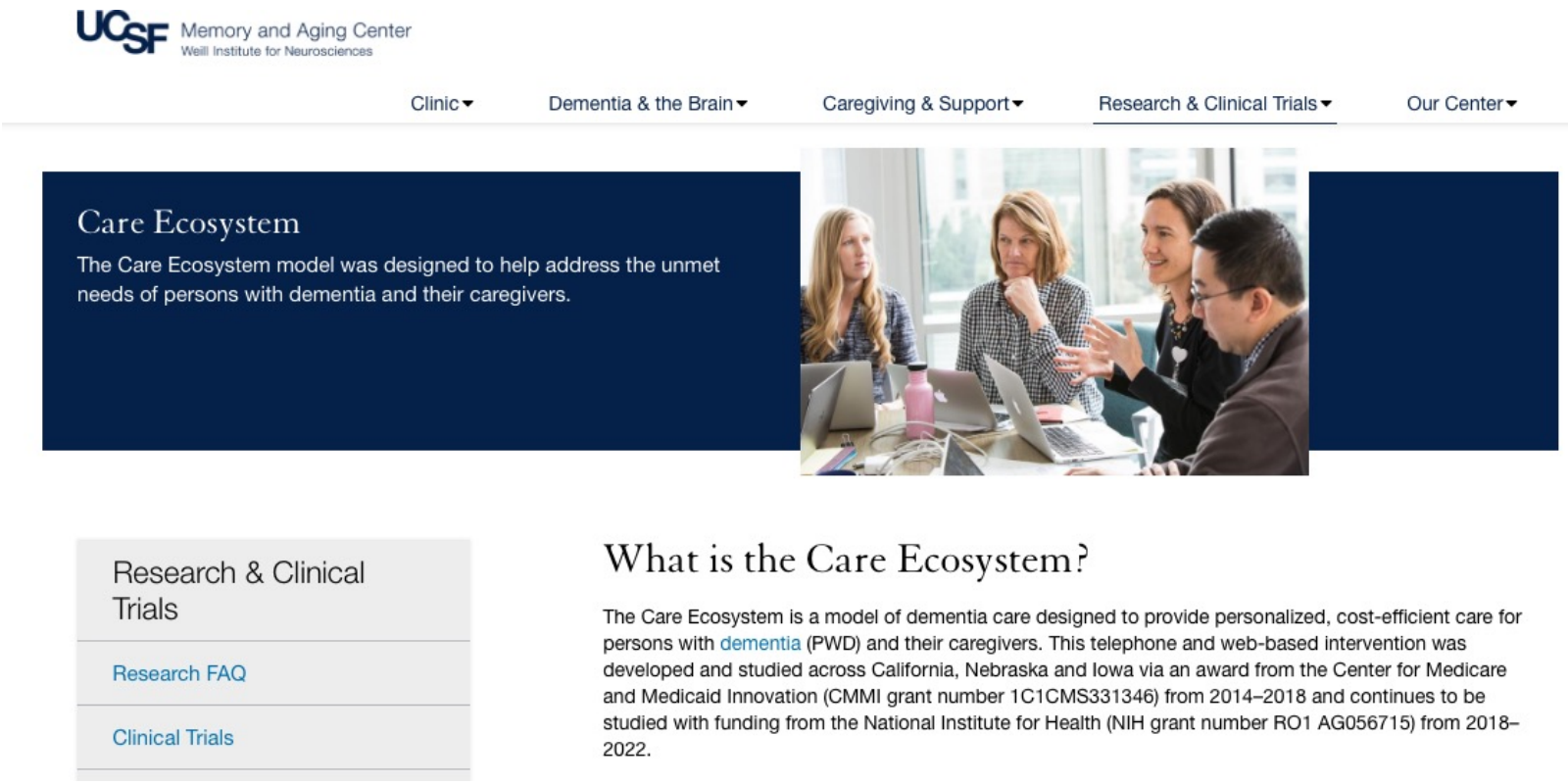




Evidence is sufficient to justify implementation of collaborative care models, including the Care Ecosystem and the UCLA program, in a broad spectrum of community settings, with evaluation conducted to continue expanding the evidence base.

Find the Care Ecosystem Toolkit, care protocols, and CTN training program at: memory.ucsf.edu/care-ecosystem

Sarah Dulaney, CNS
Care Ecosystem
Clinical Director



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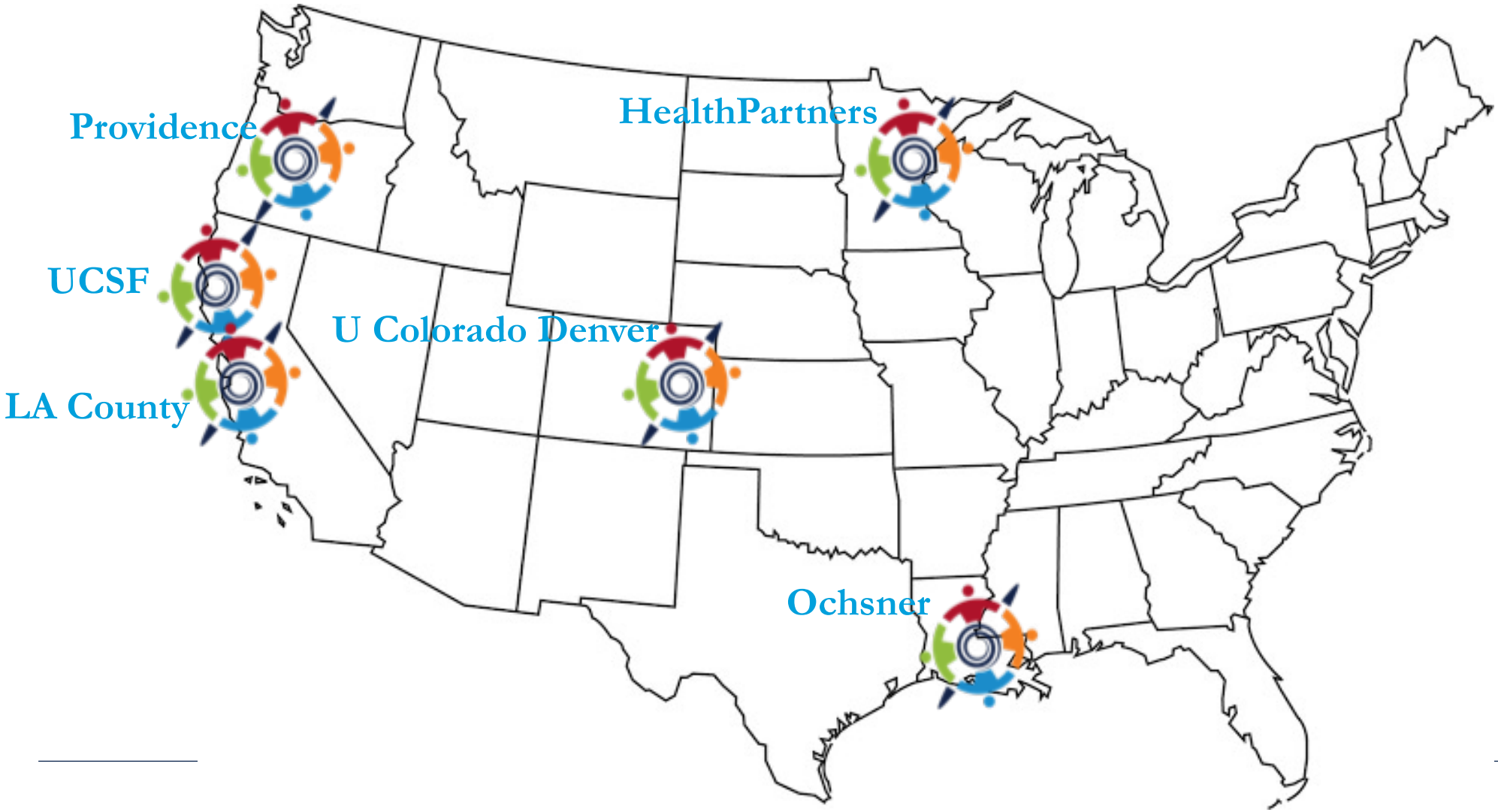
CURRENT RESEARCH: Implementation and Effectiveness of the Care Ecosystem in 6 Health Systems



The Future of Dementia Care

Concern

Detect, Diagnose, and Treat

PLWD & caregivers are navigated by a care team that personalizes care goals to their needs and prioritizes their quality of life

"These treatments and care practices will neither prevent nor cure Alzheimer's or other dementias, but they will help to change the experience of people with the conditions and their family caregivers – helping them to manage and cope with the difficult situations caused by the conditions and live as well as possible despite them."

Katie Maslow, MSW
Translating Innovation to Impact
Institute of Medicine Report 2012

UCSF:

Sarah Dulaney
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Winston Chiong
Kirby Lee
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Alissa Bernstein
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Rachel Kiekhofer
Joanne Robinson-Teran
Stephanie Pun
Shalini Lynch

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Navigating Patients and Families Through Stages of Care

Collaborating Sites:

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Tami Braley (UNMC)
Joan Ewalt (UNMC)
Christine Ritchie (MGH)
Brent Forester (MGH)
R. John Sawyer (Ochsner)
Michael Rosenbloom (HealthPartners)
Hillary Lum (UC Denver)
Nick Olney (Providence)
Mailee Hess (DHS LA County)
Katie Ward (DHS LA County)

Want to learn more?

memory.ucsf.edu/care-ecosystem

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The UCSF Memory and Aging Center

The mission of the UCSF Memory and Aging Center is to provide the highest quality of care for individuals with cognitive problems, to conduct research on causes and cures for degenerative brain diseases, and to educate health professionals, patients and their families.