

# Earlier Detection of Dementia—Challenges and Opportunities

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## Disclosures

### Current Support:

- National Institutes of Health (NIA/NINR)
- Veterans' Health Administration
- Centers for Disease Control and Prevention
- New York State Department of Health

No conflicts of interest to report

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# Learning Objectives

## Dementia Detection

- 1) to understand the demographic imperative
- 2) to appreciate the challenges of this initiative
- 3) to learn about recent efforts to address these challenges



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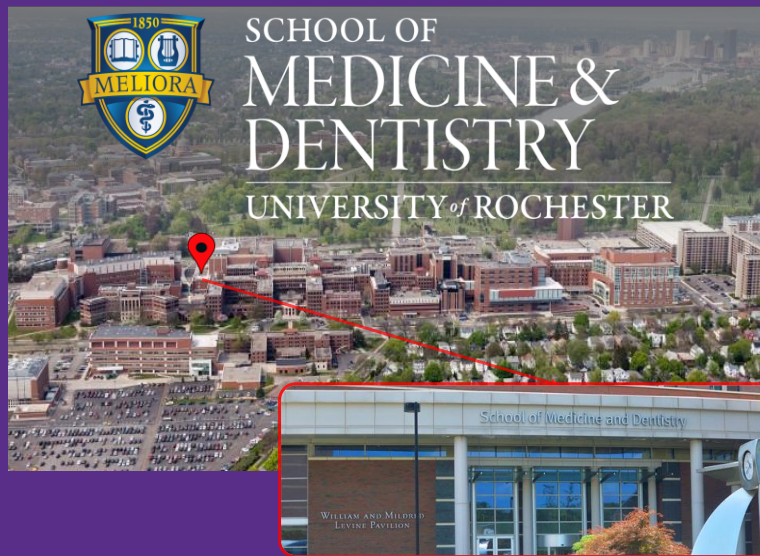
# Overview

- Revisit what has been a well-described problem
- An old study on detection – are we still making the same mistakes?
- Why do we need public health?
- What is our BOLD Center of Excellence and how did we get there?
- Current research — part of the detection puzzle
- Concluding remarks



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# A Personal Story



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## Shaped by Clinical Experience

- As a chief medical resident running an urban resident clinic
- 83 year old woman with resistant hypertension
  - SBP: 158/78; HR: 62 on no meds
- Six months / five visits later: three blood pressure medications
  - SBP: 146/82; HR: 64
- Medical resident: “She does not recognize me from last month’s visit.”
  - MMSE: 14 (*we had no idea...*)
  - Results of home visit...



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## Full bottles - hoarding



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## Do Physicians Identify or Diagnose Dementia?

*An Old Story – A New Mandate*

- Do We Detect Cognitive Impairment?
- Physicians surveyed (n=729) in southern California health maintenance organization (2000-01)
- They were asked to estimate the cognitive functioning of one of the selected patients participating in the cohort study of estrogen and memory function
- 2-Stage Dementia assessment (TICS/TDQ)
- Medical records reviewed for dementia documentation

Chodosh, et al. *J Am Geriatr Soc.* 2004;52:1051-1059



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## Do we recognize dementia when we see it?

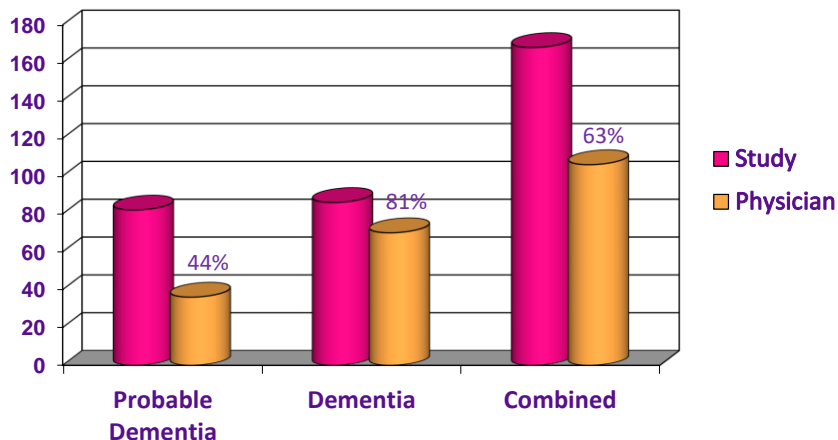
On a scale from 0 to 10 with **0** being “no cognitive impairment” to **10** being “severely impaired”, please estimate your patient’s level of cognitive impairment by placing an ‘X’ on the appropriate number.



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## Physician Recognition of Cognitive Impairment

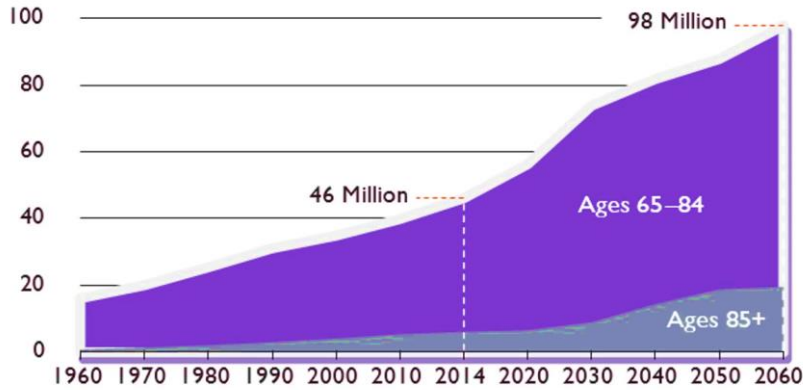
*Any ruler selection > 0 = recognition of impairment*



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## Projected Number of People Age 65 and Older (Total and by Age Group) in the U.S. Population, 1960-2060

U.S. Population Ages 65 and Older, 1960 to 2060 (Millions)



Source: PRB analysis of data from the U.S. Census Bureau. Fact Sheet: Aging in the United States. PRB. Published 2022. Accessed October 24, 2022. <https://www.prb.org/resources/fact-sheet-aging-in-the-united-states/>



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## Workforce Needed – AD/ADRD

### Clinicians / Other Providers

- Primary care physicians
- Advanced practice clinicians
- Geriatricians
- Neurologists
- Psychiatrists

### Other Licensed Providers

- Registered nurses
- Psychologists / therapists
- Social workers
- Personal care /home health aids
- Nursing assistants

**BETWEEN 2020 AND 2030 — 1.2 MILLION ADDITIONAL DIRECT CARE WORKERS**  
*(MORE THAN FOR ANY OTHER SINGLE OCCUPATION IN UNITED STATES)*

**PREVALENCE INCREASES = INCREASED NEED FOR MEMBERS OF THE PAID WORKFORCE INVOLVED IN DIAGNOSING, TREATING AND CARING FOR PERSONS LIVING WITH DEMENTIA.**

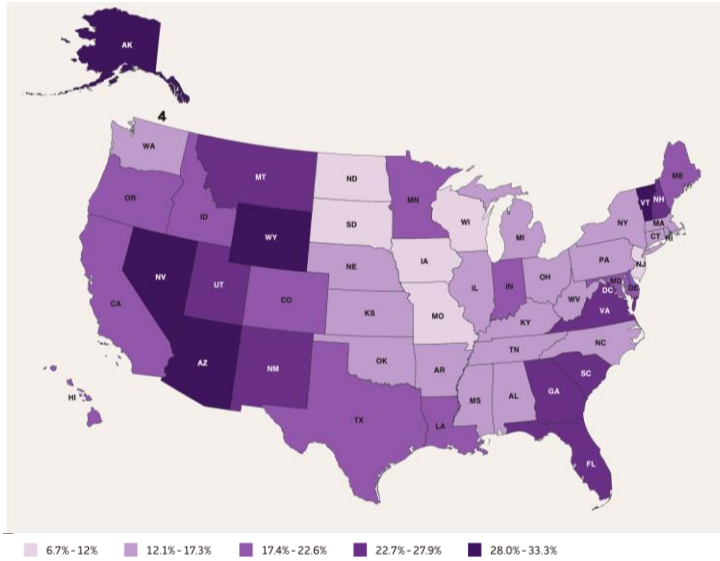


Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimer's Dement 2023;19(4). DOI 10.1002/alz.13016



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## Projected Increases Between 2020 and 2025 in Alzheimer's Dementia Prevalence by State



Adapted from:  
Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2023;19(4). DOI 10.1002/alz.13016



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**Do we need public health to solve this problem?**



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# What is public health?

- Organized structures that engage people (officials, staff, and volunteers) dedicated to **promoting** and **protecting** the health of all people and their communities
- The health care industry **treats** people who are sick—public health aims to **prevent** people from getting sick or injured in the first place.
- Public health also focuses on **entire populations**, while health care focuses on **individual** patients.
- Public health has had a major influence on **chronic disease**, notably, hypertension, diabetes, HIV, addiction healthcare, and most recently, COVID-19



# Is dementia just another chronic disease?

Component	Other Chronic Diseases	Dementia
Treatment	Effective Drugs	Marginal effect/behavioral
Decision-making	Usually preserved	Often lost esp. when late
Self-management	Patient +/- care partner	Eventually care partner
Care partner training	Disease oriented typically	Person-centered, safety
Community supports	Improving SDoH	Direct services / SDoH (?)
Prognosis	Often not thought of terminal	Shorter term life-expectancy

Adapted from: Reuben DB, Epstein-Lubow G, Evertson LC, Jennings LA. Chronic disease management: why dementia care is different. Am J Manag Care. 2022 Dec 1;28(12):e452-e454. doi: 10.37765/ajmc.2022.89258. PMID: 36525665.

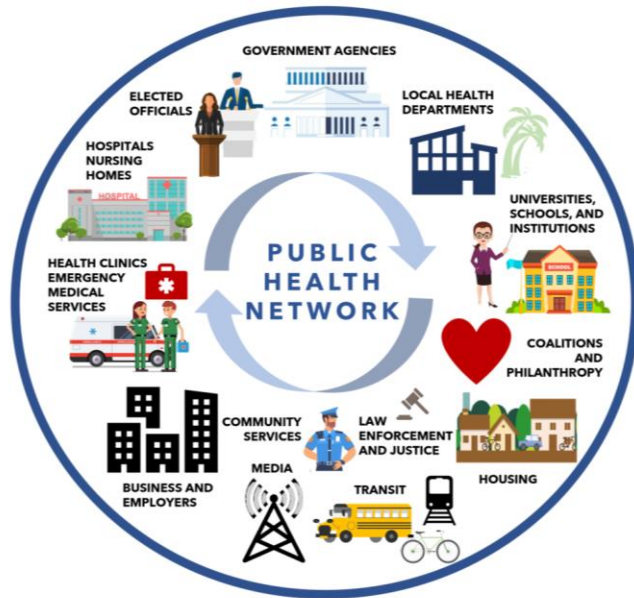




# The scope of public health

People living with dementia are everywhere...and so are the people who care about them

Graphic courtesy of the Florida State Health Improvement Plan

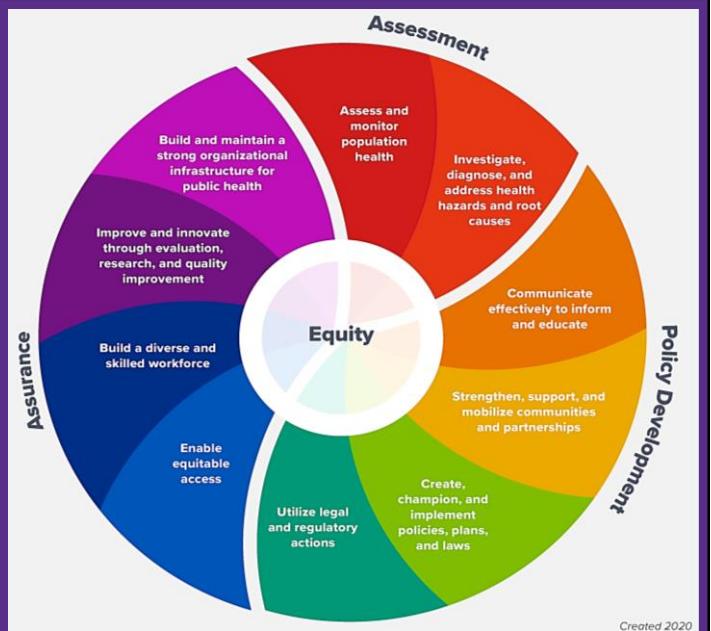


# What is the role of public health?



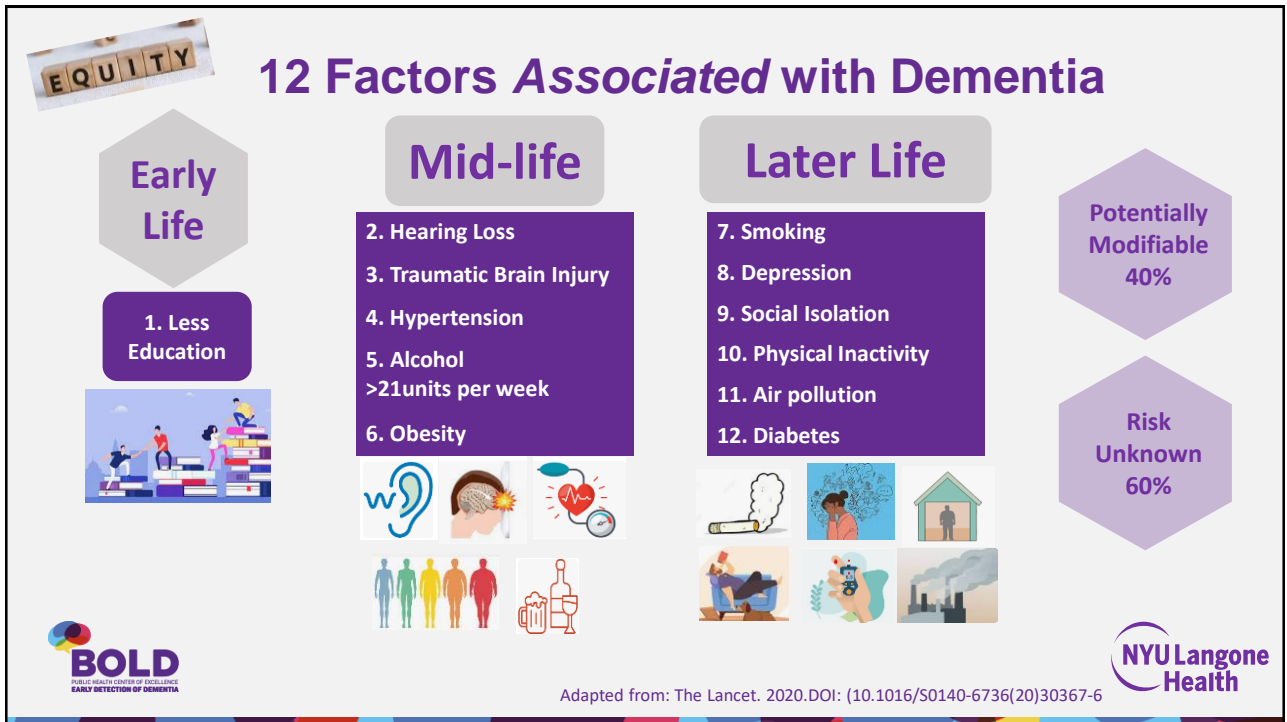
# The 10 Essential Public Health Services

- To achieve optimal health for all, the Essential Public Health Services actively promote policies, systems, and services that enable good health and seek to remove obstacles and systemic and structural barriers, such as poverty, racism, gender discrimination, and other forms of oppression, that have resulted in health inequities.
- Everyone should have a fair and just opportunity to achieve good health and well-being. **This is what health equity looks like!**



## What does dementia have to do with health equity?





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**EQUITY**

## Dementia is a health equity issue

**Black adults**  
2x more likely than White adults to develop dementia  
*(Power et al. 2020, JAMA Neurol)*

**Black and Hispanic adults**  
More than 2x likely than Whites to have MCI or dementia.  
*(Wright et al. 2021, J Alzheimers Dis)*

**BOLD**  
PUBLIC HEALTH CENTER OF EXCELLENCE  
EARLY DETECTION OF DEMENTIA

Power MC, Bennett EE, Turner RW, et al. Trends in Relative Incidence and Prevalence of Dementia Across Non-Hispanic Black and White Individuals in the United States, 2000-2016. *JAMA Neurol.* 2021;78(3):275–284. doi:10.1001/jamaneurol.2020.4471

**NYU Langone Health**

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# STARTING PREMISE

*Dementia is a manageable chronic condition, if we...*

Detect it early – *before a crisis*  
Center relationship – *foundation of effective care*  
Address complexity – *it's our reality*  
Manage risks – could *"No Crisis" be a goal of care?*



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**Early detection of dementia  
is essential to managing  
these risks**

What does this have to do with BOLD and  
how did we get there?



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# Timeline of National Public Health Policy

*Public health policy and guidance on dementia, cognitive health and caregiving*



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# WHAT IS BOLD?

## ***BUILDING OUR LARGEST DEMENTIA INFRASTRUCTURE***

- Federal enabling legislation passed in 2018
- The Centers for Disease Control and Prevention empowered to create dedicated, dementia-focused public health infrastructure
- Competitive application process
  - Initial awards – 2020: 3 Public Health Centers of Excellence, 23 public health programs
  - Second round – 2023: 43 public health programs

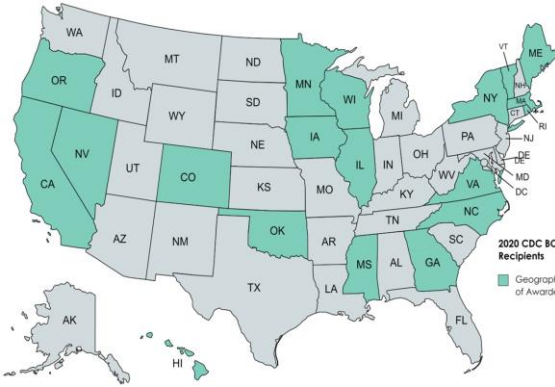


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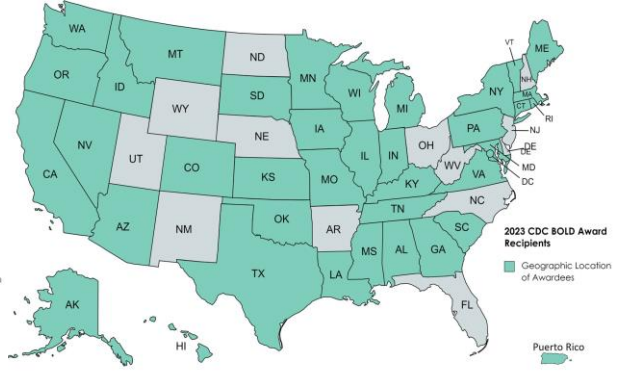
# MOST STATES NOW HAVE BOLD

2020

2023



2020 CDC BOLD Award Recipients  
 ■ Geographic Location of Awardees



2023 CDC BOLD Award Recipients  
 ■ Geographic Location of Awardees



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## Research Findings and Evidence-Informed Practices



Increasing Early Detection and Awareness of Dementia

Promoting Risk Reduction Strategies

Assisting the Development of Caregiving-Focused Programs and Initiatives

Enhancing and supporting patient-clinician-care partner encounters

Health Systems

DOHs

Expanding public awareness, enhancing programs

CBOs

Driving community action and initiatives

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# NYU BOLD Public Health Center of Excellence for Early Detection of Dementia

Mission, Vision, and Actions to Increase Early Detection

Finding evidence-based public health strategies for early detection and better care for older adults with dementia and their care partners



Collect and widely share ways to improve detection



Co-create solutions with national partners



Promote change within stakeholder organizations nationwide



## Who we are....

### BOLD Public Health Center of Excellence (PHCOE) on Early Detection of Dementia



Joshua Chodosh, MD, MSHS (Co-Lead)



Soo Borson, MD (Co-Lead)



Simona Kwon, DrPH (Co-Investigator)



Matthew Lee, MPH, DrPH (Assistant Professor)



Karyn Marsh, PhD (Co-Investigator)



Senem Suzek, MA (Program Director)



Alok Vedvyas, MS, MSJ (Program Analyst)



Alexandra Nordyke (Project Coordinator)



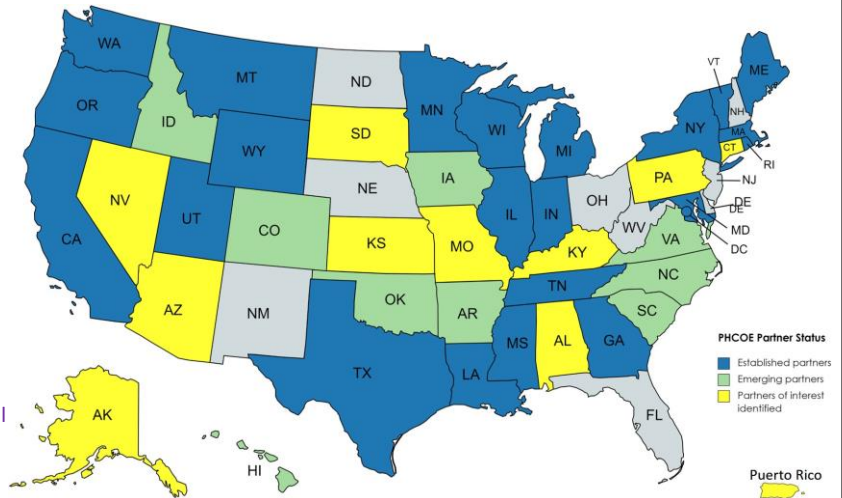
CDC: NU58DP006911  
BOLD (Building Our Largest Dementia Infrastructure)



# PHCOE-EDD National Partner Network

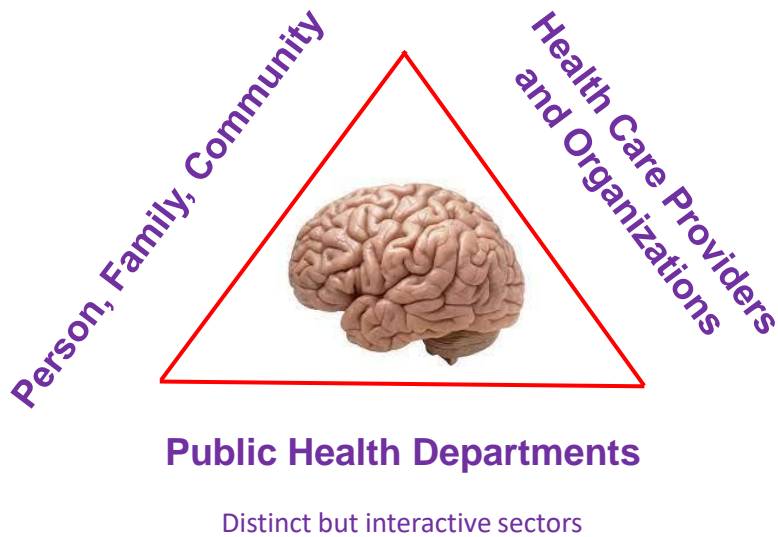
## Leveraging Our Network

- Across the country, we facilitate connections between groups conducting similar work
- We engage our national stakeholder network to ensure reach, relevance, and sustainability, which continues to inform our early detection materials.
- We provide programs with technical assistance in various forms including expert feedback.
- Our leads and co-leads routinely present at national, regional, and local venues to advocate for early detection.



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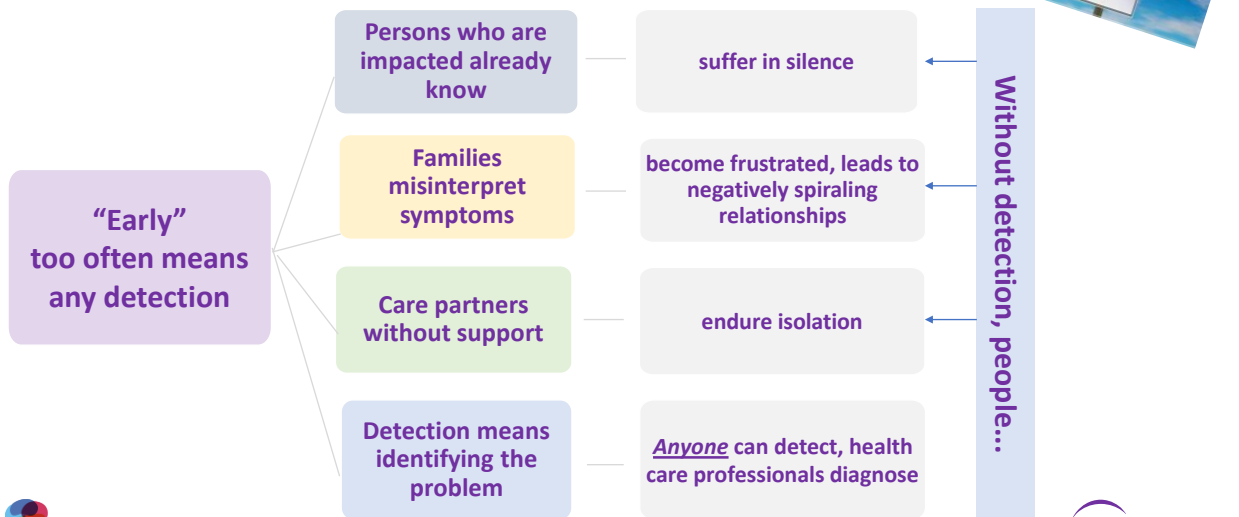
# Organizational Strategic Focus



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## “Early” Detection



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## Our strategies for effective communication include:

- Being prepared to have effective, productive conversations
  - having simple encouraging statements as openers
  - knowing that detecting a problem is just the beginning
- Understanding the role of screening tests and when they can be helpful
- Having a clear understanding of cognitive impairment and the elements of a dementia diagnosis
- Recognizing that all three sectors play an important role
- This has to happen in **Primary Care**



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# Products

## Early Detection Toolkit for Health Systems

**Early Detection of Dementia Toolkit - Health Systems**

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### EARLY DETECTION OVERVIEW

**What is early detection?**

**Why is detection important?**

**Should routine dementia screening be conducted?**

**Red flags/indicators for screening (e.g., missed appointments)**

**Ecological model of dementia detection stakeholders**

### Ecological Model of Dementia Detection Stakeholders

**Where is dementia detected?**

Dementia can be detected wherever affected people are – at home in the kitchen, in the supermarket, at the bank, on the bus, at the park, at the food bank, in the senior center, during a blood draw for lab tests – but a clinician is needed to make a medical diagnosis of dementia and identify what conditions and factors, reversible or permanent, are causing it.

This section covers the roles that health systems, communities, individuals, family, and friends can play in dementia detection.

#### Navigating post-screening conversations

Screening for cognitive impairment is a crucial first step to ensuring patients' overall health. Detailed conversations with patients about their lives and their day-to-day activities provide context for cognitive screening and establishes an important partnership in ensuring best opportunities to maintain health. Supporting brain health is vital to overall health, regardless of the results of any screening activity. In the event of a positive screening test, continuity of care is essential and often helps to "complete the story." This work is never completed on one visit as there will always be more. This is a journey for both primary care providers and those patients and their families. Primary care is exactly the vehicle for such a journey because this is where about relationships between patients, their families and providers. When impairment is detected, having readily available information to refer to other resources (e.g., community-based organizations, state or local resources) is a critical element of ongoing care.

#### Post-screening

**Building trust**

#### Cognitive Screening Overview

#### Pre-screening

**Feelings matter: Use positive framing and pay attention to your body language.**

#### Early Detection Overview

#### What is Dementia

**What are screeners?**

Screeners or screening tools are used to predict the likelihood of cognitive impairment. Screening tools can detect early changes in cognitive functioning, and can also be used to monitor changes in cognitive functioning over time. There are two types of screening tools:

Performance-based screening tools are administered to patients. Examples of performance-based screening tools include:

- Mini-Cog
- BOLD (BOLD University Memory Status Examination) (BOLDMS)
- Function-based screening tools are administered to informants (e.g., one partner, family member, close friend)
- 8-item Informant Interview (8IIT)
- Caregiver Interview (CGI)
- Caregiver Interview (CGI)
- Functional Activities Questionnaire (FAQ)

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**Many organizations, departments (local, county, and state) have embraced and are engaged in achieving better dementia detection and care**  
**Exemplars**  
**Wisconsin**

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## Early Innovator Spotlight : Wisconsin's State-Wide Early Detection Engine – Dementia Care Navigation as Part of Public Health



Kristen Felten  
Aging and Disability  
Resource Centers  
(ADRCs) county-level  
agencies – free  
services to public  
• Created dementia  
care specialist  
program



dementia-friendly  
communities



wisconsin specific  
community  
program resources

Memory Cafés

Memory cafes are unique structured social gatherings that provide opportunities for individuals with dementia, along with their family, friends and caregivers, to enjoy interactions with others in a setting free from awkwardness and stigma. They are not intended as support groups.

2023

- 70 Dementia Care Specialists working in Aging and Disabilities Resource Centers, covering all 72 counties and 5 tribes.
- 2021: Dementia Care Specialist program became a state budget line item



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## Partner Activities: Key Strategies

### Public – Academic Partnerships leverage mutually needed resources

- Telehealth – addressing issues reach and scalability (equity)
- Project ECHO – broad educational reach (equity)
- Annual wellness visits
- Webinars
- Website resources

### Linking public health – community resources

- Memory screenings
- Outreach
- Dementia-informed community services



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## Fast forward: Dementia Care Navigation as Part of Health Care Delivery GUIDE Model: CMMI's Alternative Payment Model for Dementia 2023



<https://www.cms.gov/priorities/innovation/innovation-models/guide>

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## Related Research on a National Scale Using Pragmatic Designs for Clinical Trials

### HearVA-ED ED-LEAD



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## The HEAR-VA Pilot Study: Hearing assistance provided to older adults in emergency departments

*Testing the feasibility and potential benefit of providing a simple hearing assistance device (personal amplifier) during an emergency department (ED) visit, for people who reported difficulty hearing (what if you also have cognitive challenges?)*

Screening for self-reported hearing difficulty for patients 60 years and older and likely to be discharged home (ESI: 3-5)

Hearing Handicap Inventory – Survey (10 items)

RCT – 1:1 randomization

Intervention participants received personal amplifiers



VA HSR&D HX002421-01A1



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## HEAR-VA Pilot Study: Outcome Measures

Post-discharge survey

6-item Hearing and Understanding Questionnaire (HUQ)

3-item Patient Understanding of Discharge Information (PUDI).

Use of the personal amplifier during their ED visit.

Follow-up phone calls at 4 days and 35 days post-ED visit

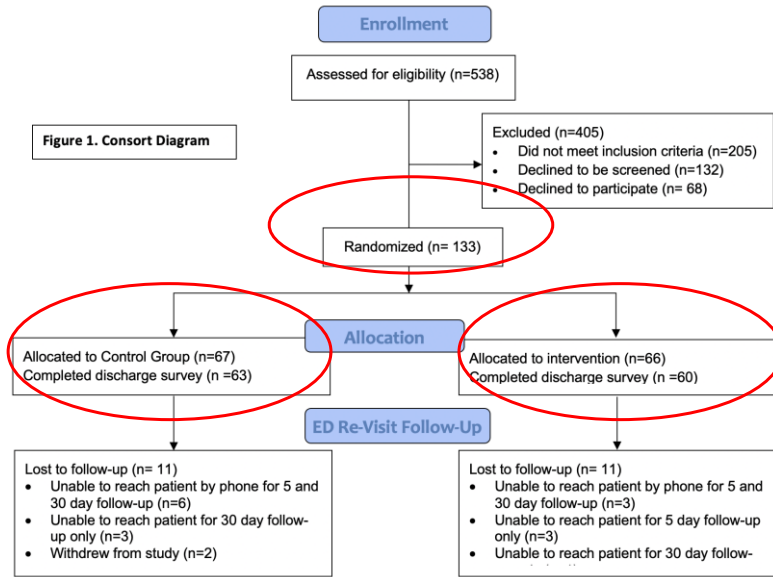
Information on return ED visits after discharge



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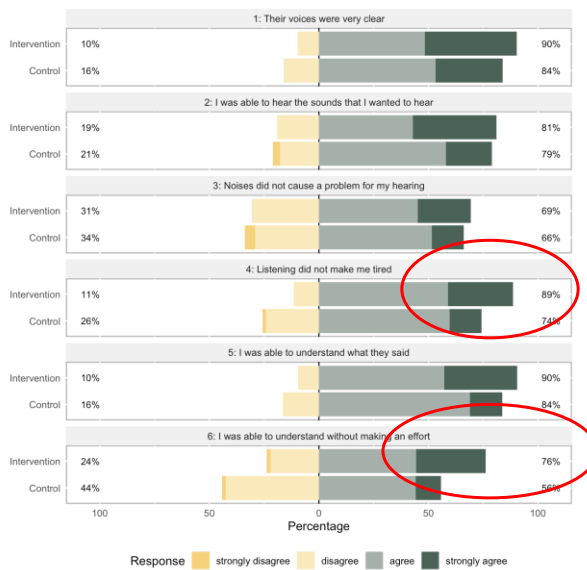
# Screening – Enrollment – Retention 7 months

Figure 1. Consort Diagram



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# Hear-VA: Hearing and Understanding



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# Understanding of Discharge Instructions



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## ED Revisits

### ED revisit within three days

Intervention group : 3%

Control patients: 9%

(95% CI = -15.4% – 3.6%)

### ED revisits within 30-days

Intervention group: 23%

Control group: 27%

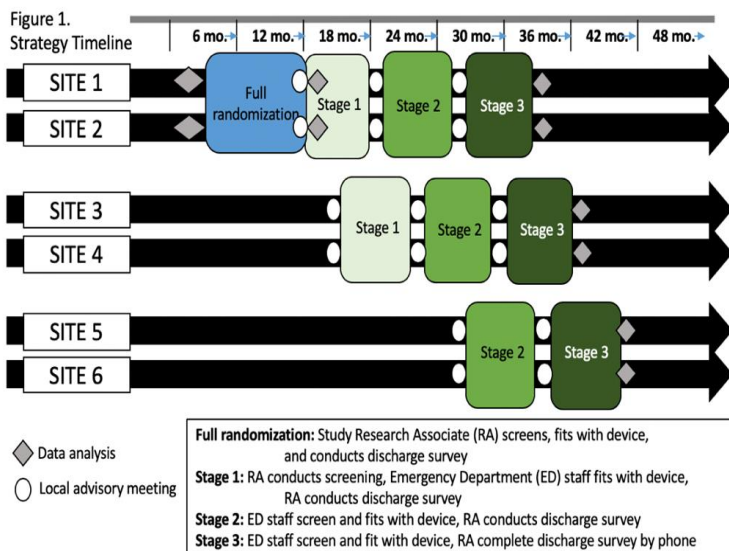
(95% CI = -20.3% – 20.0%)

**How many of these patients are cognitively impaired??**



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# HearVA-ED Stage 1 Implementation



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## ED-LEAD: Emergency Departments LEading the transformation of Alzheimer's and Dementia care

### Core Faculty



Joshua Chodosh, MD,  
MSHS  
Contact PI, Project Lead



Abraham Brody, PhD, RN,  
FAAN  
mPI, Project Lead



Corita Grudzen, MD,  
MSHS  
mPI, Core Lead



Manish Shah, MD,  
MPH  
mPI, Project Lead



Keith Goldfeld, DrPH  
Statistical Core Lead



NIH/NIA 1U19AG078105-01A1



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## Agency for Healthcare Research and Quality

August 2020, *little evidence* of widespread dissemination of any general care approaches for PLWD; identified a need for larger, longer-term, more rigorous studies

## National Academy of Science Engineering and Medicine (NASM)

Committee recommended three next steps in PLWD interventions:

- 1) the use of strong, *pragmatic designs* that incorporate both quantitative and qualitative methods to enable a better understanding of fidelity and contextual factors;
- 2) inclusivity among both the research team and participants
- 3) assessment of real-world effectiveness, with an expansion of focus from individual to community/policy-level interventions.



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## Pragmatic Trial – what is it and why do that?

- **Diverse “real world” settings**

- ED-LEAD will study 3 novel interventions in a range of health systems that vary in geography, size, academic versus community focus, and patient populations
- As a pragmatic trial using non-experimental clinical interventions, PLWD and care partners are not considered ED research participants — therefore not consented for participation
- Pragmatic design incorporates both quantitative and qualitative methods to enable a better understanding of fidelity and contextual factors

- **Methodological Challenges and Alternative Solutions**

- We are interested in identifying dyads with high need, not necessarily captured by measures of dementia severity alone.
- Our clinical selected assessment tools, including social determinants of health (SDoH) and symptom and caregiver burden screens, are used because they are actionable and can improve the health or well-being of dyads, as opposed to research assessments alone.



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## Gaps in ED Care

### Large Gaps Exist in the Emergency and Post-Emergency Care of Persons Living with Dementia and their Care Partners

- Redesign of Emergency and Post-Emergency Care Needed for PLWD and their Care Partners
- Little Evidence to Support Dissemination of Care Practices in PLWD and their Care Partners

Effective Models of Care Can be Optimized for PLWD

Core Functions of Complex Interventions Need Study in Pragmatic Trials

AD/ADRD Burden Affects Women and Persons of Color Disproportionately



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## Why do we care?

- Over **6 million** Americans have Alzheimer's Disease or an Alzheimer's Disease Related Dementias (AD/ADRD), projected to reach 13 million by 2050.
- Healthcare costs for AD/ADRD exceeded **\$305 billion** in 2020, and dementia is now the sixth leading cause of death in the United States.
- More than **50%** of older adults with AD/ADRD visit the emergency department (ED) each year and those who do are seriously ill, have excessive healthcare costs (e.g., admissions, repeat ED visits) and mortality. This amounts to approximately **3 million** ED visits annually.



*In persons living with dementia (PLWD) who have serious illness, an ED visit is a critical event and an opportunity to address the unmet needs that preceded it.*



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## Major Study Goal & Outcomes

- To improve the care of persons living with dementia (PLWD) and their informal care partners by addressing emergency and post-emergency care through different combinations of three PLWD-care partner dyad focused interventions:

**Emergency Care Redesign (ECR)**

**Nurse-led Telephonic Care (NLTC)**

**Community Paramedic-led Transitions Intervention (CPTI)**

- 1) optimize a concurrently run emergency care redesign, nurse-led telephonic care, and community paramedic-led transitions intervention in PLWD for feasibility, fidelity and usability in two EDs;
- 2) study the effectiveness of these three interventions, alone and in combination in cluster-randomized multifactorial trial embedded within 80 EDs on: **ED revisits** within 30 days (primary outcome), 14 days, and 6 months (secondary) of discharge, **hospitalizations** within 14 days, 30 days, and 6 months of discharge (secondary), and **healthy days at home** within 6 months of discharge (secondary). following the index ED visit; and
- 3) determine site, provider, patient, and care partner-level characteristics within diverse population associated with variation in implementation of each intervention.



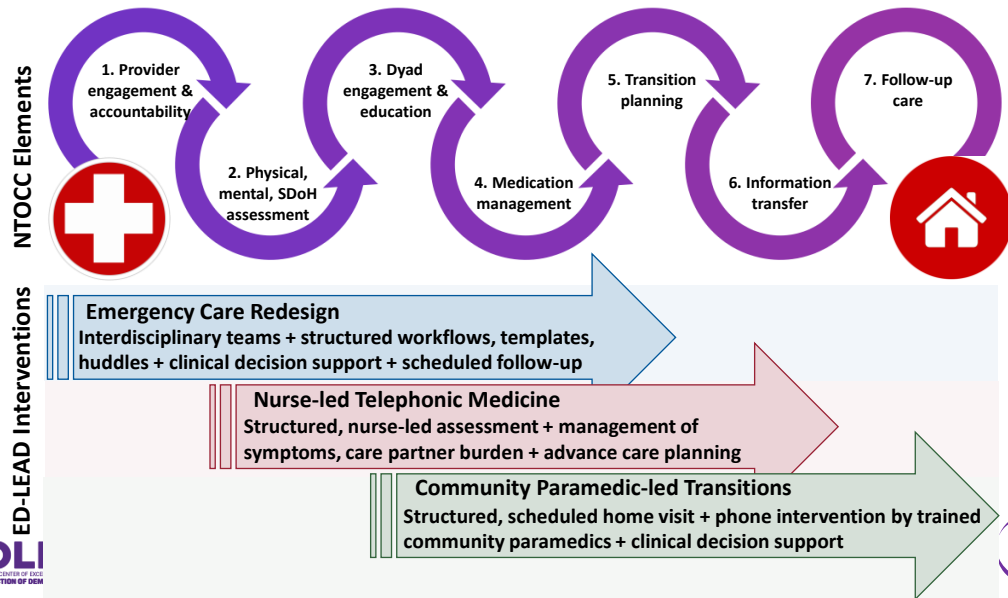
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# Interventions



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## Transitions Care Grounded in a Conceptual Model

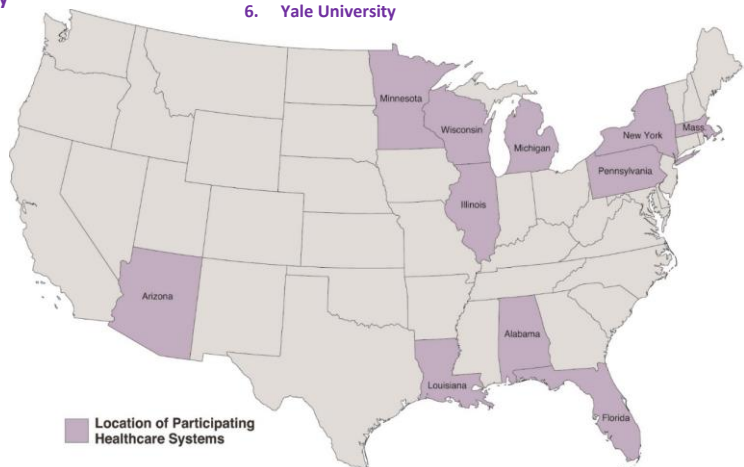


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## Participating Health Systems

1. NYU Grossman School of Medicine, NYU Rory Meyers College of Nursing
2. Advocate Aurora Health
3. Brigham and Women's Hospital (HARVARD)
4. Massachusetts General Hospital (HARVARD)
5. Henry Ford Health System
6. Mayo Clinic
7. Icahn School of Medicine at Mount Sinai
8. The Feinstein Institute for Medical Research (Northwell)
9. Northwestern University
10. Ochsner Health System
11. University of Alabama at Birmingham (UAB)
12. University of Rochester
13. University of Pittsburgh
14. University of Wisconsin

1. Caring Kind
2. Johns Hopkins University
3. Kaiser Permanente Southern California
4. Sloan Kettering Research Institute
5. Rush University
6. Yale University

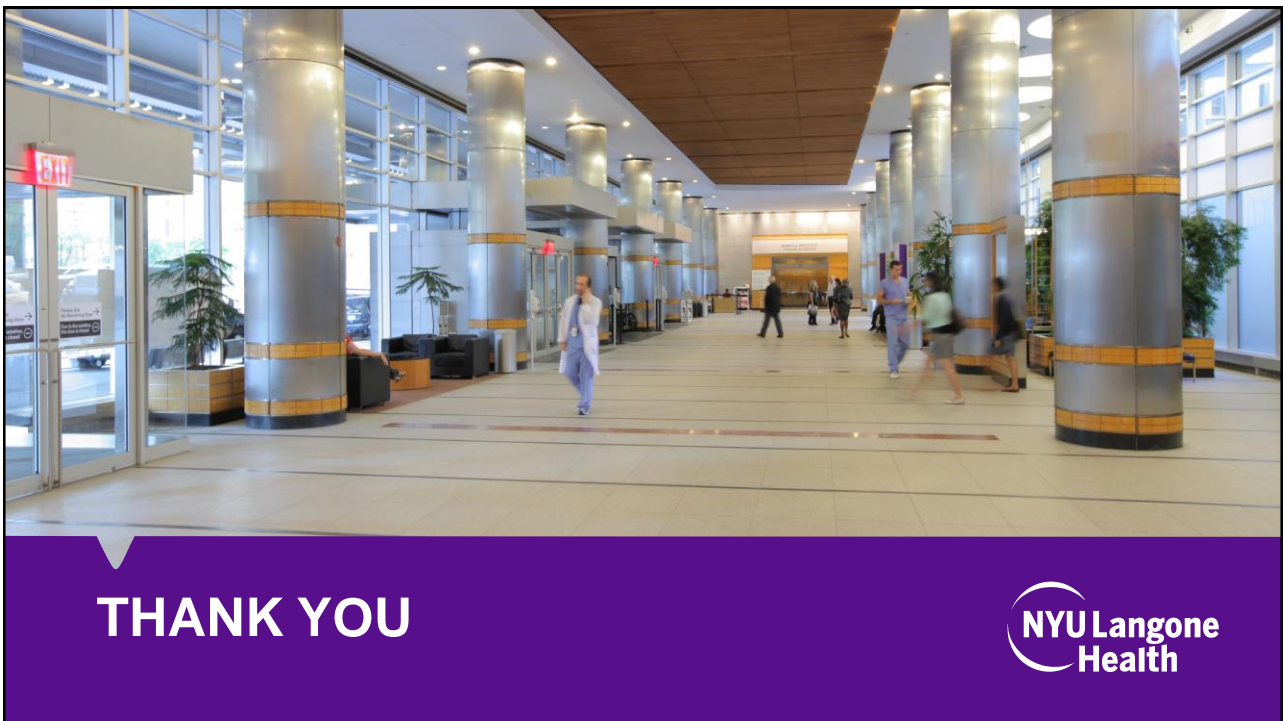


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# Acknowledgements



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