



NIA IMPACT
COLLABORATORY
SCIENTIFIC CONFERENCE

2024 Scientific Conference, Day 1

Wednesday, April 3, 2024 | 8:30 A.M. – 5:30 P.M. ET

Welcome to IMPACT's Annual Scientific Conference



NIA IMPACT
COLLABORATORY
SCIENTIFIC CONFERENCE

Susan Mitchell, MD, MPH – Hebrew SeniorLife's Marcus Institute for Aging
Research, Harvard Medical School

Session 1:

Palliative Care and Symptom Management

Moderator: Susan Mitchell, MD, MPH

Presenters:

Ab Brody, PhD, RN, FAAN – NYU Rory Meyers School of Nursing

Komal Murali, PhD, RN, ACNP-BC – NYU Rory Meyers School of Nursing

Susan Hickman, PhD – Indiana University, Regenstrief Institute, Inc.

Latarsha Chisholm, PhD, MSW – University of Central Florida

Panelists:

Christine Ritchie, MD, MSPH – Massachusetts General Hospital

Alexia Torke, MD, MS – Indiana University

Komal Murali, PhD, RN, ACNP-BC



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A photograph of two women in a room. On the left, a woman with dark, wavy hair is seated and looking towards the right. On the right, an older woman with short, grey hair is seated in a wheelchair, wearing a white floral-patterned top and a colorful, knitted blanket. She is looking towards the left. The room has a window with blinds in the background and framed pictures on the wall.

The Hospice Advanced Dementia Symptom Management and Quality of Life Trial (HAS-QOL) (NIA R33)

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No related conflicts of interest, financial or otherwise, to disclose.

Aliviado Dementia Care is a program of the Hartford Institute for Geriatric Nursing at NYU, it is not a for-profit program or service

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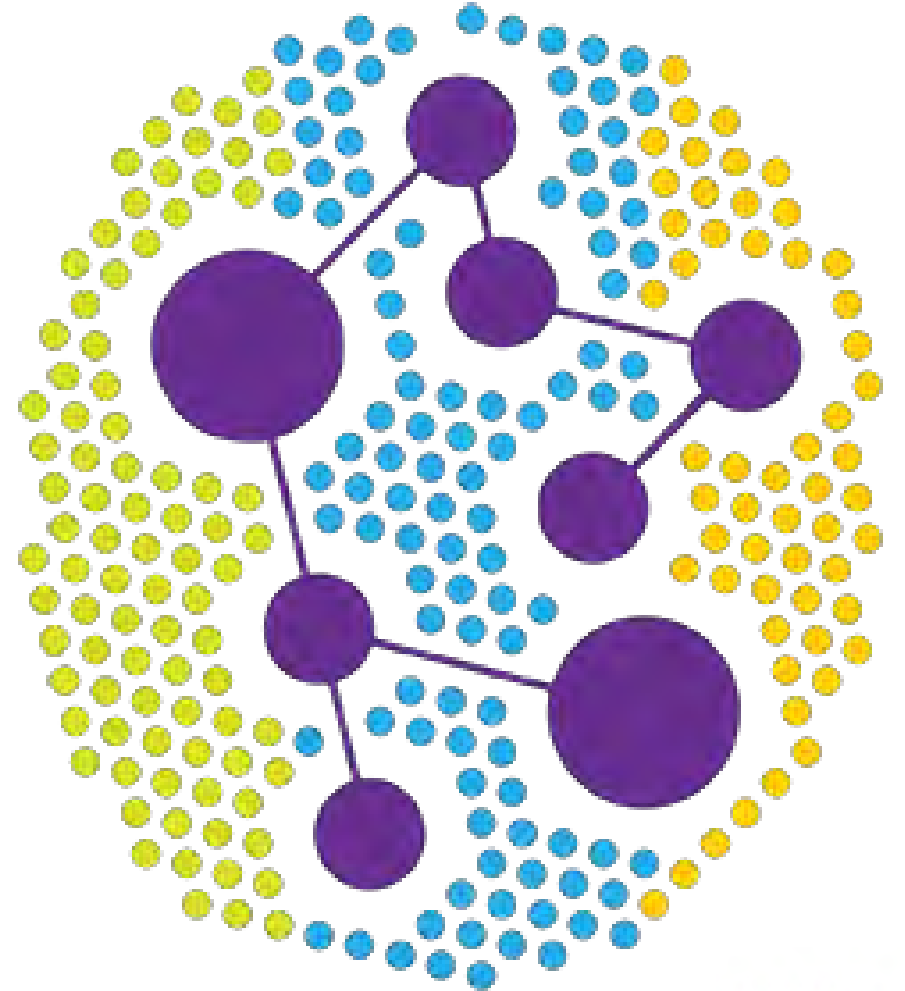
It Takes a Village



HAS-QOL Background

- Hospice was originally developed to care for seriously ill individuals with cancer
- Today in the U.S. ~46% of hospice patients are living and dying with dementia as either a primary or secondary diagnosis
- Persons living with dementia and their care partners have unique needs very different from cancer and other serious illnesses
- Very few practices have been evaluated in the hospice setting to support persons living with dementia and their care partners

We developed Aliviado Dementia Care to help interdisciplinary care teams provide comprehensive, compassionate, evidence-based symptom management and support for Persons living with dementia and their care partners



A Review of Interprofessional Dissemination and Education Interventions for Recognizing and Managing Dementia



Feature Article

Development and testing of the Dementia Symptom Management at Home (DSM-H) program: An interprofessional home health care intervention to improve the quality of life for persons with dementia caregivers

Stage 0

Stage 1 (Homecare)

Stage 3 (Homecare)



Stage 1 (Hospice)



JOURNAL ARTICLE

Findings of Sequential Pilot Trials of Aliviado Dementia Care to Inform an Embedded Pragmatic Clinical Trial [Get access >](#)


Contemporary Clinical Trials

Volume 93, June 2020, 106005



Adaptation and Piloting for Hospice Social Workers of Aliviado Dementia Care, a Dementia Symptom Management Program

Protocol for an embedded pragmatic clinical trial to test the effectiveness of Aliviado Dementia Care in improving quality of life for persons living with dementia and their informal caregivers

1-7
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Aliviado Toolbox

Mobile App



Caregiver Education Pamphlets English/Spanish

AGITATION & AGGRESSION

Agitation and aggression can be expressed verbally or physically. They may occur suddenly with no obvious cause, or from frustration/anxiety. This can make your job as caretaker more difficult. It is important to understand that the person living with dementia is not acting like this on purpose.

What Are Agitation & Aggression?

- Frustration and anxiety may cause the person to act out angrily towards other by hitting, pushing, shouting at, or arguing with them.

What Are Some Causes?

- The person feels uncomfortable.
- Large crowds, or the presence of certain people.
- Annoying sounds.
- The person feels unable to talk.

- Use a caring tone to calm the person down.
- Remind them of where they are, who you are, or who they are if they become confused and anxious.
- Try music therapy, where you have the person living with dementia listed to 20 minutes of their favorite type of music a day, every day. If they like dancing you can try dancing with them.
- Try to exercise with the person living with dementia.

What If These Things

Care Plans

INTERDISCIPLINARY CARE PLAN - SLEEP DISTURBANCE

Patient Name: _____ Provider Name: _____ Date: _____

Is this a new symptom or significant chronic worsening symptom?
 Yes
 No

If yes, have you considered dietitian?
 Yes
 No

DEFINING CHARACTERISTICS
 Identify sleep disturbance symptoms:
 Insomnia
 Shift Sleep Disorder
 Altered sleep-wake cycles
 Periodic limb movement disorder

ASSESSMENT METHOD
 Select the appropriate assessment method:
 NPI-Q - Does the patient awaken during the night, rise too early in the morning, or take excessive naps during the day?
 o Frequency and severity of symptoms: _____
 Mild
 Moderate
 Severe
 o Are there other behavioral symptoms? Yes _____ No _____
 o Do they hinder/ cause stress to the caregiver? Yes _____ No _____

INTERVENTIONS	RATIONALE
<ul style="list-style-type: none"> Appropriate day/night lighting No more than 1.5-hour nap per day 30-60 minutes exercise/day Resolving P/T/T Rise by P/T/T Limit alcohol Good sleep hygiene (no caffeine in PM or reading/TV in bed, discourage staying awake in bed) Pain management Medication management Maintain set wake and sleep times 	<ul style="list-style-type: none"> Promotes circadian rhythms Excessive daytime naps interfere with sleep cycle Exercise helps to increase stamina and decrease daytime drowsiness Alcohol is a depressant and can interfere with sleep cycle Good sleep hygiene promotes restful sleep and decreases distractions Pain management increases comfort to enhance restful sleep. Managing depression increases a positive sense of well-being Having a sleep routine will help patients have consistent sleep habits

Goals/Outcomes

- The patient will have restful sleep during the night for 4-6 hours daily
- The patient will report awakening feeling well rested and energetic daily
- The patient will report regular sleep-wake cycles on a daily basis
- The patient will develop positive sleep hygiene behaviors on a daily basis
- The patient will not exhibit troubling behavioral symptoms of decreased sleep on a daily basis

Assessment Tools/Instruments

	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling. Loud moaning or groaning. Crying.	
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
				TOTAL

Sleep Disturbance
 -Redirection
 -Distraction
 -Ensure adequate lighting
 -No more than 1.5-hour nap per day
 -30-60 minutes exercise/day
 -Limit alcohol
 -Good sleep hygiene (no caffeine in PM or reading/TV in bed, discourage staying awake in bed)
 -Discourage staying awake in bed
 -Pain management
 -Medication management
 -Maintain set wake and sleep times

Psychosis
 -Redirection
 -Distraction
 -Ensure adequate lighting
 -Reduce environmental stimulants
 -Address any hearing or visual losses
 -Address patient's feelings about the delusion or hallucination, do not dismiss.

Depression
 -Music Therapy (30-60 minutes)
 -Redirection
 -Distraction
 -Social outings or events
 -Reminiscence therapy
 -Life journaling
 -Cognitive behavioral therapy
 -Pain management
 -Manage Sleep Disturbances
 -Pet therapy
 -Art therapy
 -Aroma therapy

Aggression
 -Redirection
 -Distraction
 -If during a task such as bathing or toileting, stop and try again later.
 -Address pain
 -May need to change caregiver or receive extra help
 -Don't argue or react defensively
 -Acknowledge feelings of the person with dementia
 -Place object in hand to hold during care.

Sexual Disinhibition
 -Redirection
 -Distraction
 -Dress in clothing that is difficult to disrobe
 -Separate sleeping arrangements
 -Exercise, physical and social activities
 -Remove precipitating factors

Psychomotor Agitation
 -Redirection
 -Distraction
 -Use activity aprons or other tactile distractors
 -Pet therapy
 -Do not attempt to restrain
 -Reduce noise
 -Increase physical activity
 -Massage
 -Music therapy
 -For wandering: camouflage doorway and/or create signage for better ways to go (stop sign, arrow)

Symptom Management Algorithm

Study Design R33 Hospice Trial

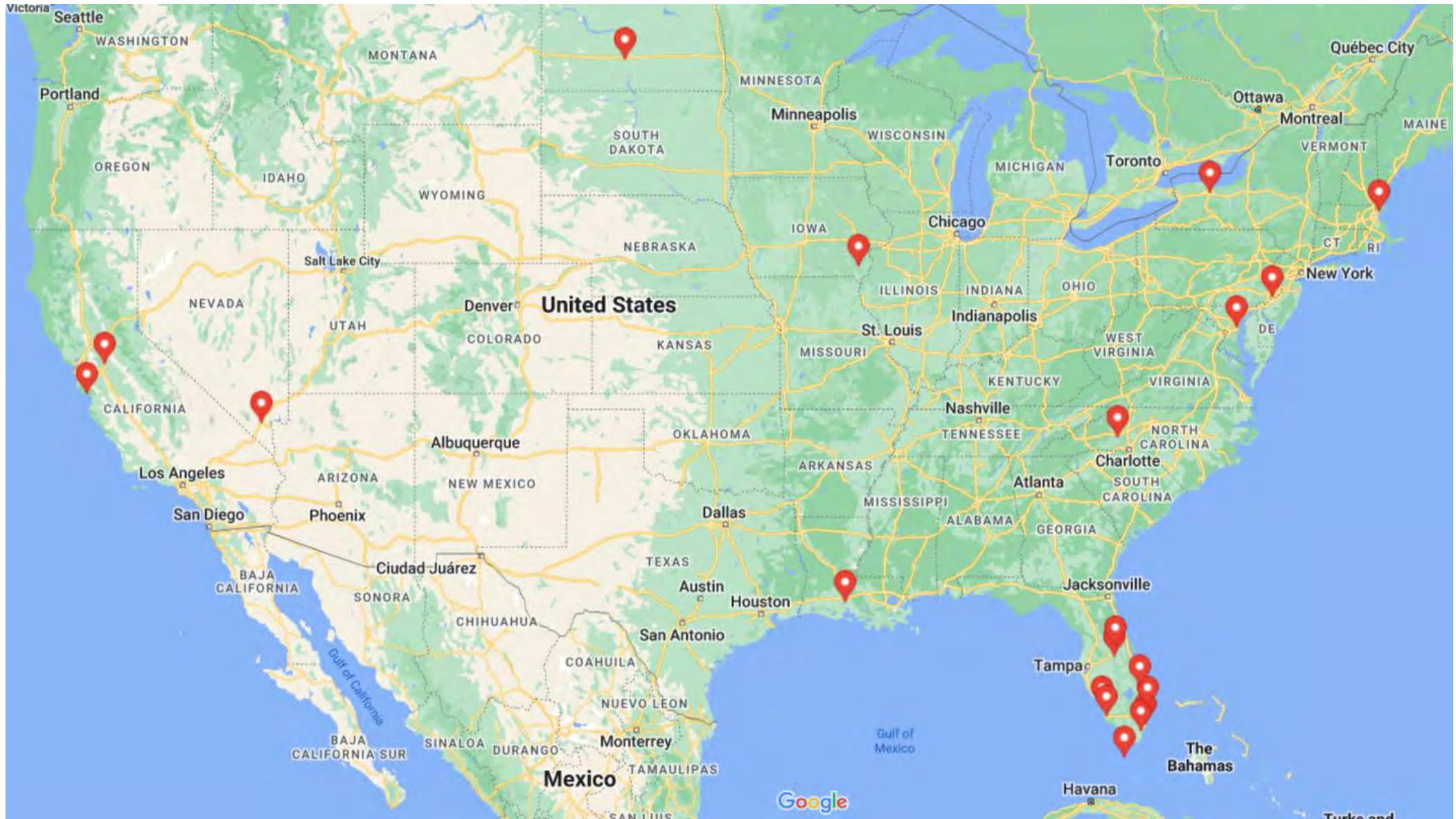
- 25-site stepped wedge trial
- Partner engagement related to:
 - Readiness
 - Data collection processes**
 - Further intervention modifications
 - Implementation processes
- Sites chosen to ensure geographic, profit status and racial/ethnic variability
- Pragmatic Data Collection-all “available” through EHR/administrative systems

Data collection

- Outcome measures:
 - Antipsychotic use, disenrollment/increased level of care required (e.g. GIP, continuous care), HCAHPS
 - Will perform secondary analyses by race/ethnicity and sex
- Implementation/Fidelity measures:
 - Staff training completion
 - Tool usage (both in EHR and app)
 - Read/Open rates of nudges/emails

Implementation Data Collected

- All Mhealth App events
- Online training completion
- Clinician turnover, well being and quality of life
- Marketing engagement; mobile push notifications and email interactions
- Quarterly and annual surveys
- Completion of toolbox instruments; assessment and care plan





Training Outcomes

- 336 champions across 19 agencies, 21% turnover during trial
- 1,842 skilled hospice IDT members (e.g. RN, SW, Chaplain, NP, MD), 16.5% turnover
- 432 Home Health Aides
- Significant improvement in knowledge, confidence and attitudes across disciplines
- 95% intend to implement change

Patient Demographics N=44,130

Sex

Female 58%

Age

Mean(SD) 85.75 (8.99)

Median (Q1-Q3) 87.00 (81.00-92.00)

Race and Ethnicity

American Indian or Alaska Native 65/43862 (0%)

Asian 462/43862 (1%)

Black or African-American 5218/43862 (12%)

Hispanic or Latino 8685/43862 (20%)

Native Hawaiian or Other Pacific Islander 33/43862 (0%)

White 28721/43862 (65%)

Unknown 157/43862 (0%)

Other 521/43862 (1%)

Insurance

Medicaid 504/43121 (1%)

Medicare 41647/43121 (97%)

Self 35/43121 (0%)

No insurance 271/43121 (1%)

Private 570/43121 (1%)

Government 94/43121 (0%)

No payor 0/43121 (0%)

Dementia Diagnosis

Primary 10208/42662 (24%)

Secondary 32454/42662 (76%)

Help with QAPI

- While required by CMS, QAPI capabilities are HIGHLY variable across organizations



1. Behavioral Symptom Management
2. Pain Management
3. Bereaved Caregiver Satisfaction

Plan (Select all that you are planning to use):

- | | |
|---|--|
| <input type="checkbox"/> Audit & Feedback during patient review in IDT | <input type="checkbox"/> Aliviado Customized Messaging (Emails & Push Notifications) |
| <input checked="" type="checkbox"/> Audit & Feedback through Selective Chart Audits | <input type="checkbox"/> Other |
| <input checked="" type="checkbox"/> Review during IDT Meetings | |

Month	Measurement	Goal	Plan
1-2	Utilization of NPI-Q	To administer NPI-Q at least once in 75% of all hospice patients with dementia in 2 months.	<input checked="" type="checkbox"/> Audit & Feedback <input checked="" type="checkbox"/> SBAR <input checked="" type="checkbox"/> Aliviado Customized Messaging
3-4	Use of Careplan/Non-pharm interventions	In individuals who show concerning behavioral symptoms as per the NPI-Q, a care plan for that symptom will be activated for 50% of those patients.	
5-6	Reduced antipsychotics use	Decrease the use of antipsychotics by 20% in 2 months	

Agency 1: Process and Tailoring

- Designated an Aliviado Dementia Care Planning Committee
- Planning Committee met with their assigned Aliviado Implementation Team to:
 - Test Aliviado App
 - Select Champion Team and Training Dates
 - Review Aliviado Toolbox Material
 - Discuss Integration Recommendations
 - Set Date for Implementation Planning Call
- Trained all employees in addition to IDT members

Agency 1: Results

- After 10 months, 0.3 % away from meeting their goal for reduction in antipsychotics medication
- Increased music therapy referrals over 10% of set goal and use of respite by 0.6%

Aliviado Project- For Dementia Patients:	2021 ('before')	Current YTD	Goal
1. Reduction in use of anti-psychotic meds** by 10%	63.9%	57.9%	57.6%
2. Increase Music Therapy referrals by 10%	9.6%	22.8%	10.6%
3. 75% die in the place they call home	73.7%	71.0%	75%
4. Increase use of respite care at KBR by 10%	5.1%	6.2%	5.6%

Start Date= Jan 1, 2022

By When Date = July 1, 2022

Agency 1: Lessons Learned

Worked Well:

1. Active Leadership and Planning Committee
2. Heavy Champion Involvement
3. Structured Work Environment
4. Quick Customer Support
5. Tech Savvy Clinicians
6. Open Communication/ Weekly Reports
7. Champion Calls
8. Weekly Staff List Updates

Barriers:

1. Covid-19 Staff Turnover
2. Quarantined Staff
3. Summer after Vaccine Released (PTO)
4. Labor Day Weekend

Agency 2: Process

- Agency connected Aliviado Team with General Managers for 6 sites to host initial call.
- Implementation call with selected champions.
- 4 sites met with their assigned Aliviado Implementation Team to plan 2-day Champion Training at least **1 month** prior to randomization month

Agency 2: Turnover Rate

Site	Initial	Left Agency from initial List	New Additions	Left Agency after initial List	Final List	Average	Turnover
Agency 2 (6 Sites)	621	194	105	11	521	571	36%

Agency 2: Lessons Learned

Worked Well:

1. Active leadership
2. Quick customer support
3. Open communication/ weekly reports
4. Champion calls with leadership
5. Weekly staff list updates
6. Meeting with each IDT Team

Barriers:

1. Staff turnover
2. Agency paused
3. Leadership change
4. Clinicians needed extra tech support
5. Not all home health aides had access to a work device
6. Rural areas for service
7. Overwhelmed, unable to respond
8. Burnout
9. Limited champion calls

Implementation with Hospice in Mind

- Everything will take more time than you think it will
- Staffing, staffing, staffing!
 - Both “bedside” and executive staff need stability
- Do not do things in only one care team, needs to be an organization wide initiative
- Technology culture and savviness of organization
- Need to remain hands on and provide support throughout
- Data extraction is challenging from EHRs and need to have thorough validation procedures in place

In



• Most for:

- M
- Ex
- Less i
- Techn
- Partn
- Multi
- Data valida

Assessments (71) Careplans (65)

Modified Caregiver Strain Index (MCSI)

Caregiver	Score	Assessment Date	Performed By
Orange Bee (2)	4	Sep 15 2022	
Pear Bee (2)	20	Oct 27 2021	
Banana Bee (1)	26	Nov 29 2021	
	21	Sep 11 2021	
	4	Aug 9 2022	Shih-yin (daughter)

Neuropsychiatric Inventory Questionnaire (NPI-Q)

Modified Caregiver Strain Index (MCSI) Score

20

Medication	Time	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Depakote 500mg tablet, give one tablet by mouth each morning for 7 days 11/4/19 - 11/10/19 Prescribed By: J. Johnson MD 11/3/19	7am	changed															
	7pm											MP	MP	MP	CN	CN	CN

You should examine which items are causing strain in the caregiver and address them where feasible through education and provision of additional services or treatments. Sometimes this is related to caregiver needs. Other times it is related to the behavioral symptoms of the person living with dementia, which must be addressed for the caregiver's strain to be reduced.

DONE

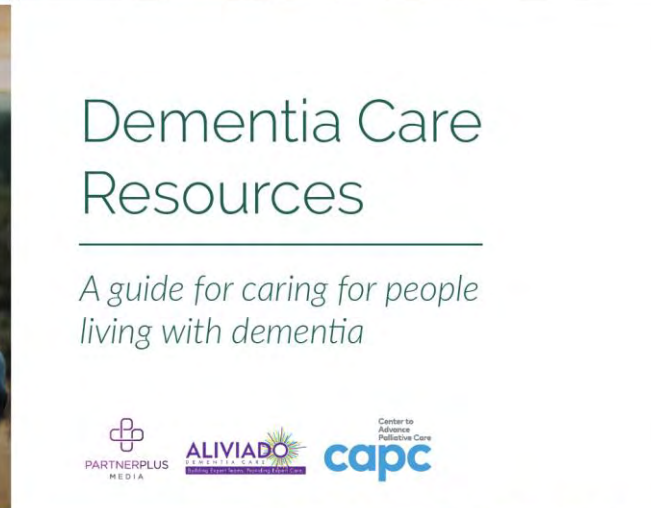
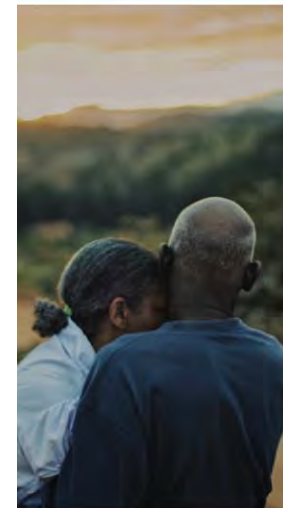
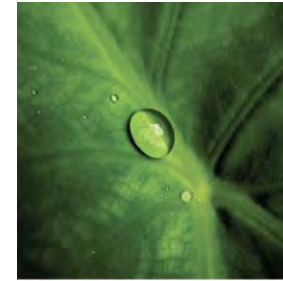
Results: Caregiver Stress Care Plan

Throughout this questionnaire you have made selections pertaining to this caregiver's source of stress, possible interventions, and goals and outcomes. Your care plan is compiled below.

- include:
- ne
- sed:
- mpression- (Physical/
- Interventions**
- Counseling/Bereavement
 - Respite Care
- Goals and Outcomes**
- Caregiver will have reduced distress scores for symptoms that have been identified as being severe to extremely severe on the NPI-Q at baseline.
 - Caregiver will report better communication with family and providers.



What Did HAS-QOL Lead To? – Sustainability...



ED-LEAD Study Design and Outcomes

80-site factorial design ePCT

Takes design & intervention elements from HAS-QOL (NIA), EMPaLLA (PCORI), PRIME-ER (NIA), CTI (NIA), POISED (NIA) trials

ED-initiated care for PLWD NOT admitted in the ED and come from the community (no nursing home residents)

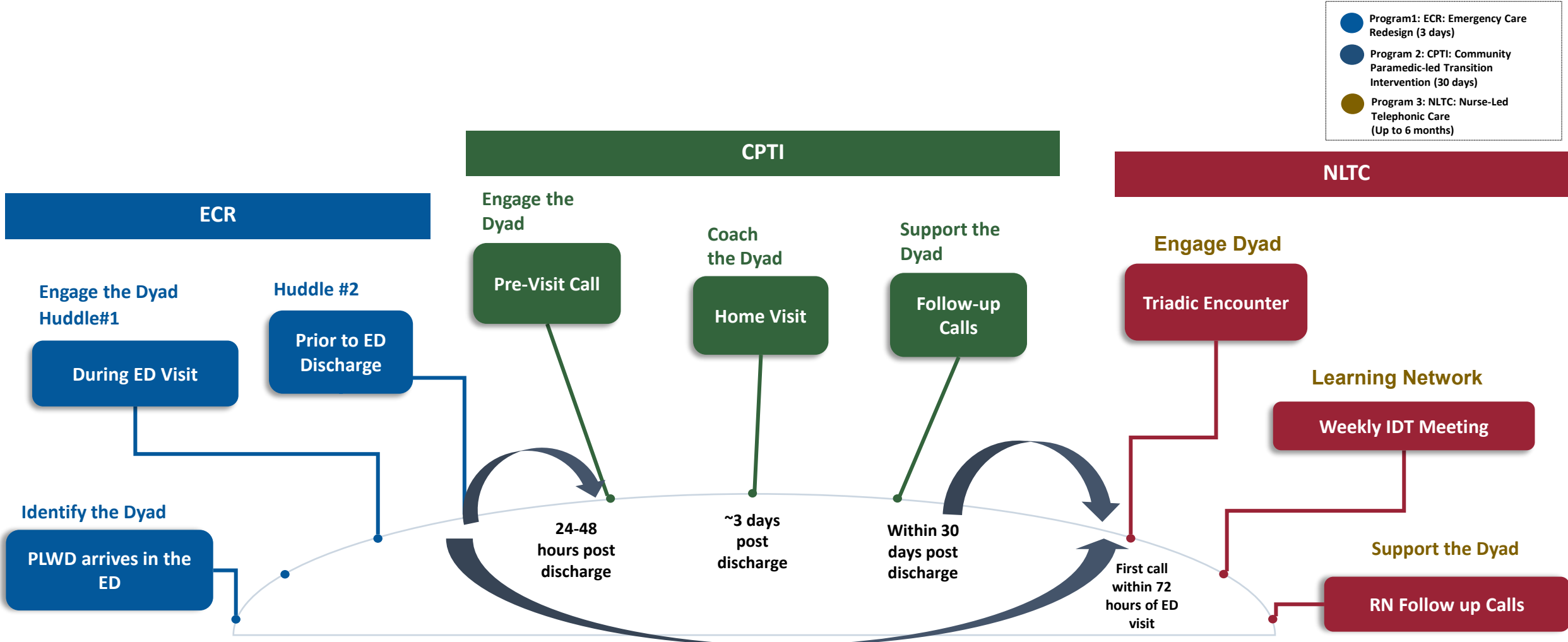
OUTCOMES

- 1) ED revisits
 - Within 30 days (primary outcome), 14 days, and 6 months (secondary) of discharge
- 2) Hospitalization
 - Within 14 days, 30 days, and 6 months of discharge (secondary)
- 3) Healthy days at home
 - Within 6 months of discharge (secondary)



Improve transitional care and reduce future ED visits and hospitalizations

Workflow overview for all 3 ED-LEAD programs: Implementation





Barriers to Hospice Care Transitions for Persons Living with Dementia (Phase I): Diverse Care Partner and Home Healthcare Professional Perspectives

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2024 Scientific Conference on Embedded Pragmatic Clinical Trials in Dementia
Bethesda, MD



Objectives

Background and Review of Literature

Significance

Phase I Findings

Next Steps (*Phases 2 and 3*)



Background



6.5 million people live with Alzheimer's disease and Alzheimer's disease related dementias in the U.S.



Hospice has been shown to be beneficial for people living with dementia (PLWD)



Racial and ethnic disparities in hospice use at the end of life for Black and Latino PLWD and caregivers



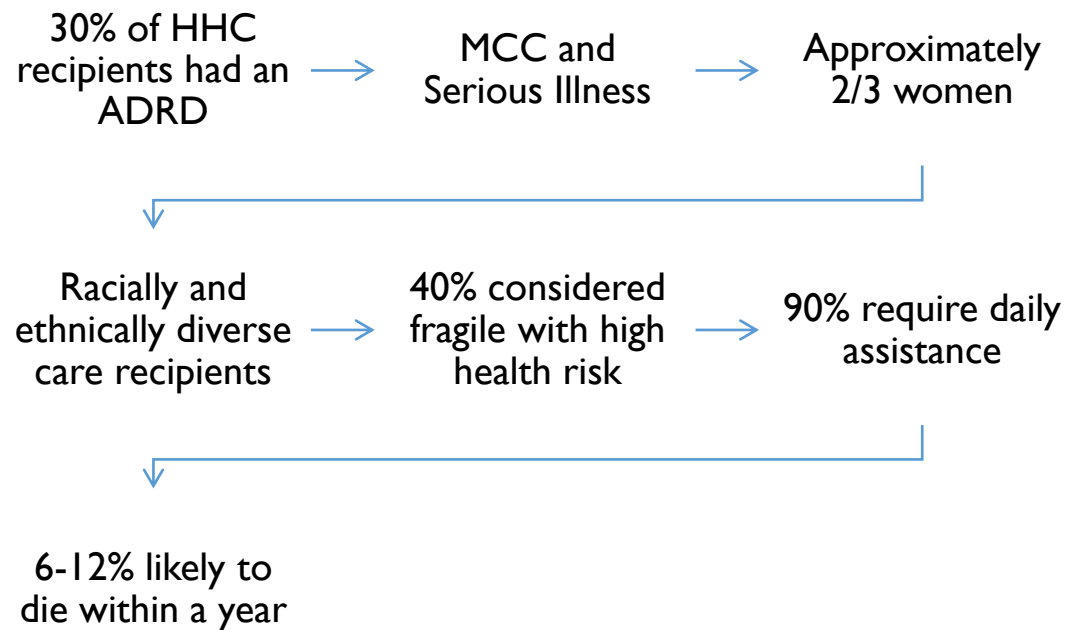
Little data reflecting use and perceptions among Asian PLWD and caregivers



Home healthcare (HHC) is a preferred setting and a key intervention point for improvement of health equity and end-of-life care

HHC Recipients with Alzheimer's Disease and Related Dementias (ADRD), 2013-2018

Findings



- ↑ • ADRD in HHC
- ↑ • Caregiver support needs
- ↑ • Disease-specific end-of-life and serious illness communication
- Palliative care integration
- Hospice care transitions



Review of the Literature: Interventions and Predictors of Transition to Hospice for PLWD

2000-2023

Any interventions focused on hospice transitions and predictors of hospice transitions

PLWD and their caregivers

PubMed, CINAHL, Web of Science, Google Scholar, Cochrane Database

MeSH terms and key words: dementia, hospice care, transitions, care management and/or coordination.



Interventions and Predictors of Transition to Hospice for PLWD - Review of the Literature

16 articles

6 retrospective cohort studies
4 secondary data analyses
2 RCTs
2 qualitative studies
1 feasibility study
1 survey

Cross-sectional
Nursing homes
Hospital-based care
US and Europe

Interventions:

Video-assisted advance care planning, checklist-based care management, and triggered palliative care for those with late-stage dementia.

Predictors:

Increasing severity of illness including multisystem organ failure, transition to intensive care, do not resuscitate and life-sustaining treatment orders, insurance status, race and ethnicity, and caregiver burden.

Moderate to high quality evidence limited in scope, sample, and racial and ethnic diversity.

Disparities in Hospice Use at the End of Life for Persons Living with Dementia (PLWD)



Racial and ethnic disparities in dementia prevalence

Racial and ethnic disparities in hospice use

Need for diverse representation in studies

Serious illness communication

Goal-concordant care

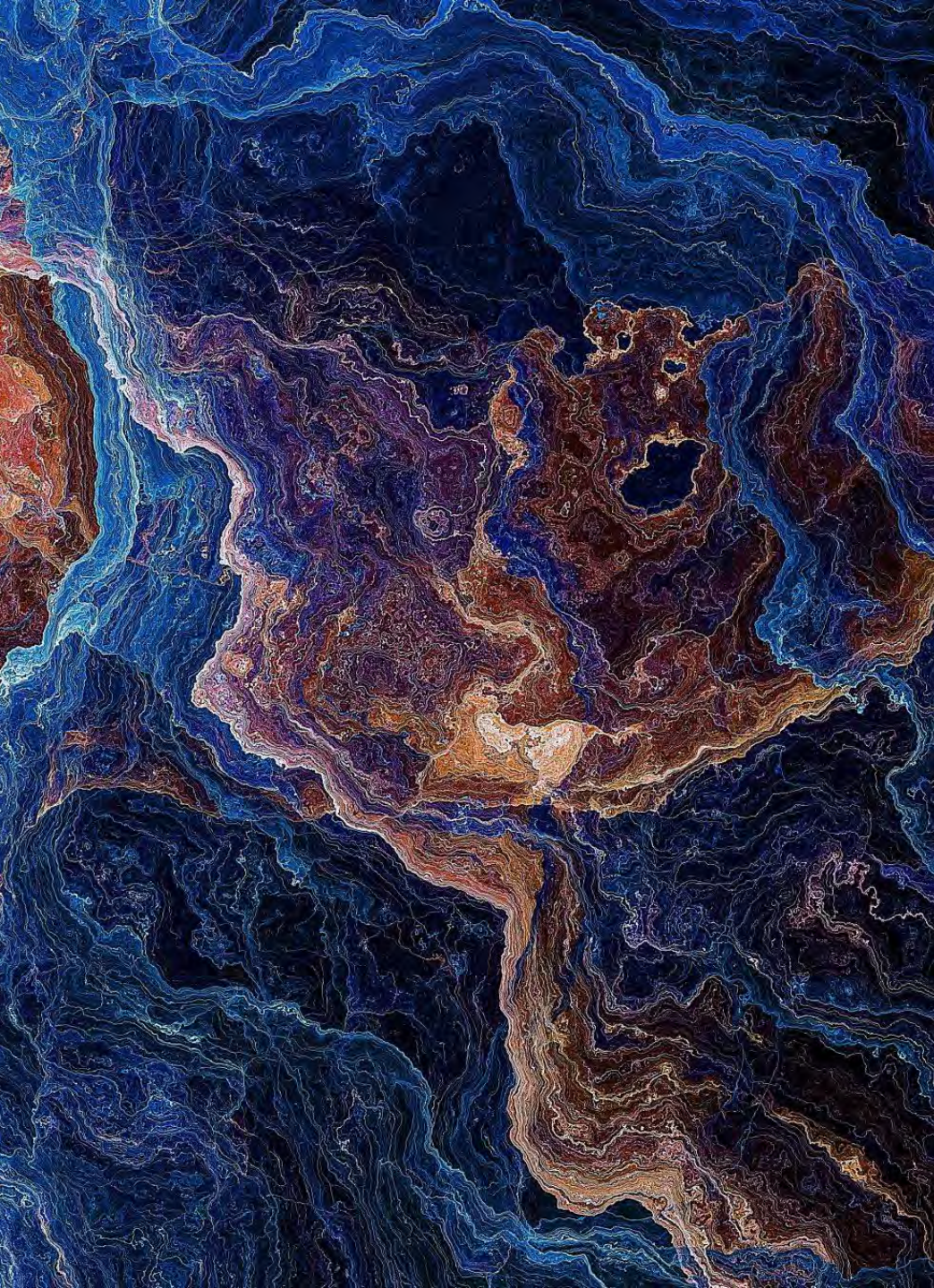
Culturally sensitive care

Lin et al., 2022 (JAMA Network Open); Osakwe et al., 2021 (HHC Now); Rhodes et al., 2022 (JPSM)



Significance

- PLWD make up one-third of the HHC population and is increasingly diverse.
- HHC has rapidly become an essential health care setting for delivering end-of-life care for PLWD and many transitions to hospice occur in this setting.
- Building equity-focused and culturally sensitive interventions for increasing hospice use from HHC is needed to advance dementia tailored and end-of-life care research.



Work in Progress

Barriers to Hospice Care Transitions for
Diverse Persons Living with Dementia

NIA IMPACT Collaboratory Career
Development Award



Design, Setting, and Participants

Exploratory Sequential Mixed Methods (Phase I – Qual)

HHC Setting in Greater New York City (VNS Health)

Care Partners of Persons Living with Advanced Dementia

Care Managers (Nurses and Social Workers)

HHC Providers (Nurse Practitioners and Physicians)

Advanced Illness Management Program Administrators

Conceptual Model

- EquIR – Equity Focused Implementation Research
- NIMHD and NIA Health Disparities Research Framework
- NIH Stage Model for Intervention Development

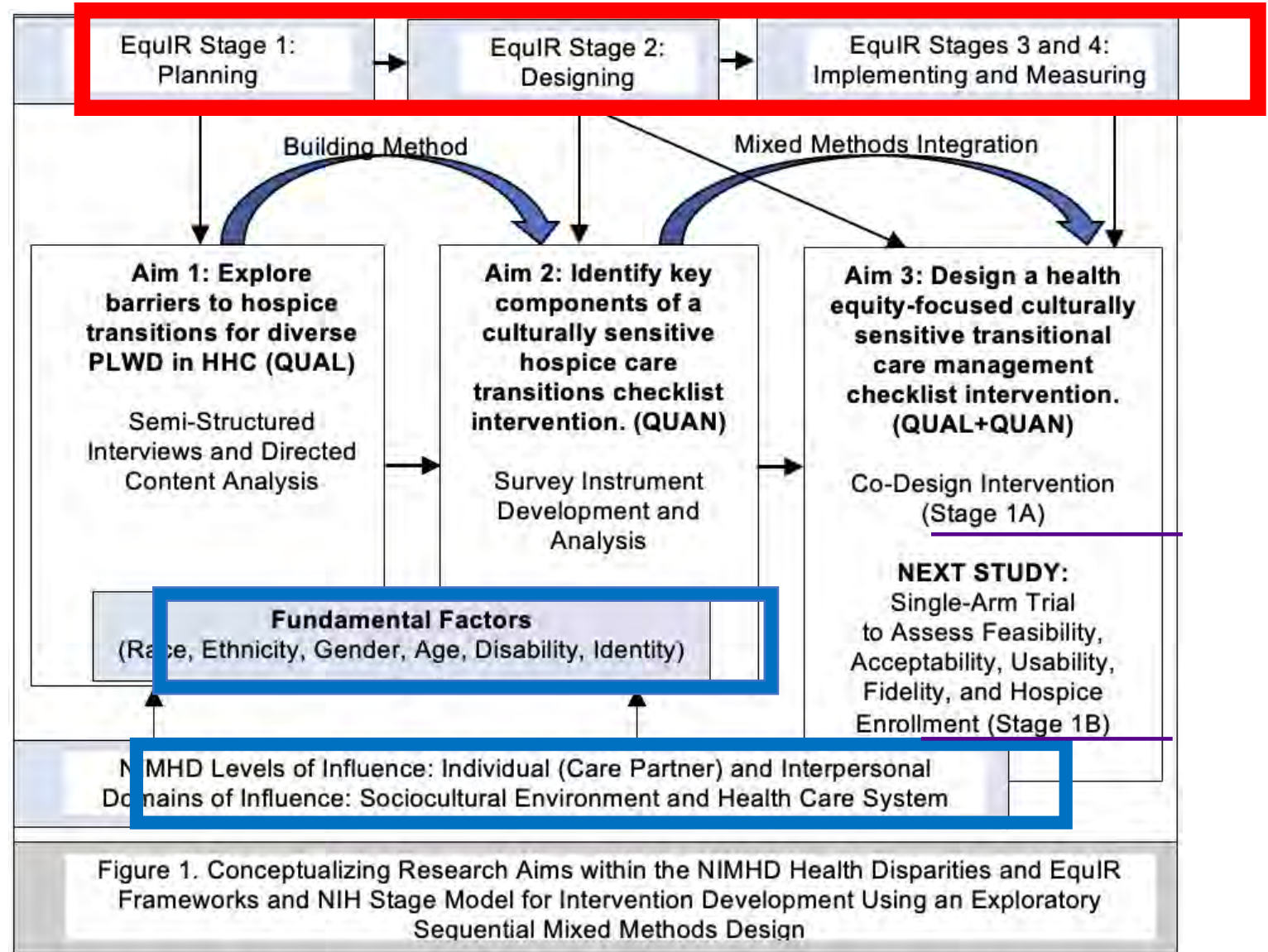


Figure 1. Conceptualizing Research Aims within the NIMHD Health Disparities and EquIR Frameworks and NIH Stage Model for Intervention Development Using an Exploratory Sequential Mixed Methods Design

Phase I – Qualitative (Semi-Structured Interviews)

Objective

- *Explore perspectives and experiences of care partners, HHC care managers, medical providers, and administrators related to hospice care transitions for racially and ethnically diverse PLWD.*

Methods



Semi-structured interviews with care partners, care managers, providers, and administrators (n=40)



Stratified sampling (Advanced dementia based on Quick Dementia Rating System and racial and ethnic minoritized PLWD)



Care Partners and PLWD (n=20, n=21)



HHC Professionals (n=12/20 Care Managers, Field RNs, MDs and NPs, Administrators)

Interview Guide Sample Questions (Care Partners)

- What is your understanding of hospice care?
- Have you had any experiences with hospice care with family members or loved ones in the past?
- How do you make decisions related to your loved one or family member about medical care in general?
 - Are there specific beliefs, values, priorities, preferences you have about hospice care, medical care, or end-of-life care? Example: dying at home, being around family, receiving comfort-oriented care, religious customs
 - If important to you, how can your home care clinicians help support your or your loved one's cultural, spiritual, and religious needs at this point in their illness?
- What would you like your home care providers to cover when providing education about or discussing hospice care for your loved one's care?
- **Prompt: How would you like that conversation to be delivered and by whom on the healthcare team?**
- **What would be helpful for you to know about a transition to hospice care?**
- **If a healthcare provider told you your loved one was eligible for hospice care, what are your thoughts about the transition to hospice care?**
- **What concerns or hesitations might you have about hospice care?**
- **What do you feel are some reasons you may decline hospice care?**

Phase I Participant Characteristics (Care Partners), n=20*

Age	
Mean Age	52.7
Age SD	16.2
Ranging from 22-80	
Race (n=)	
Black/AA	5
Non-Hispanic White	2
Hispanic White	3
Asian	7
Bi- Multi-Racial	2
Other (Indo-Caribbean)	1
Ethnicity (n=)	
Hispanic	5
Non-Hispanic	11
Other [Chinese, Indian, Filipino, etc]	4
Gender (n (%))	
Woman	16 (80%)
Man	4 (20%)

Education (n (%))	
HS or GED	4 (20%)
Some college	4 (20%)
Bachelor's	7 (35%)
Master's	3 (15%)
Professional/Doctorate	2 (10%)
Relationship to PLWD (n (%))	
Spouse	3 (15%)
Adult Child	12 (60%)
Niece/Nephew	1 (5%)
Grandchild	2 (10%)
Sibling	2 (10%)

Has a healthcare professional provided information to you or had a conversation with you about hospice care?
No 13 (62%)
Yes 8 (38%)

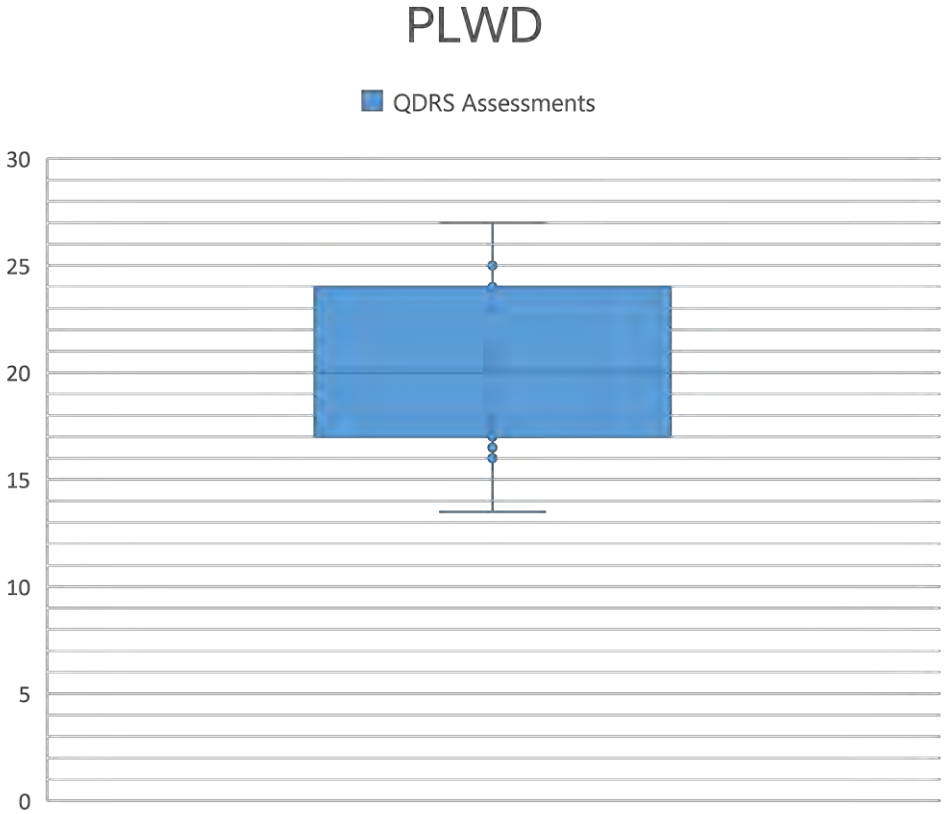
Phase I Participant Characteristics (PLWD), n=21

Mean Age	81.2
Age SD	8.57
Race (n=)	
Black/African American	5
Non-Hispanic White	2
Hispanic White	4
Asian	8
Bi- Multi-Racial	1
Other (Indo-Caribbean)	1
Ethnicity (n=)	
Hispanic	5
Non-Hispanic	10
Other [Chinese, Indian, Vietnamese, etc]	6

Gender (n(%))	
Woman	18 (85.7)
Man	3 (14.3)
Insurance (n(%))	
Medicare	4 (19%)
Medicaid	2 (9%)
Both - Dual Eligible	14 (67%)
Private/Commercial	1 (5%)

Length of time receiving home care	
<1 year	7 (33%)
1-5 years	8 (38%)
6-10 years	5 (24%)
>20 years	1 (5%)
Diagnosis Type (n=)	
Alzheimer's Disease	9
Dementia (NOS)	6
Early Onset Dementia	1
Lewy Body Dementia	1
Vascular Dementia	1
Parkinsons + Dementia	2

Quick Dementia Rating System (QDRS)



- Mean QDRS: 20.4 SD 3.74
- Min: 13.5, Max: 27
- Moderate Dementia: n=10
- Severe Dementia: n=10

Key Concepts
for Deductive
Coding and
Directed
Content
Analysis

EquiR Domains: Planning and Designing + NIMHD Levels of Influence		
	<u>Individual (Care Partner)</u>	<u>Interpersonal</u>
Sociocultural Environment (Home)	Sociodemographics SDOH Language Cultural Identity Family Dynamics Discrimination	PLWD-Care Partner Relationship Prior Stated Wishes of the PLWD Understanding of Prognosis Cultural, Religious, Spiritual Beliefs
Health Care System (HHC)	Hospice Knowledge Care Preferences Hospice Decision-Making Burden of Care	PLWD-Care Partner Relationship with HHC Clinicians Hospice Decision-Making HHC Clinician Preparedness

Care Partner Findings

1

Despite general openness to hospice, there was variable knowledge including misconceptions that it could not be received in the home

2

Limited knowledge of dementia illness trajectories and end-of-life care options including hospice

3

Communication challenges and conflicts associated with family-decision making

4

Care coordination challenges and limitations of health insurance coverage and access to dementia caregiving support and resources

5

Unmet cultural aspects of care and language barriers

6

Desire to honor and balance prior stated wishes of PLWD with end-of-life dementia care and decision-making

Representative Quotes

Preference for home hospice:	“Hospice begins at home and it's gonna end at home. And I'll bring whatever machine I need to bring in here, and we'll have it set up however it needs to be set up, and we will do what we need to do.”
Culturally specific dietary concerns:	“So it's too difficult. And then she don't—she can't eat the American food. She only eat Asian food. And it's difficult for me to two to three times make the food and send it to the nursing home and visit her. That's why I make the decision to take her home.”
Misconception about hospice care:	“No personal experience with hospice care. Um, as far as I understand hospice care, it's not in the home, it's in an institution. I don't know if I'm correct about that...they kind of do everything for the patient...but, unfortunately...it would be strangers doing it.”
Language barrier and family communication:	“Then the last one, for us, and it's probably a big one for a lot of the people that you'll end up in the study, being of two very separate generations. So, you know...while I speak Mandarin and Cantonese, it is not the language where I can best articulate myself so the communication between my siblings and I and my mother are very different.”
Limited hospice knowledge:	I would need somebody to tell me, you know, all about it. What happens? Is it in hospital? Is it at home? When does it start? How does it start? Who takes care of her? How do they take care of her? What do they do for her? How does it get paid for? What decisions can the family make? I mean, I do have power attorney and healthcare proxy over my mom, but how are we included in the decisions?
Dementia-related coordination issues:	“I'm the caregiver. You could just speak with me,” and they're like, “Oh, no, we need authorization from her [PLWD].” And then we just go on this cycle where it's never gonna be paid because she can't give consent. So I wish that there were things on file or they woulda just told them—easier way for things to be organized in the healthcare system- and get some feedback right there, that would be wonderful.”
Desire for fair and ethical treatment:	“And they [PLWD] should be treated fair and ethically across the board. It's not whether I come every day and check on my mom and so you treat her good because you figure the family is comin.”

Interview Guide Questions (HHC Professionals)

- People with dementia often have unpredictable illness trajectories. What has been your experience with hospice transitions for people with dementia and their families?
- In your experience, have patients and family members been receptive to hospice education and conversations about hospice? What does this typically look like?
- When someone declines hospice care, from your experience, what are the common reasons as to why?
- When counseling a caregiver of someone living with dementia, how do you assess for additional support they might need to prepare for decision-making and caregiving at the end of life?

Phase I Participant Characteristics (HHC Professionals, n=12)

Age		
Mean Age		50.2
Age SD		9.4
Race (n=)		
Black/AA		4
Non-Hispanic White		2
Hispanic White		3
Asian		1
Bi- Multi-Racial		2
Ethnicity (n=)		
Hispanic		4
Non-Hispanic		6
Other [Chinese, Guyanese, etc]		2
Gender		
Woman		11
Man		1

Education	
Some college	2
Bachelor's	6
Master's/Doctorate	4
Number of Years at Agency	
1-10 years	7
11-20 years	4
over 20 years	1
Number of Years in HHC or Hospice Transitions	
1-10 years	3
11-20 years	5
over 20 years	4
Professional Role	
CHHA Field Nurse/Care Manager	2
Nurse Practitioner	2
Administrator	2
AIM Liaison Care Manager	6
MD	pending



HHC Professional (Preliminary Findings)

- Unique challenges pertaining to dementia decision-making (often referred to as the most difficult cases)
- Striving for cultural sensitivity but general lack of standards and guidance
- Relationship building is key
- Prefer more involvement from referring physicians and NPs re: hospice transitions
- Fear, cultural beliefs, and limited hospice knowledge are common reasons why people decline
- Checklists and conversation starters would be helpful in the algorithm (without additional burden in the work-flow)

Representative Quotes

They trust their doctors who have not ever spoken about that aspect of care for them, or that there's a potential that this might end up...being a situation that will require services for hospice. So, first of all, it's rejection. They reject me. They reject the concept of hospice, but over a period of follow-up calls with them and care managing them, they start to have a little bit of trust...they might become more open to even listening to me and listening to the benefits...

–Care Manager

“I see a lot of confusion. I see...a lot of hope, which we would all have, right, what we would hope to have. And then those moments can...make a person believe, well, this could be remedied, right? Like my parent can get better. And it's having that empathy but also trying to give as much clarity as possible.”

–HHC Administrator

“I think...culturally, being African American myself, a lot of the times family members are like, oh, this is just another program for you guys to make money. ...I don't think my mom is really the focus of this program...Unfortunately, lack of education, socioeconomic status, those things are also sometimes barriers as well because they just don't know. They don't know the resources.”

–HHC Nurse Practitioner

“The barriers that I find are because hospice criteria is based on the physical deterioration, I can find that I feel somebody is failing to thrive, but because they're not medically in that state, they are still not qualified. And that's probably my biggest...biggest barrier that I've found.”

–HHC Field Nurse



Next Step: Phase 2 – Quantitative (Survey)

Objective

- *Survey care partners, care managers, and providers about key components of a transitional care checklist intervention to deliver culturally sensitive care prior to hospice.*

Methods

- Survey instrument development will be informed by qualitative findings (e.g., building method)
- The survey will be cognitively tested and administered to a care partners, care managers, and providers
- Participants will be sampled from the VNS health
- EHR

Final Step: Phase 3 – Intervention Co-Design

Objective

- *Design a culturally sensitive hospice transitions care management algorithm and checklist to guide transitional care to hospice for PLWD and their care partners.*

Methods

- Integrated mixed methods (e.g, joint display) findings will be used for the development of a culturally sensitive hospice transitional care management checklist prototype
- 2 Focus Groups (n=22) with care partners, care managers, providers, and administrators
- Prototype Feedback (Focus Group 1)
- Refinement and Implementation (Focus Group 2)

Acknowledgements

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Thank You!



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APPROACHES

*Aligning Patient Preferences
– a Role Offering Alzheimer’s
patients, Caregivers, and
Healthcare providers
Education and Support*

Susan Hickman, PhD & Kathleen Unroe MD, MHA
Indiana University

IU Center for Aging Research at
 Regenstrief Institute

The APPROACHES Team



Kathleen Unroe, MD, MHA
Co-Principal Investigator



Susan Hickman, PhD
Co-Principal Investigator



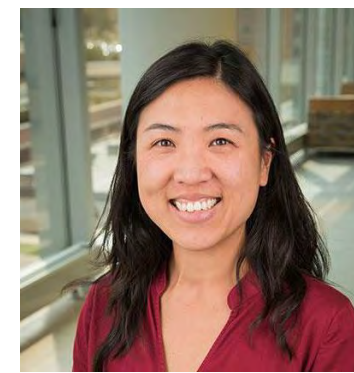
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Abby Evans
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APPROACHES – Pragmatic Trial, NIH funded

R21 phase (18 months)

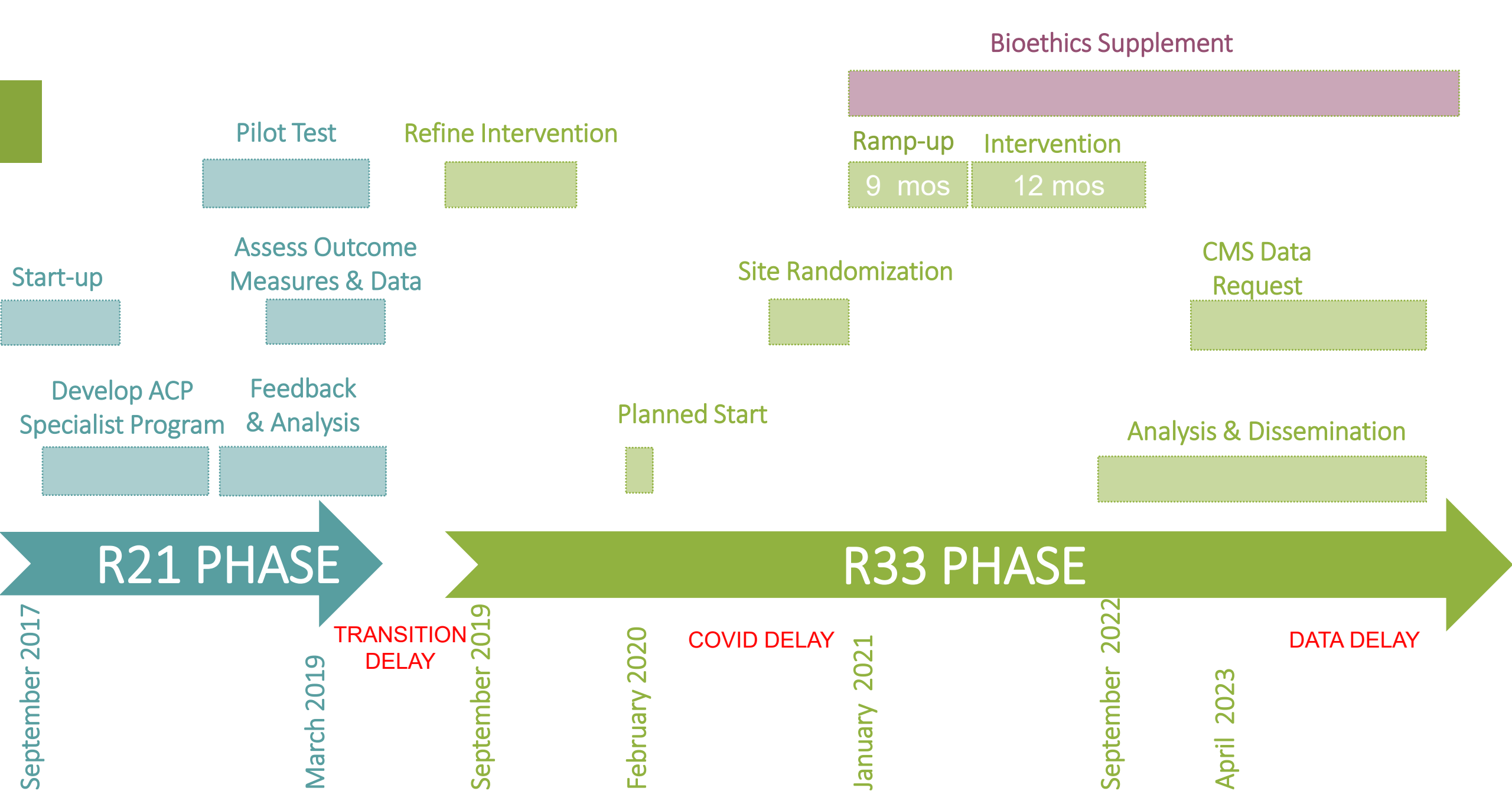
Aim 1: *To establish the organizational infrastructure and programmatic processes needed to conduct a pragmatic RCT of APPROACHES for NH patients with ADRD in partnership with 3 regional NH corporations.*

Aim 2: *Pilot test the APPROACHES study protocol for the intervention arm in 4 NHs and refine the protocol as needed.*

R33 phase (42 months).

Aim 3: *Compare hospital transfers (admissions and emergency department visits)/1000 person-days alive between ADRD patients in intervention vs. control NHs over 12 months (**Primary trial outcome**)*

Aim 4: *Compare the following secondary outcomes between ADRD patients in intervention vs. control NHs over 12 months: 1) ACP preferences documentation: % ADRD patients with do not resuscitate, do not hospitalize, no tube-feeding, or do not intubate orders, and Physician Orders for Life-Sustaining Treatment forms; 2) hospice enrollment; 3) death in hospital; and 4) satisfaction with care (family surveys).*



The ACP Specialist Program

- Aim to offer all residents the **opportunity to engage in ACP**
- Key members of the nursing facility team were **trained in ACP**
- ACP Specialists **served as internal champions**
- The ACP Specialists and nursing facility leaders **collaborated to implement policies and procedures** to support ACP processes
- The ACP Specialists **promoted strong communication** between staff and medical providers regarding patient goals for care

ACP Specialist Program Structure

- Support from a corporate champion for implementation of the ACP Specialist Program
- Use of documentation template in the Electronic Health Record to record ACP outcomes
- Tracking tools to organize ACP work
- Monthly resident assignment lists that will allow the ACP Specialist to systematically and proactively approach residents, as well as responding to requests for ACP facilitation
- Resources to share with residents and families about ACP treatment decisions and tools to document preferences
- Discussion of ACP activities at facility quality assurance meetings



ACP Specialist Role

- 1-2 ACP Specialists per building
 - Interdisciplinary existing staff
 - ~20% dedicated FTE
- Approximately 6 hours of online training
- ACP champion and resource for the building
- Facilitate ACP conversations
- Structured, supported and proven approach



ACP Specialist Training Content Overview


The following list contains the modules the ACP Specialist completed following launch.



- 1 ACP in Nursing Facilities
- 2 Person-Centered Goals of Care
- 3 Identifying and Supporting Surrogate Decision-Makers
- 4 ACP Tools
- 5 Engaging Your Team
- 6 ACP Facilitation Skills
- 7 Putting It All Together | Getting Started with ACP



Newsletter Examples



ADVANCED CARE PLANNING NEWSLETTER
October 2021

Training Highlight

Learning Modules

Have you completed yours?

- If not, get them done ASAP

Key Leaders Module can now be completed via YouTube:

- <https://youtu.be/mfA70dvUk2c>

Facility Stories

ACP Specialists worked with a resident that was in obvious decline. After two weeks of speaking with the resident, medical provider and family the decision was made to make a DNR. Two days later the resident was allowed to have a peaceful death as per their wishes.

ACP Specialist worked with resident, medical provider and family and determined that a DNR status was best for them.

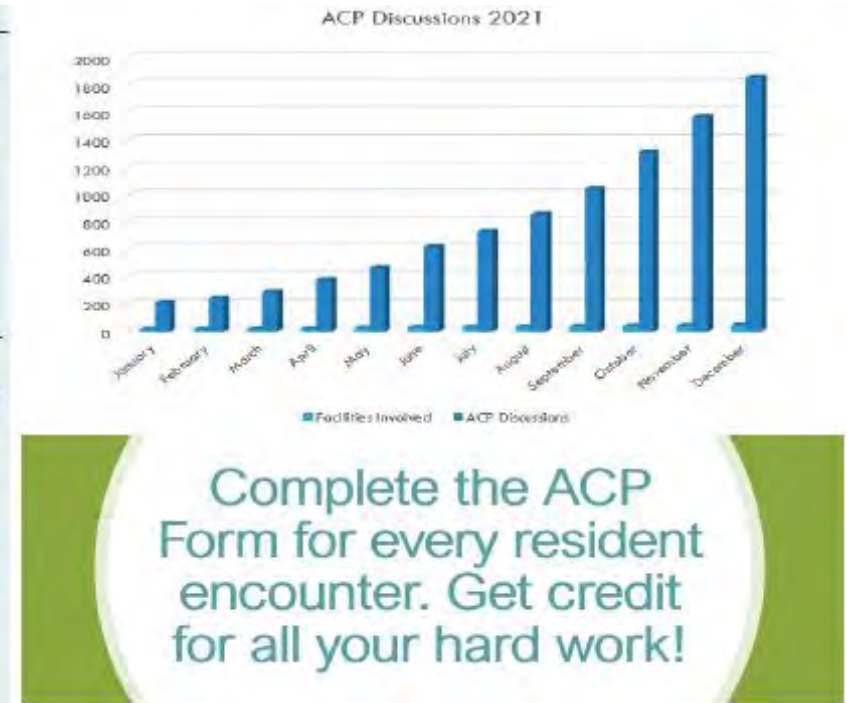
ACP Specialists worked with resident and family, the resident determined that they wanted to be a full code and not a DNR. Resident felt the hospital did not do a good job explaining what a DNR meant and felt it was not yet time to be a DNR.

Have you shared the Brochure with your residents, families?

Have you engaged your staff?

Monthly Check-ins

- All facilities are scheduled
- Please try and attend
- Only 5-10 minutes to review your facilities program



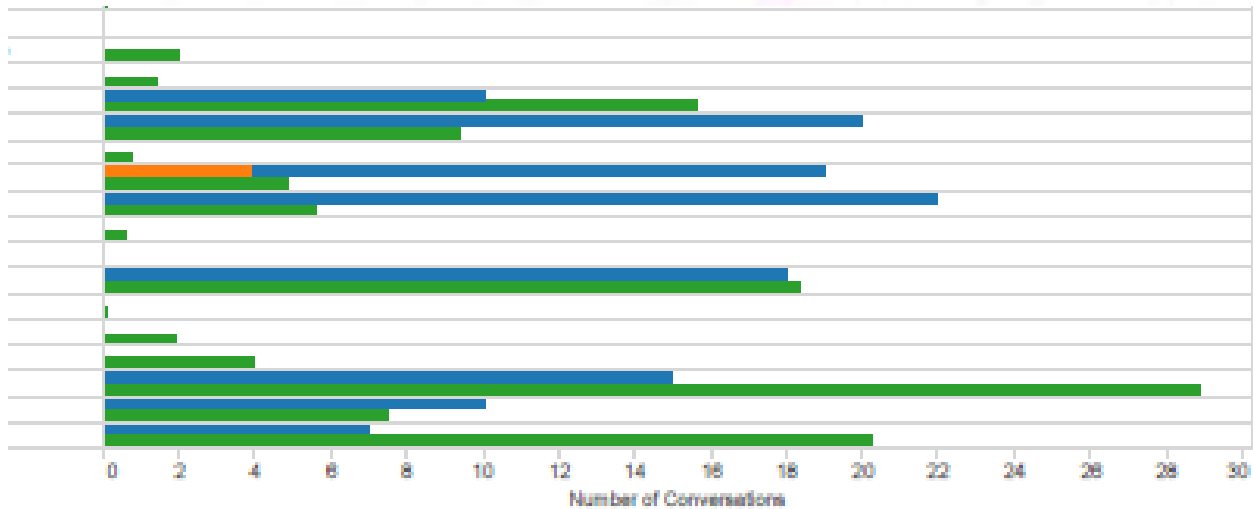
Monthly Progress Reports

Conversation Summary Additional information

Conversation Summary

Facility Name

■ This month: Number of conversations occurred
■ This month: Number of conversations attempted
■ Prior months: Average conversations per month



	June Status	July Status	August Status	August Conversation Numbers (attempts)	How to Improve
	Yellow	Yellow	Yellow	0	Facilitate conversations and record details in the Matrix ACP form
	Green	Green	Green	3	Top Performer
	Green	Green	Green	5	Top Performer
lab	Red	Red	Red	0	Facilitate conversations and complete training
center	Yellow	Yellow	Yellow	7	Complete full ACP Training
	Yellow	Yellow	Yellow	1	Complete full ACP Training
r	Green	Green	Green	24	Top Performer
er	Yellow	Green	Yellow	0	Facilitate conversations and record details in the Matrix ACP form
r	Yellow	Yellow	Yellow	0	Facilitate conversations and record details in the Matrix ACP form
	Yellow	Yellow	Yellow	0	Facilitate conversations and record details in the Matrix ACP form
r	Green	Green	Green	9(1)	Top Performer
	Green	Green	Green	4	Top Performer
	Green	Green	Green	22(1)	Top Performer
	Green	Yellow	Green	2	Top Performer
	Yellow	Yellow	Yellow	0	Facilitate conversations and record details in the Matrix ACP form
ab &	Green	Green	Green	8	Top Performer
hab	Yellow	Yellow	Red	0	Complete full ACP Training
ab &	Red	Red	Red	0	Facilitate conversations and complete training

Pragmatic Outcomes Assessment

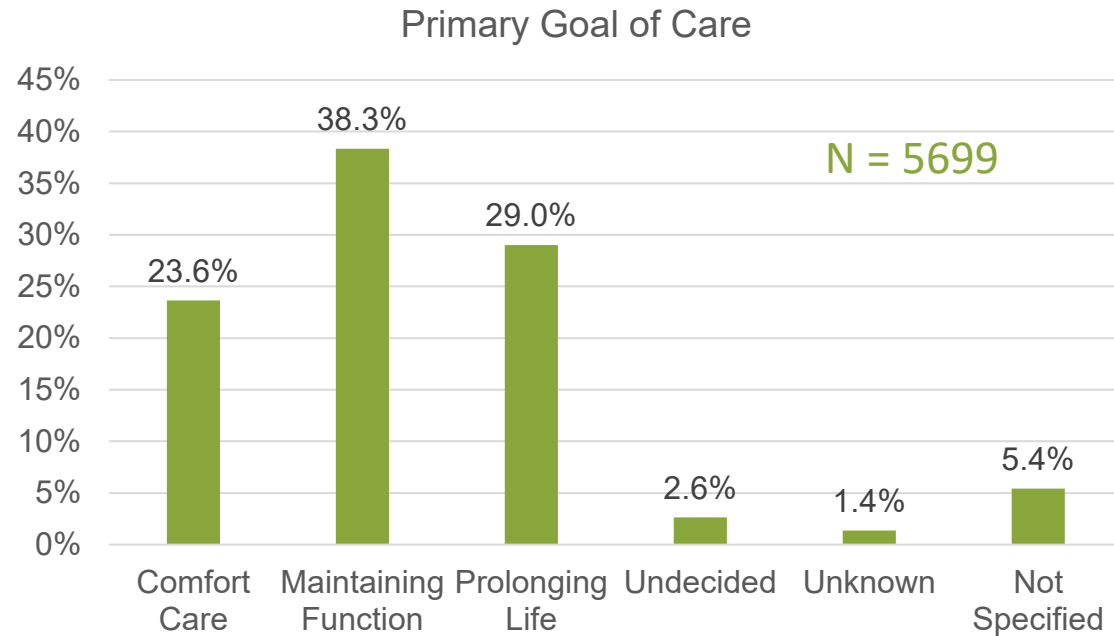
- **ACP Encounter Form**
 - Documentation about discussion and decisions
 - Transferred monthly through secure data transfers
 - Used to feed dashboard to track progress
- **Medicare claims data & MDS data**
 - Primary outcome = hospital transfers (admissions and emergency department visits) per 1000 person-days

Number of Trained ACP Specialists & Conversations Completed

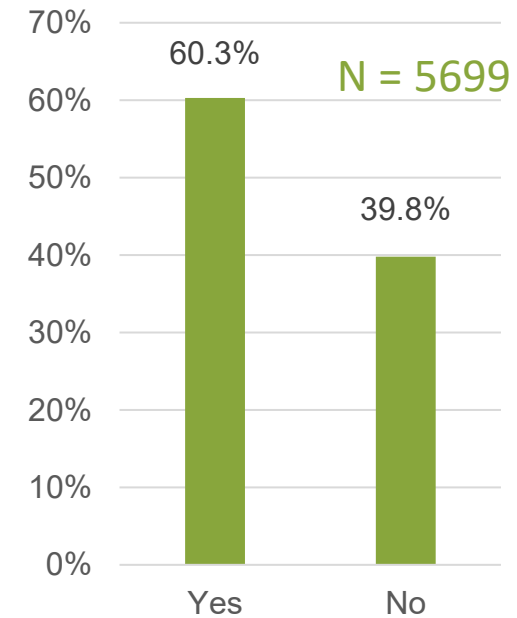
Data as of August 31, 2022

Target N=64			
Facilities with conversations recorded in the EHR N=59			
Facilities with 0 conversations recorded in the EHR N=(5)			
Buildings with 0 trained ACP Specialists	N= 1(4)	Conversations recorded in the EHR	N=8
Buildings with 1 trained ACP Specialist	N= 22(1)	Conversations recorded in the EHR	N=1732
Buildings with 2 trained ACP Specialists	N= 22	Conversations recorded in the EHR	N=2442
Buildings with 3+ trained ACP Specialists	N= 14	Conversations recorded in the EHR	N=1517
Total buildings	N= 59(5)	Total conversations recorded	N=5699

Currently Available Outcomes

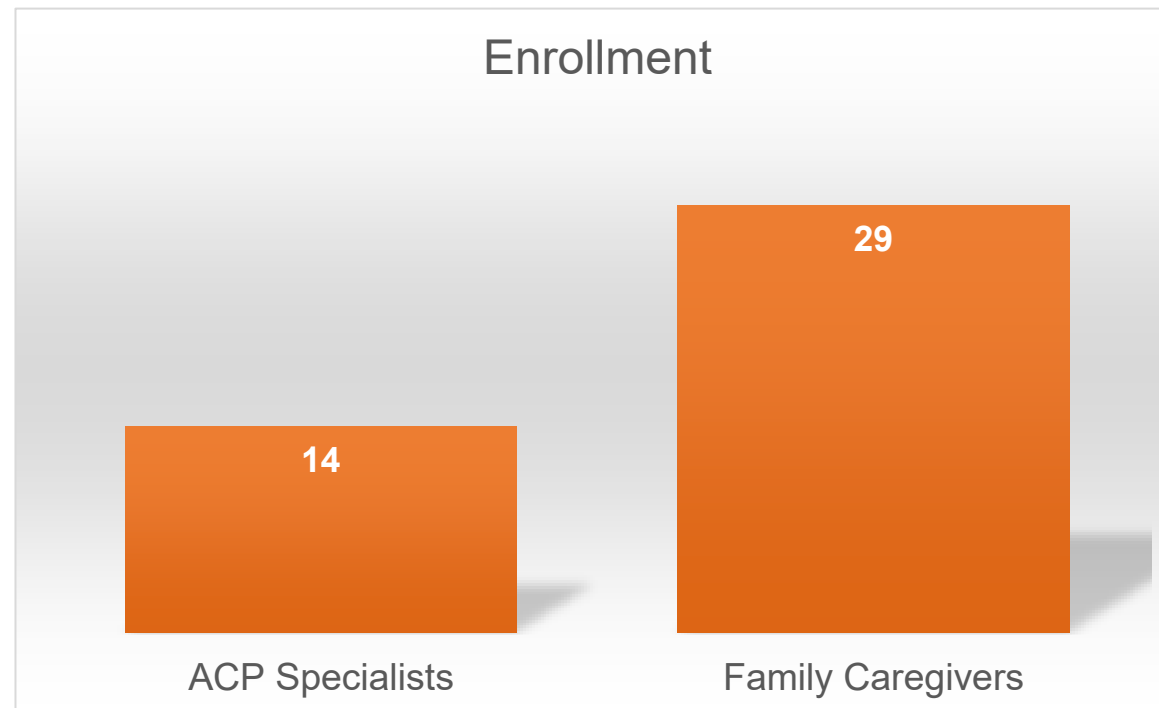


Is the resident able to make their own medical decisions?



Bioethics Qualitative Supplement

Advance care planning from the perspective of nursing home staff and the family caregivers of residents with Alzheimer's disease or related dementias.



Key Lessons Learned

- Keep a short-list of alternative partners
- Arm corporate champions with tools/be prepared for substantial support of champions
- Supplements as a complement to a pragmatic trial to add primary data collection
- Need for streamlined approaches for data acquisition



GUIDE to Identify Barriers and Enablers to Implementing Advance Care Planning Video Intervention in Nursing Homes

Latarsha Chisholm, Ph.D., M.S.W.

Associate Professor

School of Global Health Management & Informatics

University of Central Florida

Advance Care Planning (ACP) in Nursing Homes (NHs)

Advance Care Planning (ACP)

- ACP is a process that supports sharing of goals and treatments.
- ACP discussions are associated with palliative outcomes.
 - NHs are required to have these discussions.
- ACP discussions remain inconsistent across NHs.

ACP Video Interventions

- Low-cost strategy to promote ACP discussions
- Little information on how to implement ACP

Implementation of Evidence-Based Interventions

- Limited uptake of evidence-based practices:
 - Gitlin et al., (2014) found there are more than 200 dementia care interventions, but few implemented.
 - 17 years for research to reach practices.
- Not all organizations are the same:
 - Enablers and barriers to implementation
 - Implementation strategies
 - Flexibility in implementation protocol
 - Intervention fidelity



Study Objectives

To assess barriers and enablers to implementing ACP video intervention in nursing homes.

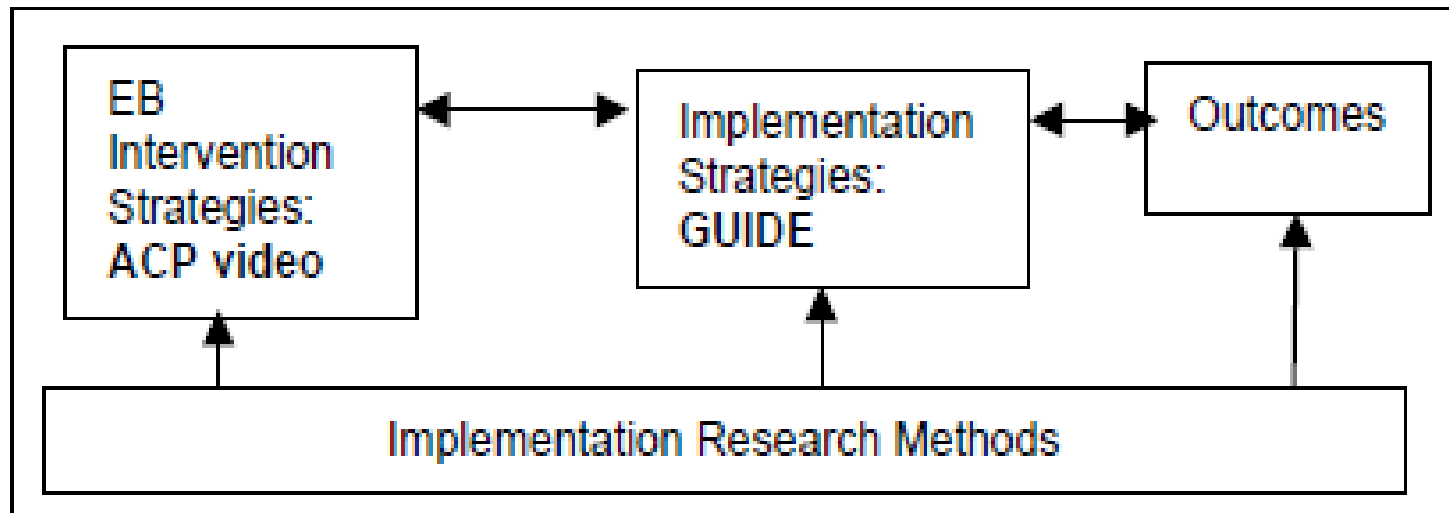
To identify implementation strategies to mitigate barriers.

To develop the **Guide Uniform Implementation Document Evaluation (GUIDE)**.

Data Collection

- Conducted face-to-face or Zoom semi-structured interviews at 4 Florida nursing homes between September 2023-April 2024
- Sample (n=9)
 - 3 Social service
 - 4 Nurses
 - 1 Physical therapy
 - 1 Administrator in training

Proctor's Implementation Framework



Guide Uniform Implementation Document Evaluation (GUIDE) Development

Consolidated Framework Implementation Research (CFIR)

Intervention Characteristics:

- Stakeholders' perception of the intervention

Outer Setting:

- External barriers and enablers

Inner Setting:

- Internal barriers and enablers

Characteristics of the Individual:

- Individual factors that may hinder or enable implementation



Identify barriers and enablers to ACP video implementation (Hickman et al. 2023)

Data Analysis

01

Review enablers and barriers from semi-structured interviews.

02

Enter barriers in Excel for each NH.

03

Map the barriers to ERIC implementation strategies using the Powell et al. 2015 article and the CFIR-ERIC mapping tool

- [Strategy Design – The Consolidated Framework for Implementation Research \(cfirguide.org\)](https://cfirguide.org)

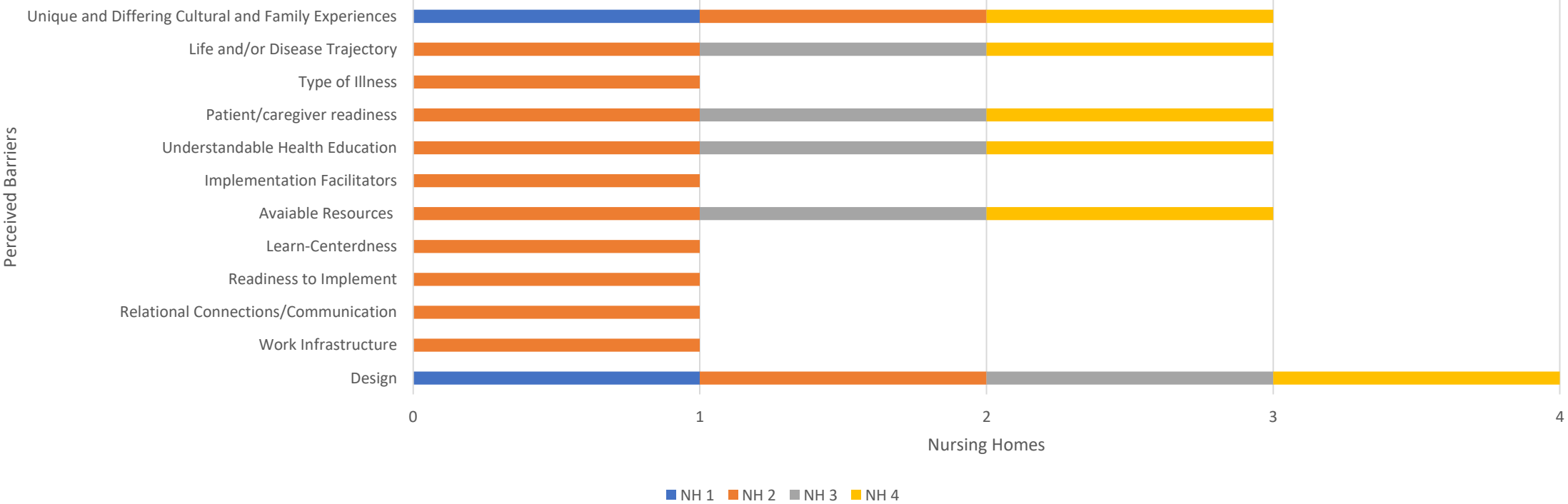
ERIC Taxonomy

- Key compilation of 73 implementation strategies
- Developed by a panel of implementation science and clinical practices experts
- Strategies to improve the adoption, implementation, sustainment, and scale-up of evidence-based interventions
- Can be used to customize implementation protocols

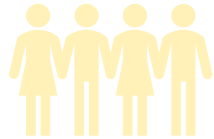
Results: Barriers and ERIC Strategies

Barriers by Nursing Homes

NH Staff Perceived Barriers to Implementing an ACP Video Intervention



Common Barriers Across Nursing Homes



Inner Setting

Affordable Resources



Characteristics of the Intervention

Intervention Design



Characteristics of the Individual

Understandable Health Education

Patient Caregiver/Readiness
Unique and Differing Cultural and Family Experiences
Life and Disease Trajectory

Implementation Strategies

Barriers	Implementation Strategies
1. ACP video design	<ul style="list-style-type: none">• Promote adaptability
2. Understandable health education	<ul style="list-style-type: none">• Develop and implement tools for quality monitoring
3. Affordable resources	<ul style="list-style-type: none">• Access new funding• Change physical structure and equipment• Alter incentive/allowance structures
4. Patient/caregiver readiness	<ul style="list-style-type: none">• Assess for readiness and identify barriers and facilitators
5. Unique culture and family experiences	<ul style="list-style-type: none">• Develop educational materials• Involve patients/consumers and family members• Obtain and use patients/consumers and family feedback• Use advisor board and workgroups
6. Life and disease trajectory	<ul style="list-style-type: none">• Conduct educational meetings• Develop educational materials

Discussion

- Identifying barriers and enablers can assist with developing implementation strategies to improve implementation.
- While barriers vary across nursing homes, some barriers are similar across facilities.

Implications

- Assessing barriers and enablers prior to implementation can be useful for identifying implementation strategies to mitigate potential barriers.
 - Gives a “voice” to key stakeholders.
- Customized implementation protocols can be developed for nursing homes that may have more or less challenges during the implementation process.
 - Not all nursing homes are the same.

Next Steps

- Complete semi-structured interviews with ACP champions.
- Have another team member review and identify barriers and enablers.
- Develop the GUIDE.
- To conduct online surveys with each nursing home care plan teams to assess perceptions of the GUIDE and ACP video.



UCF

Thank you!

Questions

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Session 2:

METHODS: Advancing the electronic health record platforms to improve outcome ascertainment in ePCTs



NIA IMPACT
COLLABORATORY
SCIENTIFIC CONFERENCE

Moderator: Leah Hanson, PhD – HealthPartners Institute

Presenters:

Sudeshna Das, PhD – Massachusetts General Hospital, Harvard Medical School

Ellen McCreedy, PhD, MPH – Brown University School of Public Health

Natalie Ernecoff, PhD, MPH – RAND Corporation

Robert Y. Lee, MD, MS – University of Washington

Dae Hyun Kim, MD, MPH, ScD – Hebrew SeniorLife's Marcus Institute for Aging Research, Harvard Medical School

Panelists:

Joshua Niznik, PharmD, PhD – The University of North Carolina at Chapel Hill

David Dorr, MD, MS – Oregon Health & Science University

V.G. Vinod Vydiswaran, PhD – University of Michigan

A Deep Learning Algorithm to Detect Signs of Cognitive Impairment in Electronic Health Records

SUDESHNA DAS, PHD

Department of Neurology

NIM Impact Collaboratory Scientific Conference

April 3, 2024



What is the problem?

- 50% of patients with cognitive impairment remain undiagnosed or have a delayed Dx
- Even when they are diagnosed, the most common Dx is “Dementia unspecified”

GOAL - Formalized Dx in clinical records, which is important for

Clinical care

- Planning and management of patient care
- Reduce the incidence, severity, and/or duration of delirium in ED/Surgery
- Prevention of prescription errors (e.g., antipsychotics for patients with DLB)

Research studies & clinical trials

- Studies of risk factors
- Drug repurposing
- Health policy questions
- Recruiting for research studies and trials

What types of methods are used for ADRD Dx?

GOLD STANDARD



Clinical Diagnosis



Neuropsychological
Testing



Biomarkers
that Measure
ADNC

**HOW CLOSE CAN WE GET
TO A GOLD-STANDARD
DX??**



Real World Data
(Electronic Health
Records,
Wearables, and
Sensors)



Increasing levels of accessibility

eRADAR: A Tool Using EHR Data to Detect Unrecognized Dementia

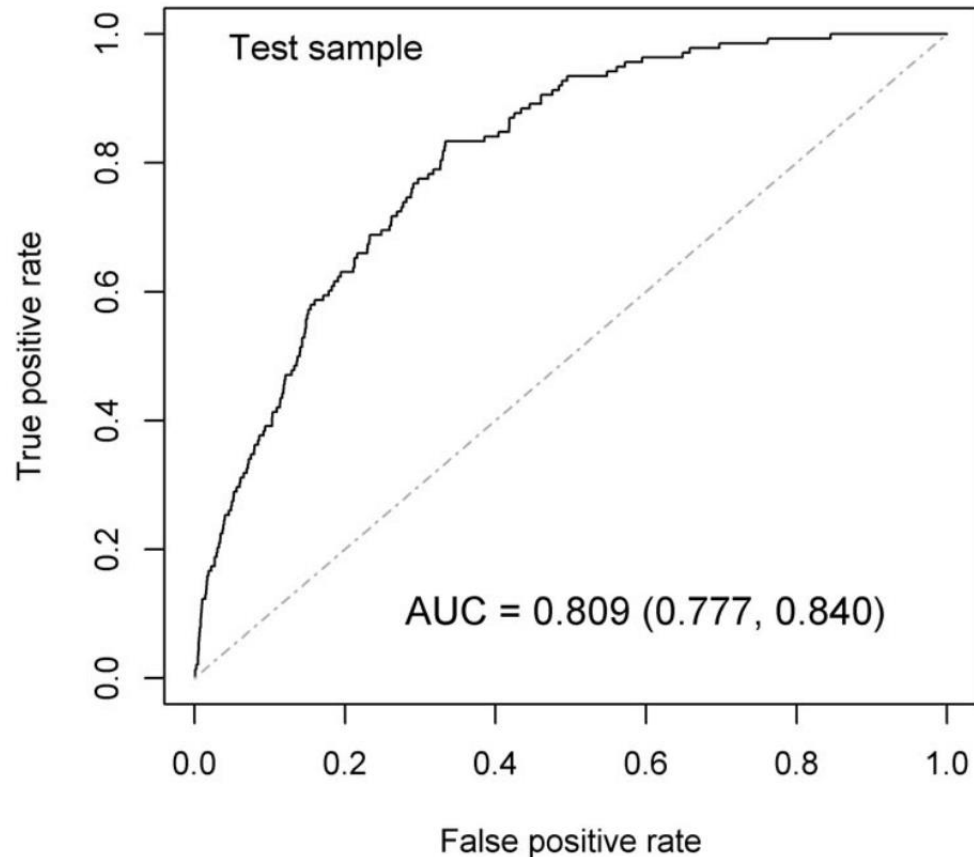


Table 3. Key predictors of undiagnosed dementia in the electronic health record

Dementia Risk Factors

- Congestive heart failure
- Stroke
- Diabetes
- Traumatic brain injury
- Gait abnormality

Dementia-Related Symptoms

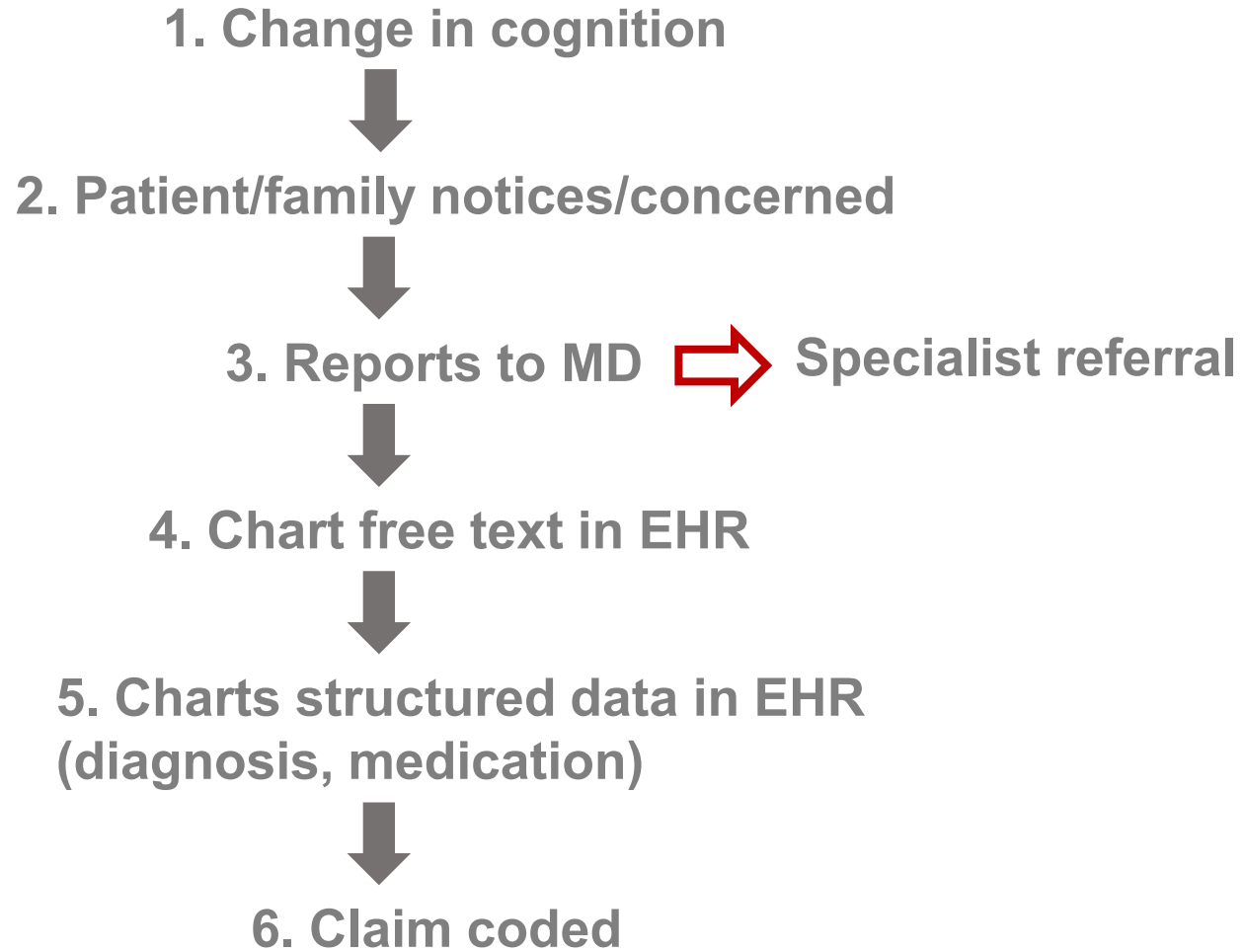
- Psychosis
- Nontricyclic antidepressant fills
- Underweight

Healthcare Utilization Patterns

- Emergency department visits
- Clinic no shows
- Potentially avoidable hospitalizations
- Medication nonadherence

Barnes, D.E 2020. Development and Validation of eRADAR: A Tool Using EHR Data to Detect Unrecognized Dementia. J Am Geriatr Soc 68, 103–111.

Is there information about cognition in EHR?

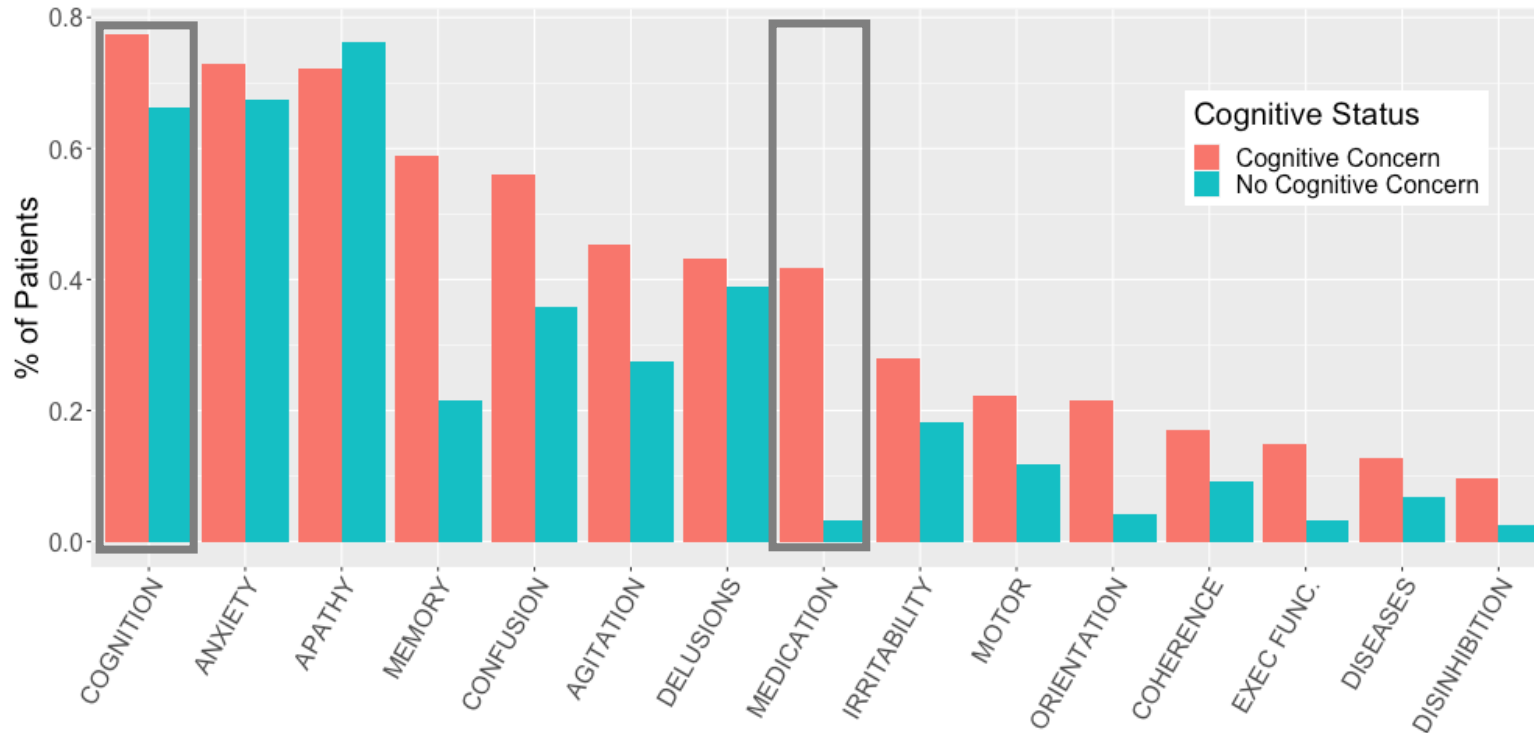


- Formal Dx is widely available to clinicians as well as research studies.
- Information on cognitive dysfunction is often found in unstructured clinician notes
- Automated mining of these notes and EHR data presents a potential opportunity to label patients with cognitive impairment who could benefit from an evaluation or be referred to specialist care AND to provide better phenotyping for research studies using EHR

Credits: Deborah Blacker, MD, ScD

Is there information in clinical notes?

Percentage of Patients with at Least One Category Match



REGEX CATEGORIES: GILMORE-BYKOVSKYI et al. J AM MED INFORM ASSOC. 09/01/2018

Regular Expressions Lasso Model Performance

AUC	Accuracy	Sensitivity	Specificity	PPV	NPV
0.88	0.84	0.76	0.91	0.97	0.83

Deep Learning Embeddings: Sentences with COGNITION

No Cognitive Concerns

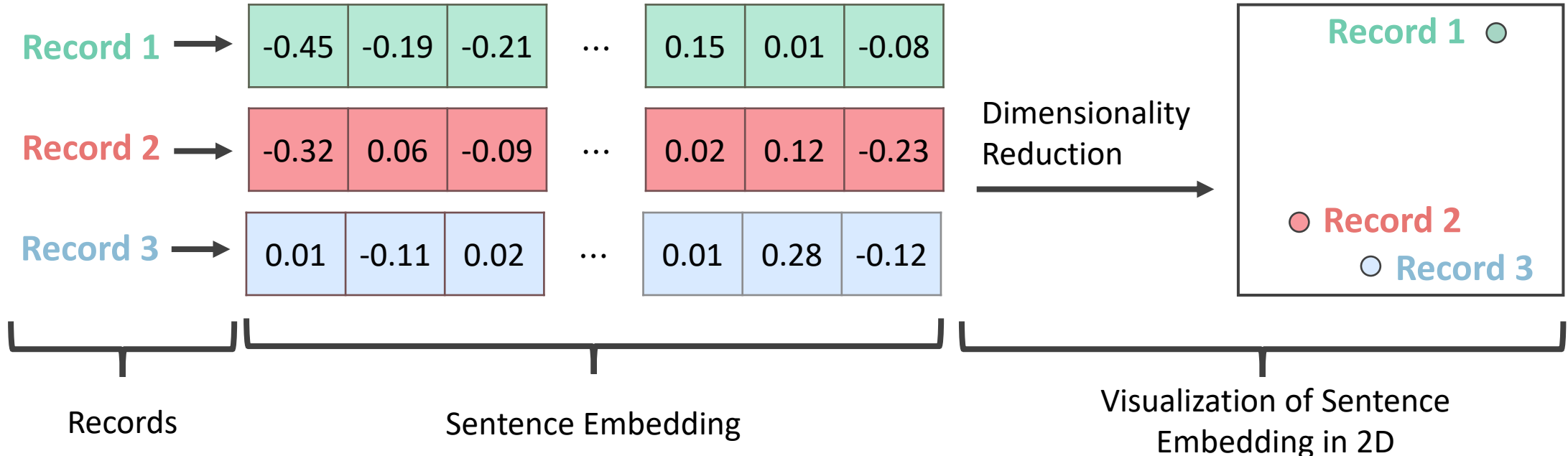
Record 1: "...Based on detailed report, **intact cognition**, no prior hx of CVA..."

Cognitive Concerns Presents

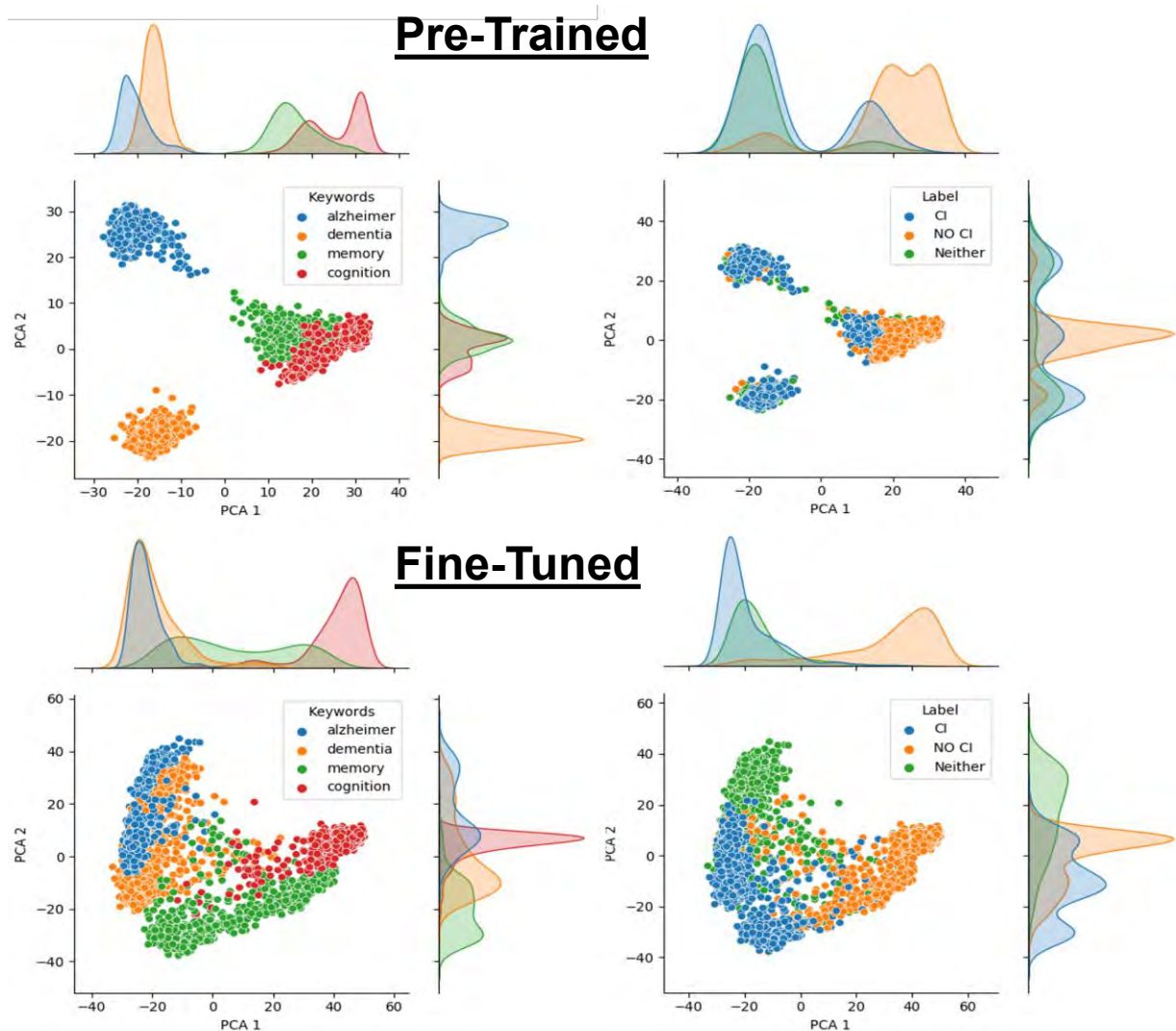
Record 2: "A 81 y.o. female who presents to PT with **impaired cognition**"

Neither

Record 3: "**Mother had cognition** problems in her 70s"



Principal component projections of pre-trained and fine-tuned embeddings



Plots on the top are the Pre-Trained **ClinicalBERT** model and the bottom are the Fine-tuned model

The plots are the principal component projections of embeddings of notes with keywords Alzheimer, dementia, memory, and cognition.

Plots on the left are colored by the keywords and the plots of the right are colored by label: CI, No CI, Neither

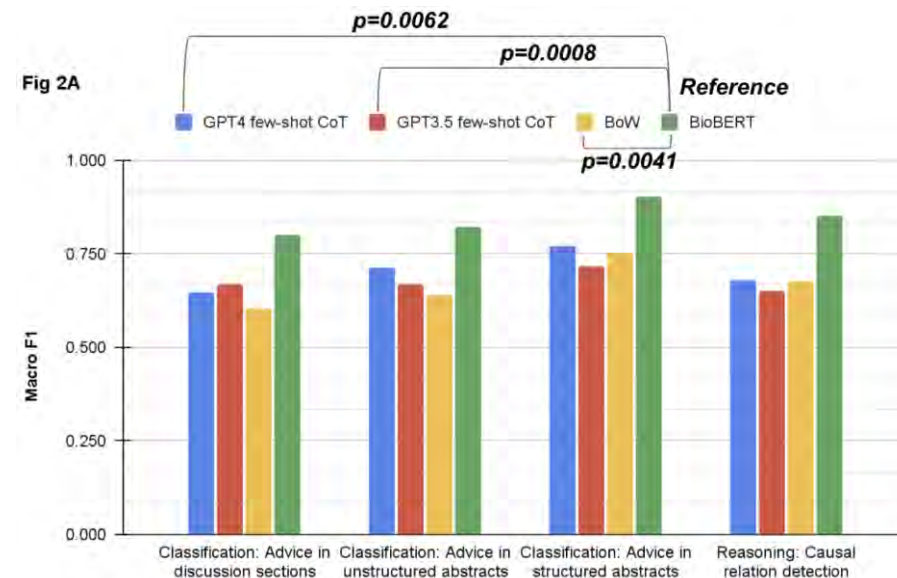
The fine-tuned model was able to accurately discriminate between all three classes in comparison to the pre-trained model.

What about the new LLM models?

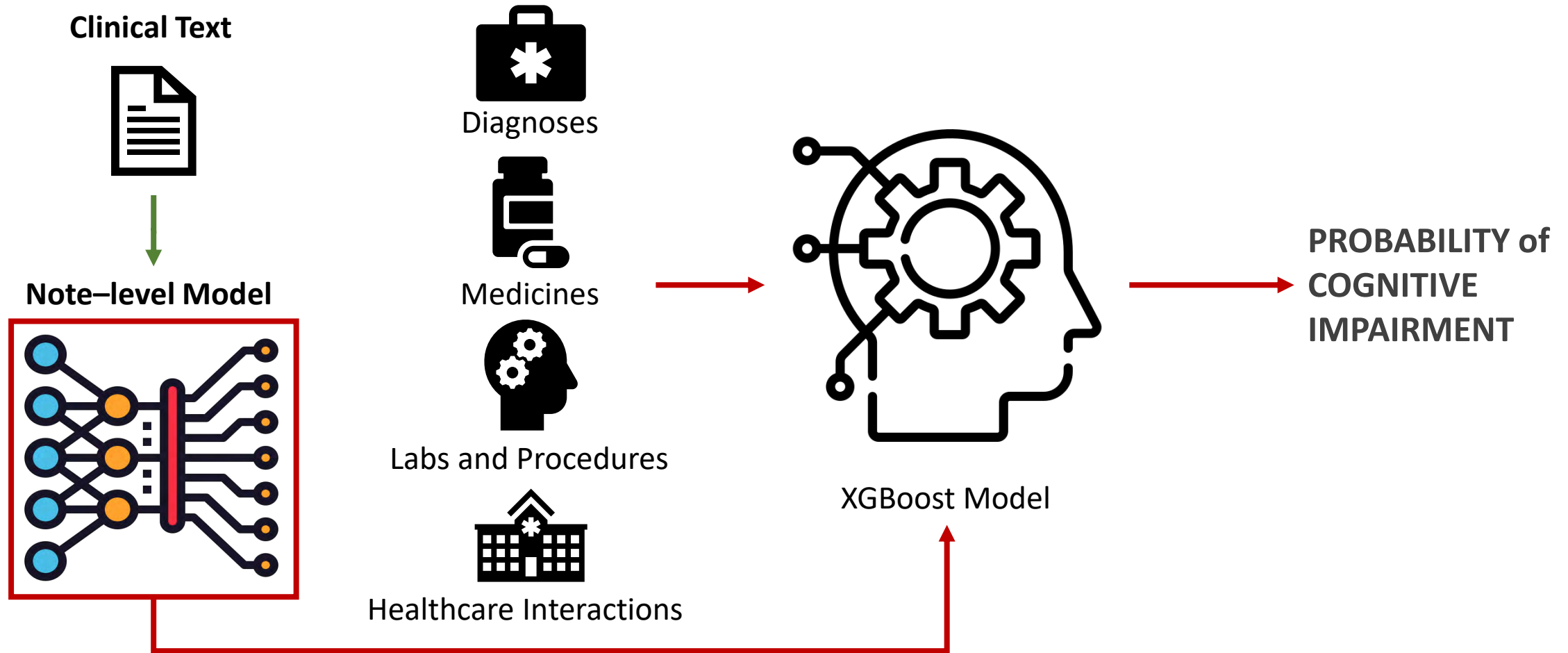
- Using prior knowledge helps improve signal-to-noise
- Generative models can make training more efficient (i.e., less labeled samples)
- Can reduce time required for feature engineering

Chen et al. (2023) Evaluation of ChatGPT Family of Models for Biomedical Reasoning and Classification

Chen *et al* demonstrated that BioBERT outperforms the GPT models in biomedical reasoning and classification.



Decipher-AI: DEtection of Cognitive Impairment Phenotypes in EHR



Gold-Standard Dataset of Patients

- **Cohort**

- Medicare beneficiaries within the MGB Accountable Care Organization, ACO
[N = 942]
- 65 years or older as of 1/1/2016
- Physicians with expertise in memory disorders reviewed 942 charts for 3-year period (1/1/2016-12-31/2018)
- Confidence level of 1-4 assigned

- **Cognitive Impairment labels**

- Cognitive concerns: implicit or explicit evidence of concerns relayed from patient, patient's family or friends, or providers
- MCI/dementia (mild, moderate, or severe)

Characteristics	N (%)	
Age on 12/31/2018		
< 75 years	191	(20.3%)
75-79 years	243	(25.8%)
80-84 years	202	(21.4%)
>= 85 years	306	(32.5%)
Sex		
Female	559	(59.3%)
Male	383	(40.7%)
Duration of care	17.9 y	± 8.6
PCP within system	710	(75.4%)

Gold-Standard Dataset Comparison to Claims

We compared the Expert-Adjudicated Labels to records of dementia-related ICD codes or medication in the patient's electronic health records (EHR)

A visit diagnosis code of MCI or dementia (290.X, 294.X, 331.X, 780.93, G30.X and G31.X)

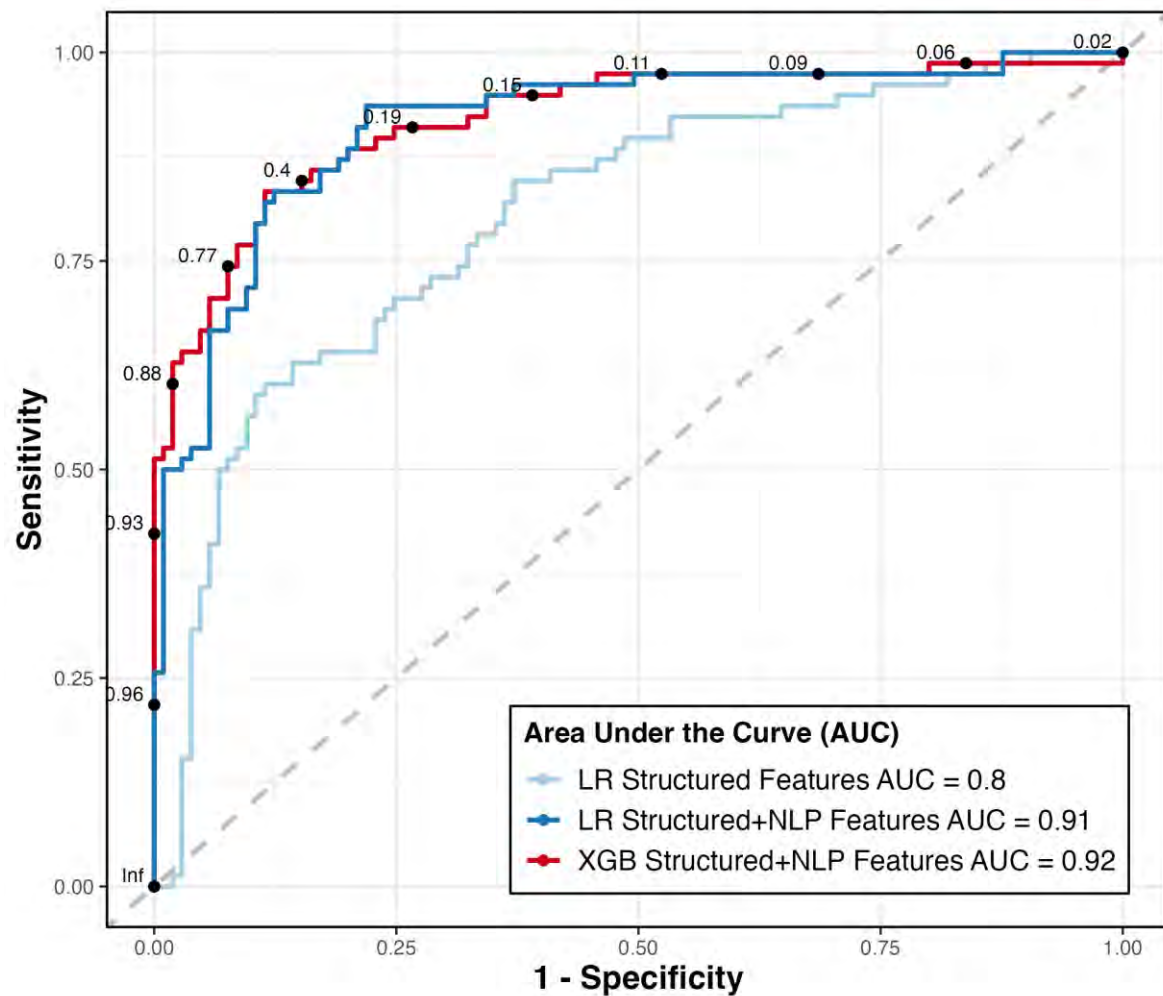
OR

An anticholinesterase inhibitor or memantine on medication list in EHR

Comparison of Dx-Rx with Gold-Standard Labels			
Clinician Adjudication	ICD code or medication	No ICD code or medication	Total
Cognitive Concern present*	273 (70.9%)	112 (29.1%)	385
Cognitive Concern absent*	43 (7.7%)	514 (92.3%)	557

*With a medium-to-high certainty score

Decipher-AI Performance



ROC-AUC: 0.92 [0.87 , 0.96]

Accuracy: 0.86 [0.81 , 0.91]

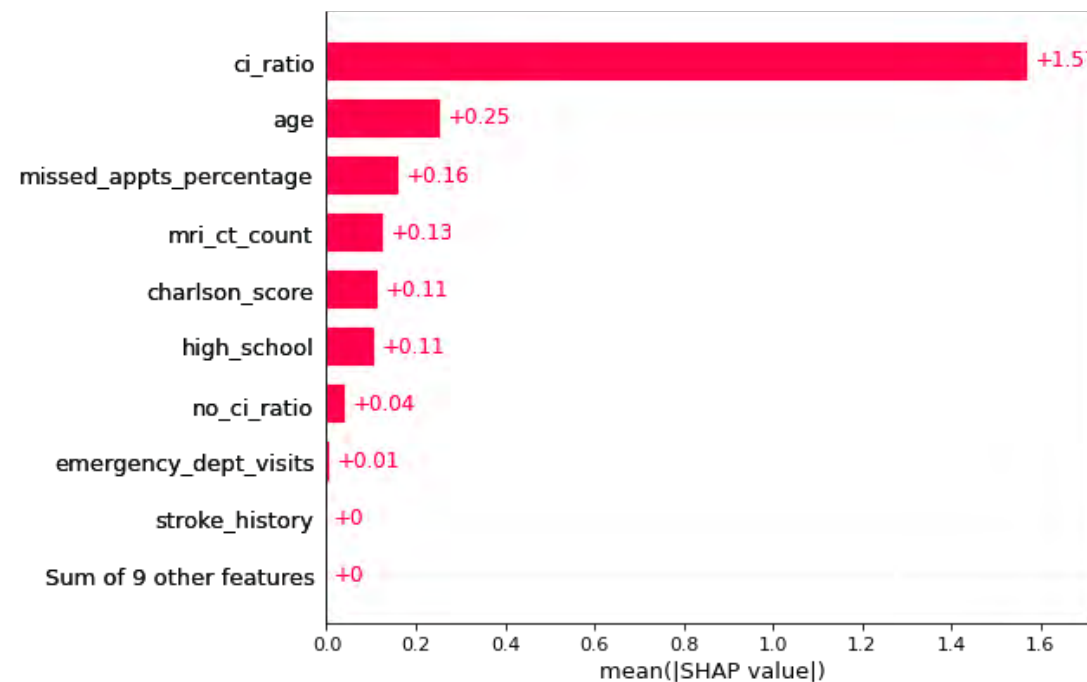
Specificity: 0.89 [0.82 , 0.94]

Sensitivity: 0.83 [0.74 , 0.91]

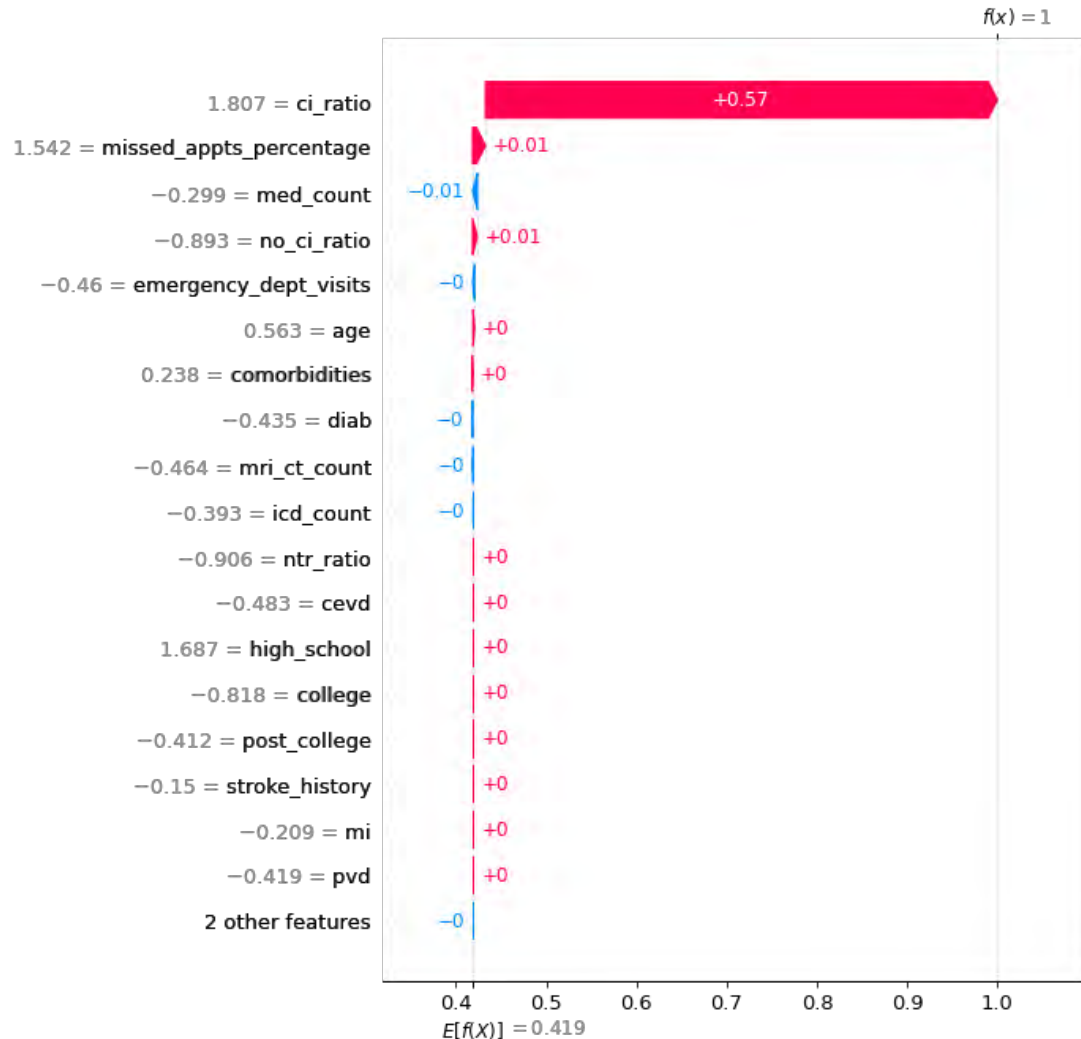
Micro F1: 0.86 [0.81 , 0.91]

PPV: 0.88 [0.82 , 0.93]

NPV: 0.84 [0.78 , 0.91]



SHAP Analysis of a “Undiagnosed” Patient



Call from XXXX Np. She is very concerned about patient's failure to thrive and decline in cognition. When she visited her in the home x/x at agreed upon time she was quite concerned as pt had door locked to her apt, did not answer the phone or the knock at door so she had to get security to let her in. ..could not seem to cooperate/understand any suggestions for increasing protein intake, BRAT diet for her diarrhea, and not relying on just gatorade for nutrition.

MGB Primary Care Patients >65 years old

Characteristics	Total	No ADRD	ADRD	Metrics	Value (95% CI)
Patients Total Number, N (%)	22251	16750 (75.3)	5501 (24.7)	Accuracy	0.70 ([0.69, 0.71])
Mean Encounters (Office & Telemedicine)	470066	22.7	16.26	ROC-AUC	0.80 ([0.79, 0.81])
Age at Study Entry, mean (SD), years	82.09 (9.27)	81.87 (9.03)	79.75 (9.95)	Micro F1	0.70 ([0.69, 0.71])
Sex, N (%)				Sensitivity	0.75 ([0.74, 0.77])
Female	13888 (62.4)	10319 (61.6)	3569 (64.9)	PPV	0.89 ([0.89, 0.90])
Male	8363 (37.6)	6341 (38.4)	1932 (35.1)	Specificity	0.68 ([0.67, 0.69])
Race and Ethnicity, N (%)				NPV	0.44 ([0.42, 0.45])
non-Hispanic White	11601 (52.1)	8745 (52.2)	2856 (51.9)		
non-Hispanic Asian	2077 (9.3)	1544 (9.2)	533 (9.7)		
non-Hispanic Black	4385 (19.7)	3278 (19.6)	1107 (20.1)		
Hispanic or Latino	4188 (18.8)	3183 (19.0)	1005 (18.3)		

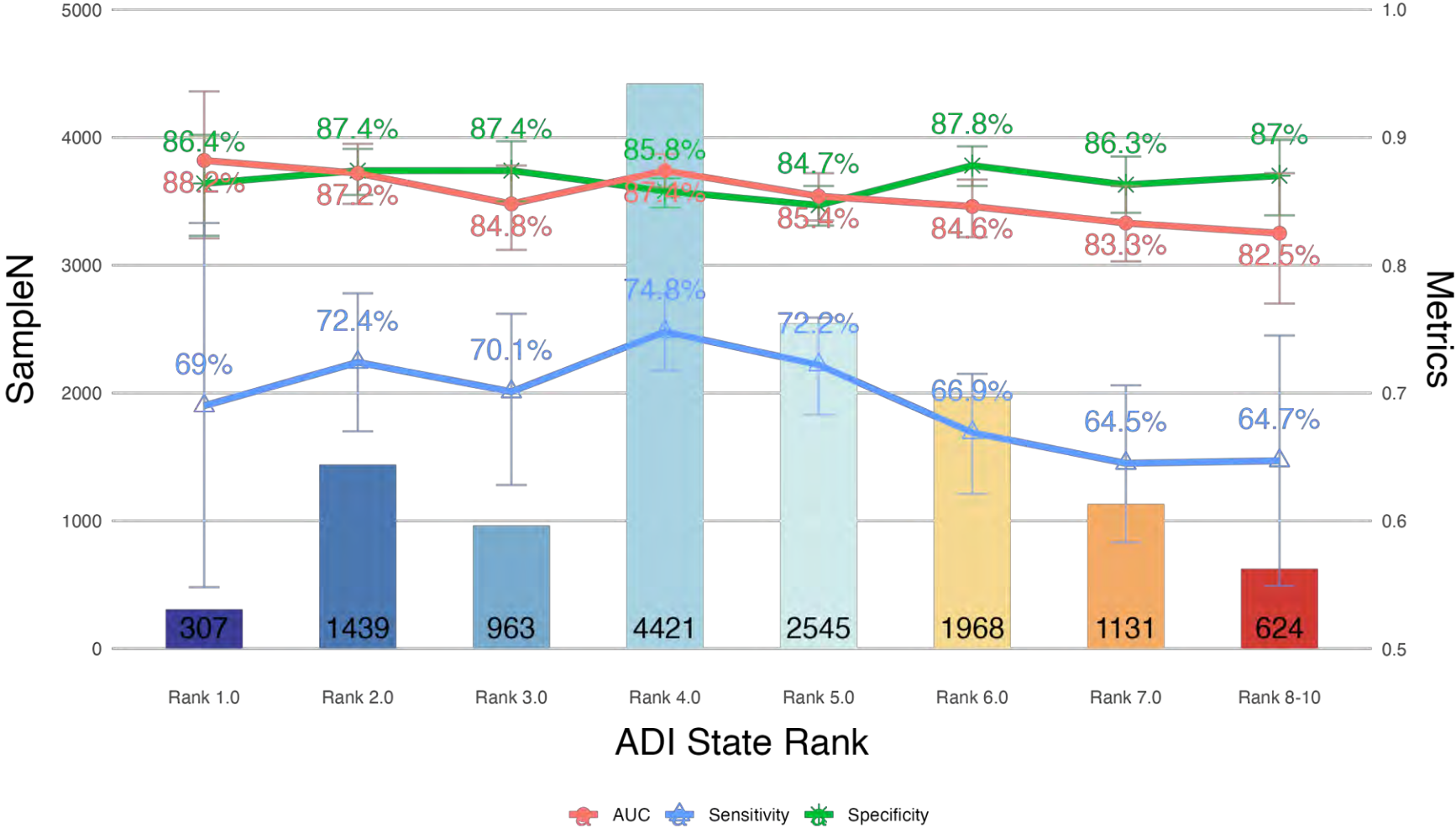
Labels:

Diagnosis Codes of
cognitive impairment (CI)

Model Input:

3-year data before first Dx of CI
or latest encounter

Sensitivity of Decipher-AI drops in patients from higher Area Deprivation Index (ADI)



Decipher-AI Summary

- AI-assisted screening tool in primary care using EHR data
- Hurdles
 - Algorithm bias among demographic subgroups – better data
 - Generalizability across health systems – fine-tune models
 - Physician trust – model interpretability
 - Regulatory approval
- Higher quality, standardized notes -> improved cognitive phenotyping

Acknowledgements

Colin G. Magdamo, Yingan He, Tanish Tyagi, Lily Cheng, Ayush Noori, Mrunal Malekar, Lidia Moura, John Hsu, Shibani Mukerji, Michael B. Westover, John Dickson, Christine Ritchie, Deborah Blacker, Bradley T. Hyman

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- MGH Neurology Transformative Scholar Award
- Harvard Initiative on Aging Planning Grant
- Mass Life Sciences Internship Award
- National Institute on Aging NIA P30AG062421
- National Institute on Aging NIA R56AG082698

Using Nursing Home EMRs to Improve Capture of Agitated Behaviors in Residents with ADRD

Hyunkyung (Yulia) Yun, MS
Ellen McCreedy, PhD



Acknowledgement

Hyunkyung (Yulia) Yun

- PhD Student at Brown University
- Conducted analyses for goal concordant care and agitated behaviors papers (both under review, Yulia first author for the agitation paper)
- Second paper in process, describing racial and ethnic inequities in behavioral detection based on data source
 - Recently presented at Duke as part of the NIA-sponsored Workshop “Leveraging Existing Data and Analytic Methods for Health Disparities Research Related to Aging and Alzheimer’s Disease and Related Dementias”)
- Only have time to list key findings - Check out Yulia’s poster tonight for more details!

Background

- Agitated behaviors decrease the quality of life for nursing home residents with ADRD
- Pragmatic trialists are interested in testing the effect of nonpharmaceutical interventions for managing agitated behaviors
- BUT, pragmatically available (MDS-based) measures under-detect agitated behaviors
 - Incomplete identification of residents who are likely to benefit from interventions
 - Incomplete outcome capture for enrolled residents

Methods

- First available quarterly or annual assessment for residents with ADRD from January 2020 - August 2022 (results similar without 2020 data)
- MDS & EMR data from large, non-profit corporation representing 322 NHs in 25 states
- Agitated behaviors defined three ways (EMR events occurring in month of MDS assessment)
 - MDS: Any agitated behaviors (physical behaviors directed toward others, nonphysical behaviors directed toward others, behaviors not directed toward others, wandering)
 - EMR eINTERACT: any increase in agitation (verbal or physical)
 - EMR orders: Any psychiatric consult, restraint for behaviors, supervision for behaviors, or medication prescribed or increased for behavioral management

Results

Percent of long-stay residents with ADRD and any agitated behavior	Total sample (19,705 residents 322 NHs)	High INTERACT Use (10,923 residents 167 NHs)	High Orders Use (10,008 residents 169 NHs)
MDS Only	14.8	14.8	15.8
MDS or INTERACT	16.2 (+1.4 pp)	16.5	17.5
MDS or Order	17.4 (+2.6 pp)	17.5	19.7
MDS, INTERACT, or Order	18.6 (+3.8 pp)	19.0	21.1

Over 25% relative increase in detection
EMR sources not overlapping

Limitations and Key Considerations

- MDS produces snapshots of behaviors over one week, EMR data continuous
- More severe / dangerous behaviors requiring increased supervision, restraint, or medications
- Need to think about the type of behavior your intervention is likely to affect & choose the data source to best identify residents with those behaviors
- Yun et al. (forthcoming) highlights potential inequities:
 - Latinx and Asian residents less likely to live in NHs regularly using EMR sources
 - Even in NHs regularly using EMR sources, Black and African American residents are less likely than whites to have behaviors documented in all three sources (MDS, INTERACT, and orders), despite similar levels of cognitive impairment
- Need for replication / validation in LTC Data Cooperative

Thank You

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Ellen McCreedy: ellen_mccreedy@brown.edu



School of
Public Health

BROWN UNIVERSITY

Developing Pragmatic Methods to Measure Goal-Concordant Care

Natalie C. Ernecoff, PhD, MPH

April 3, 2024



HEALTH CARE

Objective

To define a pragmatic outcome measure for goal-concordant care using existing nursing home (NH) electronic health record (EHR) data for people living with late-stage ADRD.

Design, Setting, & Participants

- 222 Genesis HealthCare NHs, a national chain
- NH residents with Cognitive Function Score (CFS) > 2, comparable to moderate to advanced AD/DRD
- Structured nursing home EHR data & unstructured orders

Methods

Step 1: Identify resident with comfort-focused orders (i.e., comfort-focused care, do not hospitalize (DNH) orders, and hospice)

Step 2: Identify potentially discordant treatments that residents received via structured treatment orders in EHR data (e.g., hospitalization, ventilation, tube feeding)

Step 3: Identify the percent of NH residents prioritizing a goal of comfort who received goal-discordant treatments

Cohort

- Among long-stay NH residents:
 - N=4,285 had moderate to advanced ADRD
 - 68% female
 - 78% white
- N=823 (19%) unique residents had comfort-focused orders

Among residents with any comfort-focused order (N=823), 13.0% received at least one goal-discordant treatment within the subsequent year.

Treatments N (%)	Goals All residents N=4,285	CMO n=154 (3.6%)	DNH n=61 (1.4%)	Hospice n=669 (15.6%)	CMO or DNH or Hospice n=823 (19.2%)
Hospital transfers	797 (18.6)	9 (5.8)	5 (8.2)	59 (8.8)	71 (8.6)
Tube feeding	153 (3.6)	2 (1.3)	1 (1.6)	12 (1.8)	14 (1.7)
Mechanical ventilation	6 (0.1)	0	0	0	0
Parenteral therapy	313 (7.3)	7 (4.6)	1 (1.6)	21 (3.1)	29 (3.5)
Chemotherapy	8 (0.2)	1 (0.7)	0	1 (0.2)	2 (0.2)
Transfusions	7 (0.2)	0	0	0	0
Dialysis	20 (0.5)	0	0	5 (0.8)	5 (0.6)
Any specified treatments	1,047 (24.4)	17 (11.0)	5 (8.2)	88 (13.2)	107 (13.0)

The most common were hospital transfers (8.6%) and parenteral therapy (3.5%).

Treatments N (%)	Goals All residents N=4,285	CMO n=154 (3.6%)	DNH n=61 (1.4%)	Hospice n=669 (15.6%)	CMO or DNH or Hospice n=823 (19.2%)
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Any specified treatments	1,047 (24.4)	17 (11.0)	5 (8.2)	88 (13.2)	107 (13.0)

A feasible pragmatic approach to identify goal-concordant care

- We defined a new pragmatic method to measure goal-concordant care for NH residents with late-stage ADRD who prioritize comfort.
- We identified NH resident with moderate to advanced ADRD who received goal-concordant care (87%).
 - Goal-discordant care was not rare (13%).
- This work informs outcome selection in pragmatic trials to improve care concordant with comfort-based goals.
- Future work can incorporate more EHR data to ascertain goals, including from free text notes.

Thank you!

- Yulia Yun, MS, MSW
- Ellen McCreedy, PhD, MPH
- Laura C. Hanson, MD, MPH
- Susan L. Mitchell, MD, MPH




Needle in a haystack

Using natural language processing to measure
documented goals-of-care discussions
for a pragmatic clinical trial



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Cambia Palliative Care Center of Excellence at UW Medicine
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A ^{HE}UNIVERSITY *of* WASHINGTON







J. Randall "Randy" Curtis, MD, MPH
1960 – 2023

Disclosures

- I have no conflicts of interest to disclose.
- Funding sources:

 National Institute on Aging
R01 AG062441 (Curtis, Kross, Engelberg)

 National Heart, Lung, and Blood Institute
K23 HL161503 (Lee)
K12 HL137940



UW Medicine

Background

- Goals-of-care discussions are important!

ORIGINAL INVESTIGATION

HEALTH CARE REFORM

Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning

Daren K. Heyland, MD, MSc, FRCPC; Doris Barwich, MD, CCFP; Deb Pichora, RN, MSc; Peter Dodek, MD, MHSc; Francois Lamontagne, MD, MSc, FRCPC; John J. You, MD, MSc; Carolyn Tayler, RN, BN, MSA, CON(C); Pat Porterfield, RN, MScN; Tasmim Sinuff, MD, PhD, FRCPC; Jessica Simon, MB, ChB, FRCPC;

for the
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Missed Opportunities during Family Conferences about End-of-Life Care in the Intensive Care Unit

J. Randall Curtis, Ruth A. Engelberg, Marjorie D. Wenrich, Sarah E. Shannon, Patsy D. Treece, and Gordon D. Rubenfeld

Departm
and Hea

Original article

Barriers and facilitators for goals of care discussions between residents and hospitalised patients

Kalpa Shah,^{1,2} Marilyn Swinton,³ John J You^{1,3}

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Patient and Family Engagement During Treatment Decisions in an ICU: A Discourse Analysis of the Electronic Health Record

Jacqueline M. Kruser, MD, MS^{1,2}; Brian T. Benjamin, MD¹; Elisa J. Gordon, PhD, MPH³; Kelly N. Michelson, MD, MPH⁴; Richard G. Wunderink, MD⁵; Jane L. Holl, MD, MPH^{1,4,5}; Margaret L. Schwarze, MD, MPP^{6,7}

Objectives: Shared decision-making is recommended for critically ill patients. However, shared decision-making is often not implemented in the intensive care unit (ICU). This study aims to describe the frequency and content of shared decision-making discussions in the ICU.

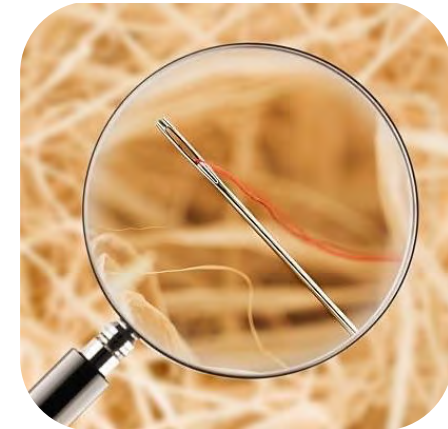
Background

- Goals-of-care discussions are important!
- GOC discussions are hard to measure, especially in hospitalized patients.



Background

- Goals-of-care discussions are important!
- GOC discussions are hard to measure, especially in hospitalized patients.
- Electronic health records (EHR) allow us to measure *documented* GOC discussions...



... which are often found in **unstructured free text.**

The Problem

We were conducting a large pragmatic randomized trial:

- **Participants:** N=2,512 hospitalized patients who had chronic life-limiting illness
- **Intervention:** Clinician-facing “Jumpstart Guide,” a prompting intervention to promote GOC discussions
- **Primary outcome:** Documented GOC discussion in EHR (beyond code status)

Research

JAMA | Original Investigation | CARING FOR THE CRITICALLY ILL PATIENT

Intervention to Promote Communication About Goals of Care for Hospitalized Patients With Serious Illness A Randomized Clinical Trial

J. Randall Curtis, MD, MPH; Robert Y. Lee, MD, MS; Lyndia C. Brumback, PhD; Erin K. Kross, MD; Lois Downey, MA; Janaki Torrence, MS; Nicole LeDuc, BS; Kasey Mallon Andrews, MS; Jennifer Im, MS; Joanna Heywood, BS; Crystal E. Brown, MD, MA; James Sibley, BS; William B. Lober, MD, MS; Trevor Cohen, MBChB, PhD; Bryan J. Weiner, PhD; Nita Khandelwal, MD, MS; Nauzley C. Abedini, MD, MSc; Ruth A. Engelberg, PhD

IMPORTANCE Discussions about goals of care are important for high-quality palliative care yet are often lacking for hospitalized older patients with serious illness.

OBJECTIVE To evaluate a communication-priming intervention to promote goals-of-care discussions between clinicians and hospitalized older patients with serious illness.

DESIGN, SETTING, AND PARTICIPANTS A pragmatic, randomized clinical trial of a clinician-facing communication-priming intervention vs usual care was conducted at 3 US hospitals within 1 health care system, including a university, county, and community hospital. Eligible hospitalized patients were aged 55 years or older with any of the chronic illnesses used by the Dartmouth Atlas project to study end-of-life care or were aged 80 years or older. Patients with documented goals-of-care discussions or a palliative care consultation between hospital admission and eligibility screening were excluded. Randomization occurred between April 2020 and March 2021 and was stratified by study site and history of dementia.

INTERVENTION Physicians and advance practice clinicians who were treating the patients randomized to the intervention received a 1-page, patient-specific intervention (Jumpstart Guide) to prompt and guide goals-of-care discussions.

MAIN OUTCOMES AND MEASURES The primary outcome was the proportion of patients with electronic health record–documented goals-of-care discussions within 30 days. There was also an evaluation of whether the effect of the intervention varied by age, sex, dementia, minoritized race or ethnicity, or study site.

RESULTS Of 3918 patients screened, 2512 were enrolled (1255 men and 1257 women) and randomized (1255 to the

+ Visual Abstract

+ Editorial page 2021

+ Supplemental content

Curtis et al, *JAMA* 2023;329(23):2028-2037



Why use NLP?

In hospitalized patients with serious illness,
GOC discussions represent

~ 0.2 – 0.5%

of text in medical records.

(restricted to physician/NP/PA notes)



Why use NLP?

To manually review for GOC discussions:

2,500 patients' notes from randomization to +30 days

= 45,000 notes

= 320 million words

Why use NLP?

To manually review for GOC discussions:

2,500 patients' notes from randomization to +30 days

= 45,000 notes

= 320 million words

= 640,000 pages

= 1,300 reams of printer paper

= a stack of paper as tall as this 26-story building:



Why use NLP?

To manually review for GOC discussions:

2,500 patients' notes from randomization to +30 days

= 45,000 notes

= 320 million words

= 640,000 pages

= 1,300 reams of printer paper

= a stack of paper as tall as this 26-story building:

= 3000 abstractor-hours

= 3 abstractors x 0.4 FTE x 1.2 years

= **\$200,000**



Why not just *search* for “goals of care”?

Search string	Sensitivity (note-level)	Specificity (note-level)
“goals of care”	38.3%	97.4%
“goals of care” or “GOC”	53.6%	94.3%
“goals of care” or “GOC” or “family meeting”	58.0%	93.7%
+ <i>a bunch of other stuff</i>	80.0%	85.7%
+ <i>even more stuff</i>	92.9%	59.5%

Secondary analysis of data from 4,391 EHR notes from Lee RY et al, *JAMA Network Open* 2022;5(4):e225088.

BERT NLP

BERT (Bidirectional Encoder Representation from Transformers)

- Deep-learning model released by Google Research as free software in 2018, with ~110 million parameters
- Analyzes relationships between each word and the words that surround it, to better capture true meaning
- Pre-trained on large collections of unlabeled text (Wikipedia + 11,000 unpublished books)

Further reading about BERT:

- Devlin J et al, arXiv:1810.04805, 2018
- Devlin J, Chang M-W. Open Sourcing BERT (web page), <https://bit.ly/releasingbert>
- Khalid S. BERT Explained (web page), <https://bit.ly/whoisbert>

“My dog loves to **bark**.”



“Trees need their **bark** to survive.”



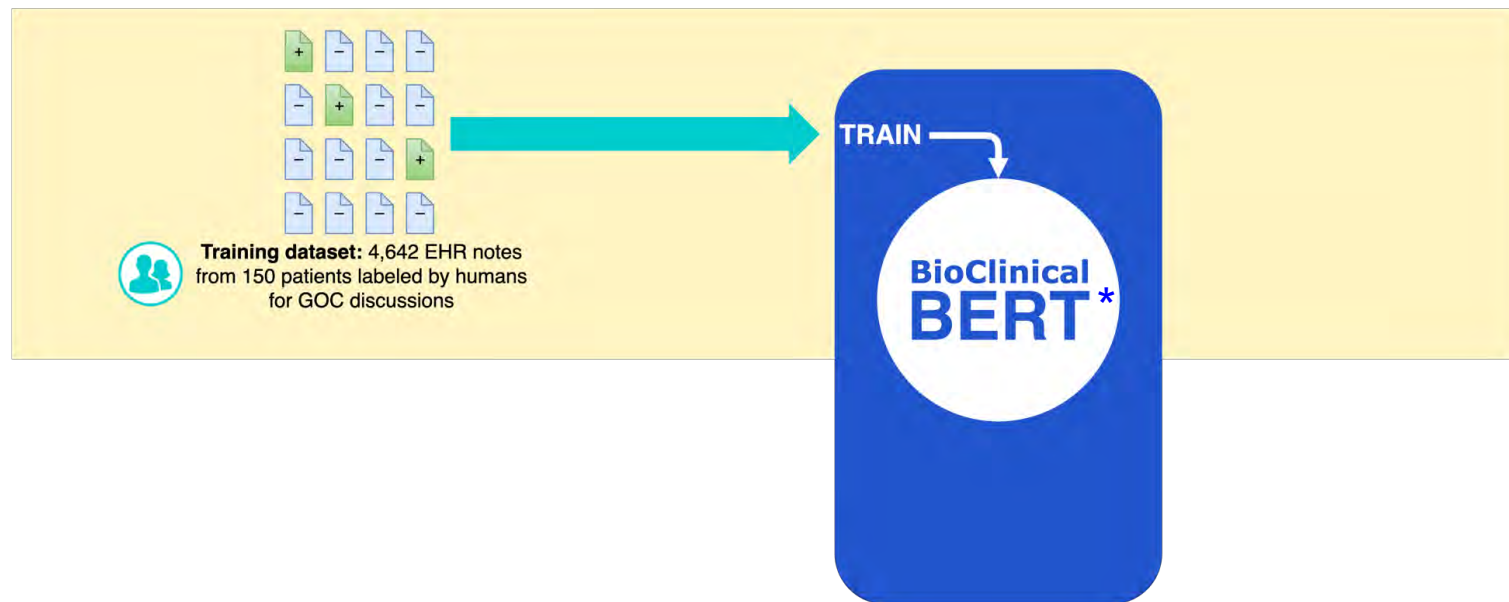
“The general began to **bark** orders.”
“The sergeant **shouted** orders.”



Training & Validation

1 TRAINING (task-specific)

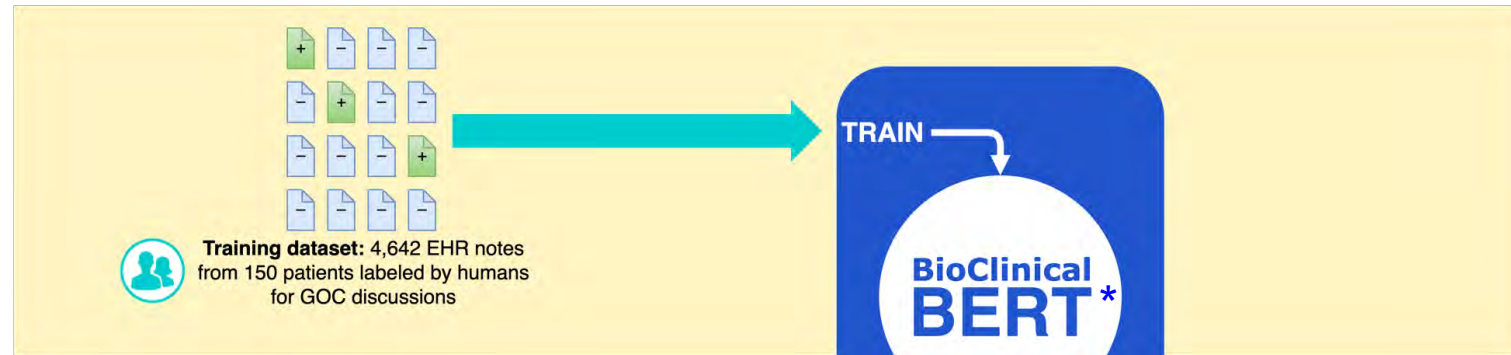
Fit BERT model to
human-labeled
external data



Training & Validation

1 TRAINING (task-specific)

Fit BERT model to human-labeled external data



2 PREDICTION

Use fitted model to predict likelihood of GOC in candidate EHR texts



* BioClinicalBERT: Alsentzer et al, arXiv:1904.03323, 2019

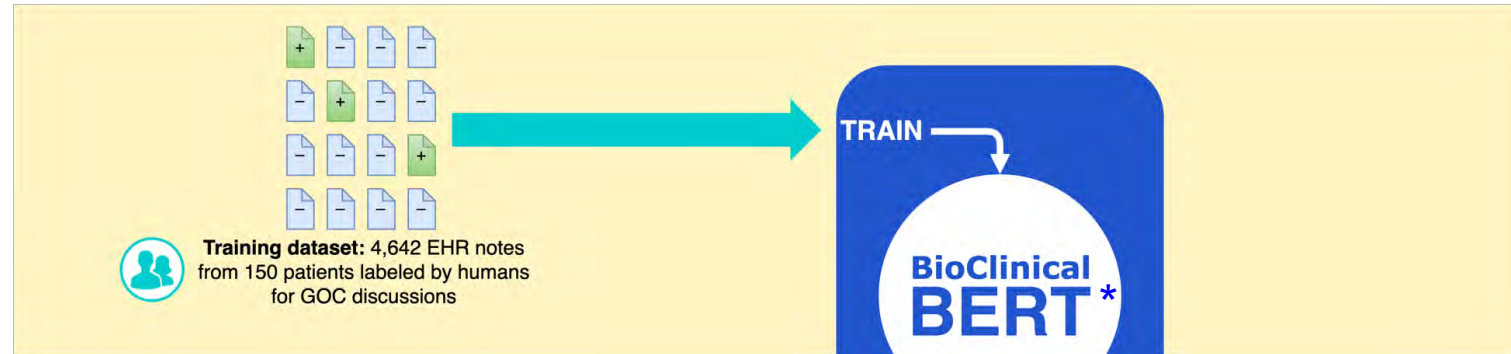
Lee RY et al, *JAMA Network Open* 2023;6(3):e231204



Training & Validation

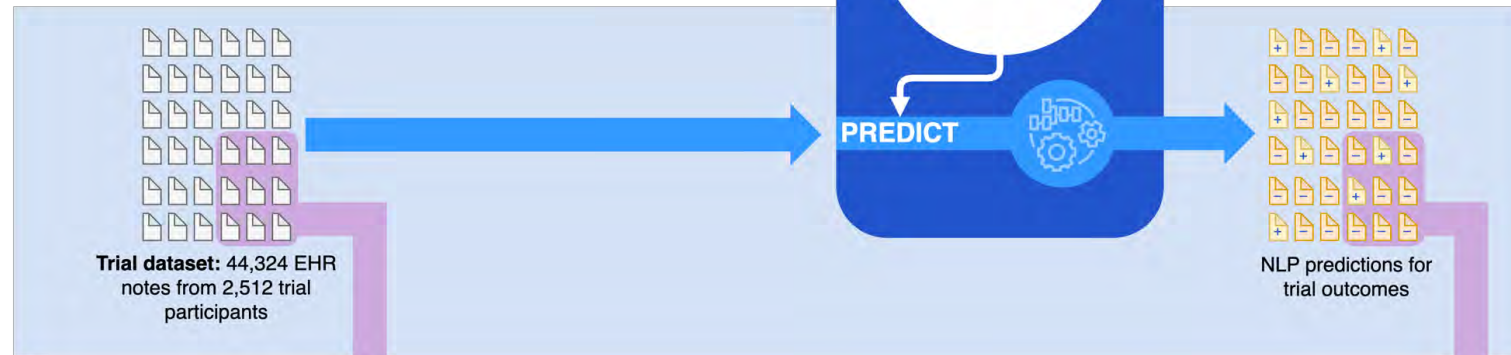
1 TRAINING (task-specific)

Fit BERT model to human-labeled external data



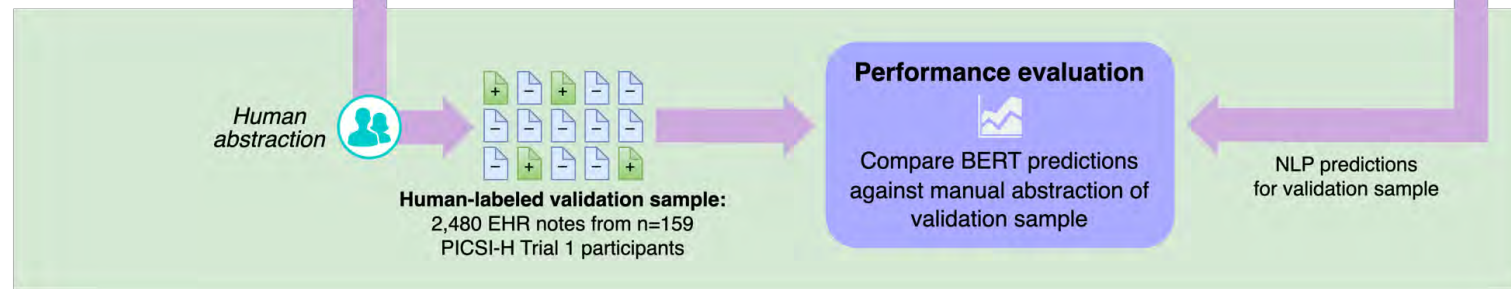
2 PREDICTION

Use fitted model to predict likelihood of GOC in candidate EHR texts



3 VALIDATION

Compare NLP predictions against human review



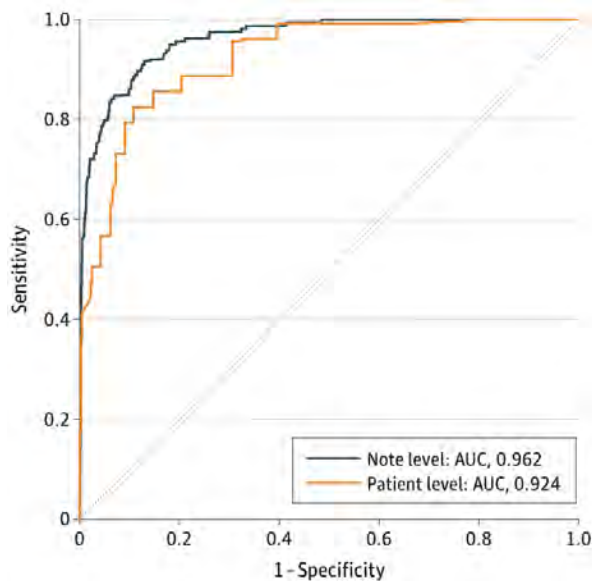
* BioClinicalBERT: Alsentzer et al, arXiv:1904.03323, 2019

Lee RY et al, *JAMA Network Open* 2023;6(3):e231204

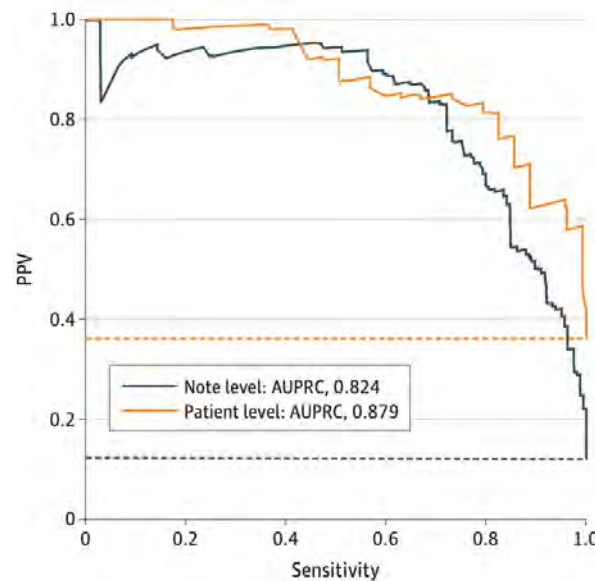
Performance of NLP model

in identifying 30-day documented GOC discussions for hospitalized patients

ROC curve



Precision-recall curve



Note-level performance (n=2,480)

Sensitivity	Specificity	PPV	NPV	F ₁
70.1%	98.1%	83.6%	95.9%	0.76
79.9%	94.5%	66.9%	97.1%	0.73
89.7%	88.1%	51.0%	98.4%	0.65
AUC 0.962, AUPRC 0.824				

AUC = Area under receiver operating characteristic (ROC) curve
 AUPRC = Area under precision-recall curve (Cook et al, *Stata Journal* 2020;20(1):131-148)

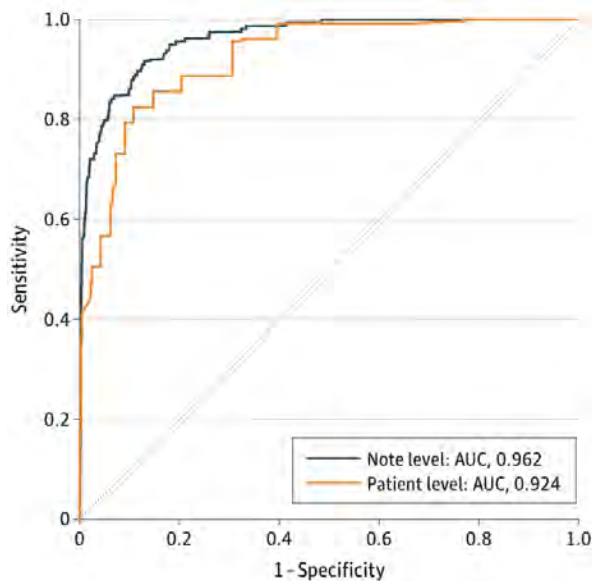
Lee RY et al, *JAMA Network Open* 2023;6(3):e231204



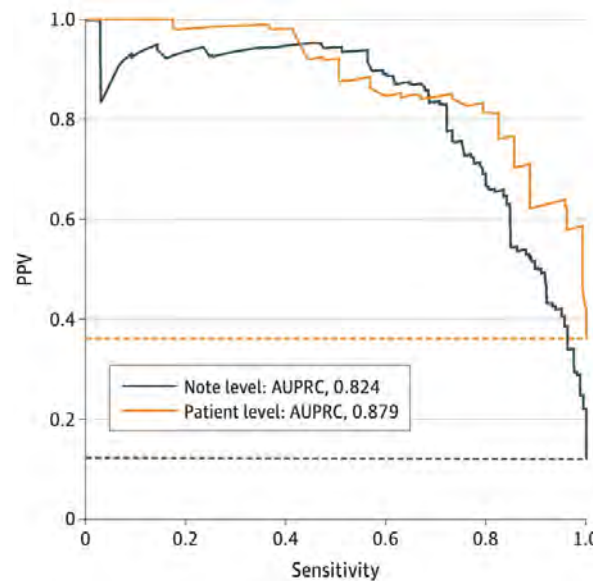
Performance of NLP model

in identifying 30-day documented GOC discussions for hospitalized patients

ROC curve



Precision-recall curve



Note-level performance (n=2,480)

Sensitivity	Specificity	PPV	NPV	F ₁
70.1%	98.1%	83.6%	95.9%	0.76
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Patient-level performance (n=159)

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70.0%	92.8%	84.5%	84.6%	0.77
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89.5%	69.5%	62.3%	92.1%	0.73
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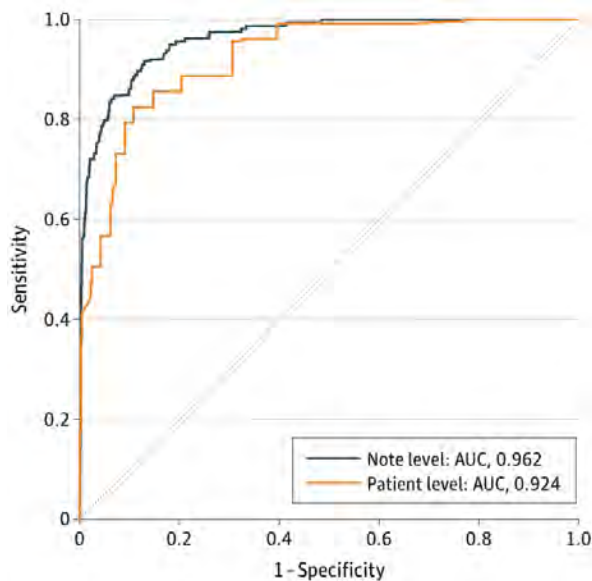
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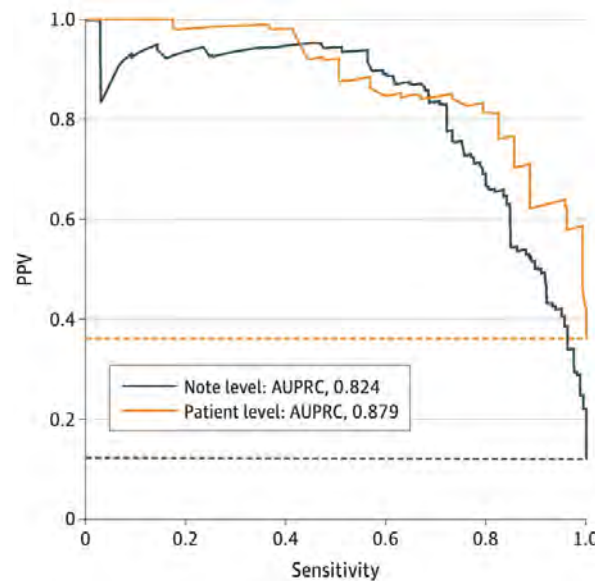
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Good enough to use for screening

AUC = Area under receiver operating characteristic (ROC) curve
 AUPRC = Area under precision-recall curve (Cook et al, *Stata Journal* 2020;20(1):131-148)

Lee RY et al, *JAMA Network Open* 2023;6(3):e231204



NLP-screened human abstraction

Assessment:

- Patient [Patient's Name] maintains reluctance towards chemotherapy, expressing concerns about potential side effects.
- Previous discussions suggest a preference for hospice care over aggressive treatments due to prioritizing quality of life.
- Observable signs of increasing frailty, including [specific signs like decreased functional status, weight loss].

Plan:

- Considering involving Palliative Care due to patient's hesitation regarding chemotherapy and prior interest in hospice care.
- Engage in a discussion with the patient to explore alternative treatment options aligned with their preferences and goals.
- Initiate supportive measures to optimize comfort and quality of life during the inpatient stay.
- Regularly monitor and adapt care according to evolving patient needs and choices.

PRIMARY OUTCOME: Does the text shown above represent a goals-of-care discussion?

[Reference: [PICSI-H1 Coding Flowchart.](#)]

Yes – codes GOCD or ACP/DPOA

No – does not meet criteria for either code

Not real data; fabricated by ChatGPT 3.5 (chat.openai.com).



NLP-screened human abstraction

We chose a screening threshold with:

- 92.6% patient-level sensitivity in validation sample
- 22,187 (0.8% of 2.6M) EHR passages from 1,957 patients (78% of 2,512) screened positive
 - estimated abstraction burden of ~8,500 passages to reach completeness for cumulative incidence and time-to-first-GOC
 - median 52 words per passage
- Detectable RD 5.7% at 80% power, $\alpha=0.05$



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**3,000 hours
over 1.2 years**



**34.3 hours
over 3 weeks**



Where do we go from here?

Major limitations of this approach:

- Some pragmatic outcomes are not represented in EHR text, or are not linguistically amenable to NLP.
 - ** GOC discussions certainly push the boundary on what is “linguistically amenable”!
- Expenses:
 - Up-front hardware and development costs
 - Expensive, outcome-specific training data
 - Expensive validation data
- NLP-related error or misclassification
- NLP-related bias?

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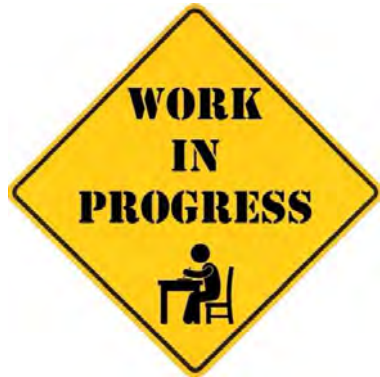
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- NLP-related bias?

BERT models are already outdated!



Source: Peter Lee PhD, Microsoft Research, <https://youtu.be/bEovhfxJsM4>

Where do we go from here?



- Can newer *large language models* obviate the need for training data?
 - ChatGPT (OpenAI), Gemini/Bard (Google), LLaMA (Meta), *et al*
 - May facilitate new outcome measures (e.g. content domains, quality metrics)

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 - How do we best evaluate for such biases in NLP models?
 - End-goal is to avoid perpetuating health disparities!

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 - How do we best evaluate for such biases in NLP models?
 - End-goal is to avoid perpetuating health disparities!
- Can statistical approaches overcome NLP-related misclassification and address potential biases?

Conclusions

- NLP is a promising tool for measuring **pragmatic outcomes** in electronic health records—including linguistically complex constructs.
- NLP can facilitate research studies that would otherwise be infeasible.



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 - Misclassification and measurement error
 - Bias, and perpetuation of disparities



Conclusions

- NLP is a promising tool for measuring **pragmatic outcomes** in electronic health records—including linguistically complex constructs.
- NLP can facilitate research studies that would otherwise be infeasible.
- Exciting progress in AI is tempered by caution against limitations.
 - Misclassification and measurement error
 - Bias, and perpetuation of disparities
- *There is more to come...!*





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- Ruth A. Engelberg, PhD

Statistical Analysis

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- Lois Downey, MA

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- Kelson Okimoto, MSW
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- Sudiptho R. Paul, MS
- Elizabeth L. Nielsen, MPH

Gratitude



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-  National Institute on Aging
R01 AG062441 (Curtis, Kross, Engelberg)
-  National Heart, Lung, and Blood Institute
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K12 HL137940

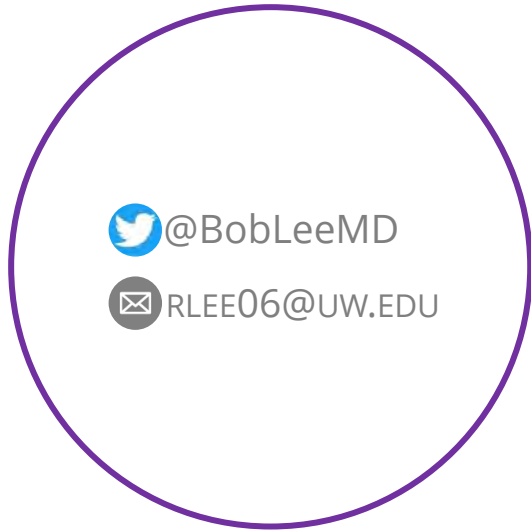
-  **CAMBIA**
health foundation
- UW Medicine

Infrastructure Support

-  National Center for Advancing Translational Sciences
UL1 TR002319
-  **ITHS** | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

CAMBIA PALLIATIVE CARE **CENTER OF EXCELLENCE**
AT THE **UNIVERSITY of WASHINGTON**





Anonymous Evaluation
(for my faculty position)

Talk title: NLP for GOC

Talk date: 4/3/24

Eval URL: bit.ly/evalbob

CAMBIA PALLIATIVE CARE **CENTER OF EXCELLENCE**
AT THE UNIVERSITY *of* WASHINGTON



Medicare Claims-Based Frailty Index as a Proxy for the Stage of Dementia

*IMPACT Collaboratory Scientific Conference
April 3, 2024*

Dae Hyun Kim, MD, MPH, ScD

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Disclosures

- NIH grant R01 AG071809
- Personal consultant fee from Alosa Health and VillageMD

Measuring dementia stage for ePCT

- Understanding where a patient is on a continuum of the disease progression is useful for prognostication and care planning.
- Reasons for measuring dementia stage in ePCT:
 - Eligibility criteria: an intervention may target patients in a specific stage.
 - Outcome: an intervention may slow the disease progression.
 - Covariate: an intervention may have different effects by dementia stage.

Measures of dementia staging

- The Global Deterioration Scale (GDS)
- The Functional Assessment Staging Test (FAST)

Stage of Dementia

- 1 Normal
- 2 Subjective cognitive impairment
- 3 MCI
- 4 Mild dementia
- 5 Moderate dementia
- 6 Moderately severe dementia
- 7 Severe dementia

The Functional Assessment Staging Test

1	Normal	No deficits
2	Subjective cognitive impairment	Subjective functional deficit
3	Mild cognitive impairment	Objective functional deficit interferes with complex tasks
4	Mild dementia	IADLs (e.g., finances, cooking, cleaning, traveling) affected
5	Moderate dementia	Need help selecting proper clothing
6a		Need help putting on clothes
6b		Need help with bathing
6c	Moderately severe dementia	Need help with toileting
6d		Urinary incontinence
6e		Fecal incontinence
7a		Speaks 5-6 words during day
7b		Speaks only 1 word clearly
7c	Severe dementia	Can no longer walk
7d		Can no longer sit up
7e		Can no longer smile
7f		Can no longer hold up head

Measuring function from claims data

- Claims-based frailty index (CFI) estimates a deficit-accumulation frailty index (range: 0 to 1)
- Uses 93 variables derived from ICD, CPT and HCPCS codes
- Validated against clinical assessment
 - Deficit-accumulation frailty index and frailty phenotype
 - Severe ADL dependence (≥ 2 ADLs): C-statistic 0.84

What variables are included in CFI?

HCPCS codes

Hospital beds
Wheelchairs
Walking aids
Oxygen delivery devices
Diabetic footwear & supplies
Transportation services

CPT codes

Nursing facility care

Diagnose codes

Organic psychotic conditions
Degenerative CNS diseases
Other forms of heart disease
Open wound of lower limb
Ischemic heart disease
Hypertensive disease
Cerebrovascular disease
Arthropathies
COPD
Pneumonia and influenza
Ill-defined causes of morbidity & mortality



Claims-Based Frailty Index (Hebrew SeniorLife)

Harvard Dataverse >

Contact Share

Claims-based frailty index (CFI) estimates a deficit-accumulation frailty index using International Classification of Diseases (ICD) diagnosis codes, Current Procedural Terminology (CPT) codes, and Healthcare Common Procedure Coding System (HCPCS) codes in the prior 12 months in administrative claims data.

Please refer to "Research Background - Claims-Based Frailty Index" file within each sub-dataverse for interpretation, validation data against clinical measures and health outcomes, and annotated references. Refer to "Frailty Index Code Guide" file to implement CFI algorithms in different statistical softwares and programming languages.

The original SAS program was developed and validated by Dr. Kim and his team at the Brigham and Women's Hospital Division of Pharmacoepidemiology and Pharmacoeconomics, supported by National Institute on Aging (grants K08 AG051187 and R01 AG062713). Programs in Python, R, and Java were developed by Westat and VillageMD and are based on the original SAS program.

Search this dataverse...

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Dataverses (0)

Datasets (5)

Files (47)

Publication Year

2021 (1)

2020 (4)

Subject

Medicine, Health and Life Sciences (5)

Author Name

Bedell, Douglas (4)

Coulthard, Christopher (1)

Gautam, Nileesa (1)

Kim, Dae Hyun (1)

Tambellini, Vincent (1)

Author Affiliation

Westat (4)

Harvard University (1)

VillageMD (1)

1 to 5 of 5 Results

Sort

SAS Programs - Claims-Based Frailty Index

Jun 17, 2021



Kim, Dae Hyun; Gautam, Nileesa, 2020, "SAS Programs - Claims-Based Frailty Index", <https://doi.org/10.7910/DVN/HM8DOI>, Harvard Dataverse, V12, UNF:6:bnNfccNq1mGW3HZBUY8YA== [fileUNF]

This SAS program calculates CFI for each patient from analytic data files containing information on patient identifiers, ICD-9-CM diagnosis codes (version 32), ICD-10-CM Diagnosis Codes (version 2020), CPT codes, and HCPCS codes. NOTE: When downloading, store "CFI_ICD9CM_V32.tab"...

Stata Program - Claims-Based Frailty Index

Jul 14, 2021



Bedell, Douglas, 2021, "Stata Program - Claims-Based Frailty Index", <https://doi.org/10.7910/DVN/WFDPNH>, Harvard Dataverse, V3, UNF:6:Hm0TGXWduQJqfVaY0T3XJQ== [fileUNF]

This STATA program calculates CFI for each patient from analytic data files containing information on patient identifiers, ICD-9-CM diagnosis codes (version 32), ICD-10-CM Diagnosis Codes (version 2020), CPT codes, and HCPCS codes. NOTE: When downloading, store "CFI_ICD9CM_V32.ta..."

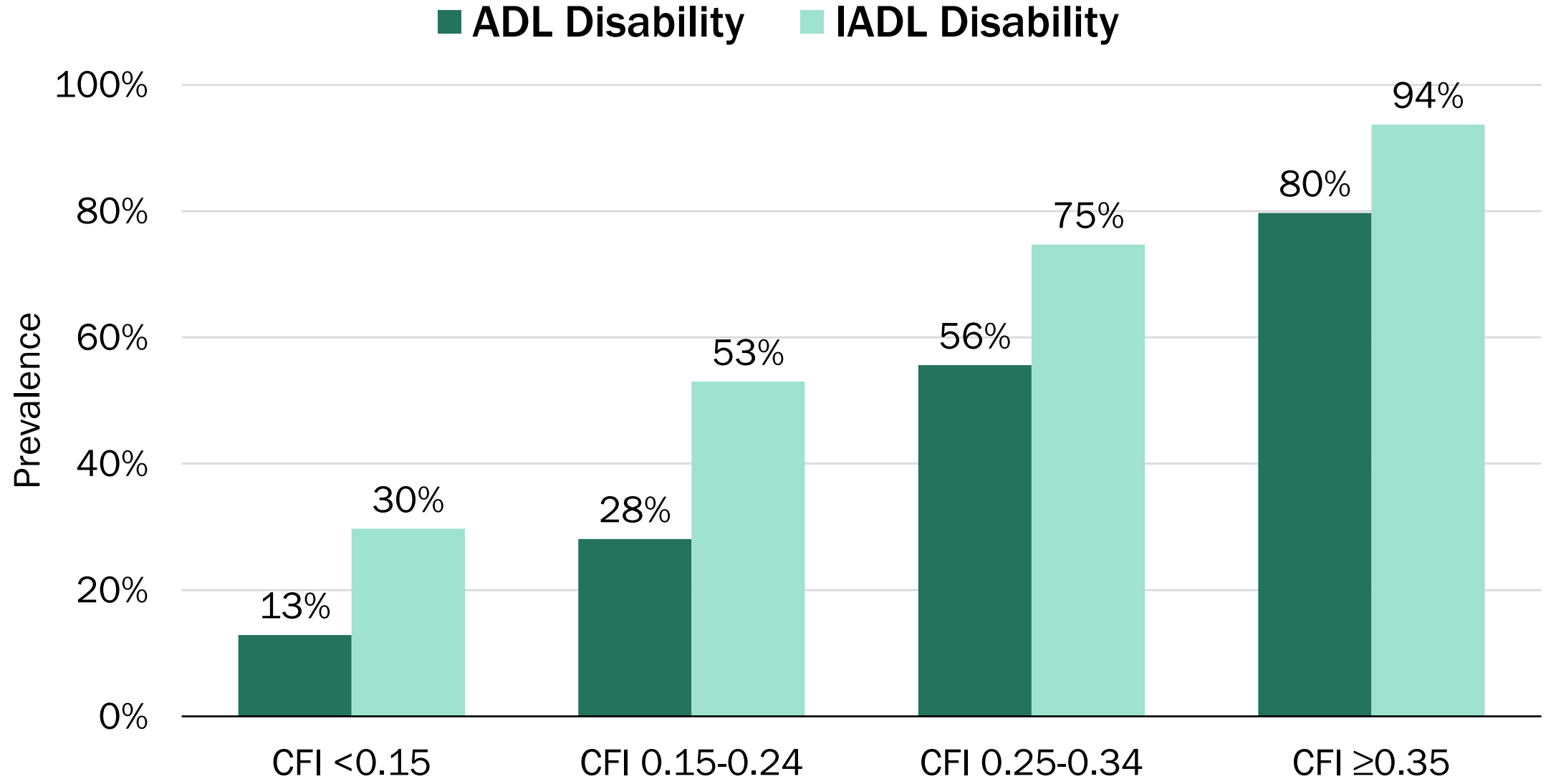
R Program - Claims-Based Frailty Index

Jul 14, 2021



Bedell, Douglas, 2020, "R Program - Claims-Based Frailty Index", <https://doi.org/10.7910/DVN/4Y3Y23>, Harvard Dataverse, V5, UNF:6:Hm0TGXWduQJqfVaY0T3XJQ== [fileUNF]

This R program calculates CFI for each patient from analytic data files containing information on patient identifiers, ICD-9-CM diagnosis codes (version 32), ICD-10-CM Diagnosis Codes (version 2020), CPT codes, and HCPCS codes. NOTE: When downloading, store "CFI_ICD9CM_V32.tab" a...



Study objectives

- Can CFI be used as a proxy for FAST stage in claims data?
- What is the optimal CFI cutpoint for moderate-severe dementia?

Data sources and study design

- National Health and Aging Trends Study (NHATS)
 - To derive the optimal cutpoint of CFI that maximizes sensitivity and specificity combined
- Medicare Current Beneficiary Survey (MCBS)
 - To validate the optimal CFI cutpoint derived from NHATS

Study population

NHATS (Development cohort)

- **Eligibility criteria:**
 - Participants in round 5 (2015)
 - 65 years or older
 - Living in the community
 - Possible or probable dementia in survey
 - FFS enrollment for ≥ 12 months
- **Dementia identification:**
 - Self-reported diagnosis
 - AD-8 score ≥ 2 points
 - ≤ 1.5 SDs below the population mean in at least one of the tests (orientation, memory, and executive function)

MCBS (Validation cohort)

- **Eligibility criteria:**
 - Participants in the 2016-2018 panels
 - 65 years or older
 - Living in the community
 - Dementia in survey or claims
 - FFS enrollment for ≥ 12 months
- **Dementia identification:**
 - Self-reported diagnosis
 - CCW dementia algorithm

Operationalizing FAST in NHATS

7f		#1 AND #2 AND #3 AND (#4 OR #5)
7e		1) 3-6 IADL disabilities (one must be finances, meds, or cooking)
7d	Severe dementia	2) Need help with dressing, bathing, and toileting
7c		3) Incontinence
7b		4) Unable to speak or has impaired speech
7a		5) Need help with getting out bed or has not moved inside house
6e	Moderately severe dementia	#1 AND #2 AND #3 AND NOT Stage 7
6d		1) 3-6 IADL disabilities (one must be finances, meds, or cooking)
		2) Need help with dressing, bathing, and toileting
		3) Incontinence
6c	Moderately severe dementia	#1 AND #2 AND NOT Stage 6d-7
		1) 3-6 IADL disabilities (one must be finances, meds, or cooking)
		2) Need help with dressing, bathing, and toileting

Operationalizing FAST in NHATS

6b Moderately severe dementia

#1 AND #2 AND NOT Stage 6c-7

- 1) 3-6 IADL disabilities (one must be finances, meds, or cooking)
- 2) Need help with dressing and bathing

6a Moderately severe dementia

#1 AND #2 AND NOT Stage 6b-7

5 Moderate dementia

- 1) 3-6 IADL disabilities (one must be finances, meds, or cooking)
- 2) Need help with dressing

4 Mild dementia

#1 AND NOT Stage 5-7

- 1) 3-6 IADL disabilities (one must be finances, meds, or cooking)

3 Mild cognitive impairment

NOT Stage 4-7

Operationalizing FAST in MCBS

- Similar to NHATS
- Modifications due to the unavailability of the items:
 - IADL medication management: 5 IADLs were used (vs 6 IADLs in NHATS).
 - Speech: use of a proxy due to the individual's mental incapacity was used.

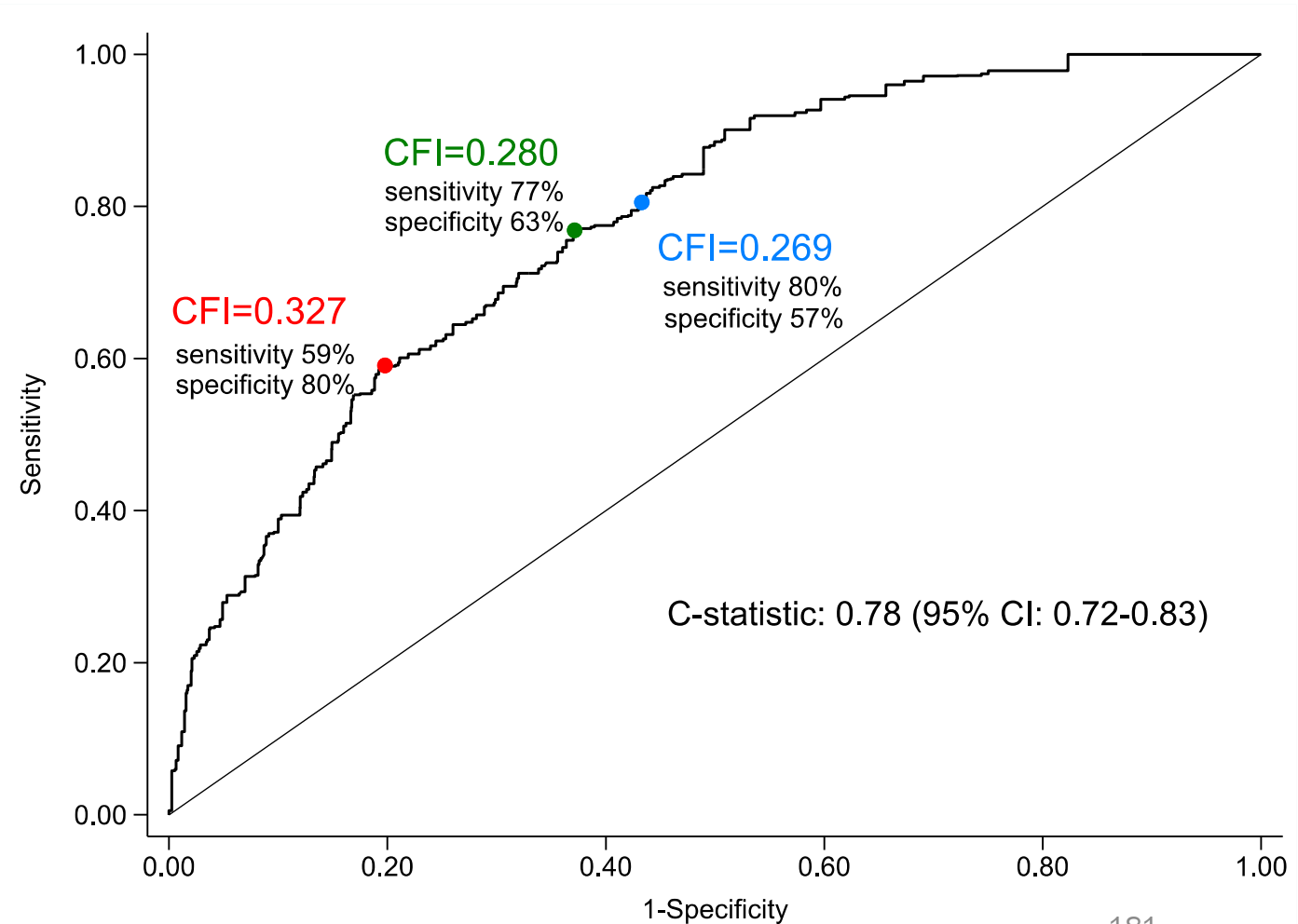
Characteristics of study populations

Characteristics	NHATS (n=814)	MCBS (n=658)
Age, years, mean	80.2	80.7
Female, %	50.8%	58.8%
Non-Hispanic white race	70.1%	81.3%
Black race	12.9%	10.6%
Other race	21.0%	8.1%
ADL disability, %	37.7%	29.3%
IADL disability, %	81.5%	59.7%
FAST stage 5-7	25.9%	14.9%
CFI, mean	0.29	0.22

Survey weights were applied to reflect national estimates.

Deriving CFI cutpoints in NHATS

- Outcome: moderate-severe dementia (FAST 5-7)



Performance of CFI for identifying moderate-severe dementia (FAST 5-7)

CFI cutpoint	NHATS (n=814)				MCBS (n=658)			
	SEN	SPE	PPV	NPV	SEN	SPE	PPV	NPV
≥ 0.28 (optimal)	77%	63%	67%	73%	49%	80%	30%	90%
≥ 0.15	100%	14%	29%	100%	85%	30%	28%	86%
≥ 0.25	89%	49%	38%	93%	59%	74%	42%	85%
≥ 0.35	49%	85%	53%	83%	19%	97%	69%	79%

Survey weights were applied to reflect national estimates.

Main findings from NHATS and MCBS

- CFI seems reasonably good in identifying moderate-severe dementia.
 - *Moderate-severe dementia* vs *dementia and moderate-severe frailty*
- Somewhat lower performance in MCBS may be due to:
 - Healthier MCBS sample than the NHATS sample
 - Lack of cognitive testing in MCBS in identifying participants with dementia
 - Different operationalization of FAST in MCBS due to item unavailability

NLP approach for ADL and IADL in EHR

- Patients (mean age 83 years) with dementia diagnosis code in Mass General Brigham EHR
 - Require at least one clinical note in 365 days before the diagnosis code
 - Training set: 10,000 sentences filtered with key terms (441 patients)
 - Validation set: 1,000 unfiltered sentences (80 patients)

Unfiltered sentences			
ADL	Prev	IADL	Prev
ADL (unspecified)	0.5%	IADL (unspecified)	0.1%
Ambulation	1.1%	Finances	0.3%
Toileting	0.2%	Medication	0.1%
Bathing	0.2%	Cooking	0.1%
Incontinence	0.1%	Shopping	0.1%
Feeding	0.1%	Housekeeping	0.1%

Performance of NLP approach

<i>Unfiltered validation set</i>	Any ADL disability		Any IADL disability	
Classifier	AUROC	AUPRC	AUROC	AUPRC
Deep learning	0.991	0.817	0.794	0.568
Bio+Clinical BERT	0.785	0.621	0.750	0.584
Logistic regression	0.981	0.737	0.960	0.538
LASSO	0.969	0.675	0.986	0.271
Random forest	0.990	0.806	0.945	0.521
Support vector machine	0.986	0.822	0.959	0.456
XGBoost	0.978	0.771	0.991	0.553

Claims-based vs EHR NLP-based approach

- **CFI** provides *fair to good discrimination* for FAST stage 5-7, offers generalizability, and is relatively easy to implement.
- **NLP** provides *excellent discrimination* for ADL and IADL (any disability) at the sentence level, but it is limited due to *sparse documentation* and *uncertain generalizability across health systems*.

Session 3:

ePCTs of Deprescribing Interventions in Dementia

Moderator:

Niteesh Choudhry, MD, PhD – Brigham and Women's Hospital,
Harvard Medical School

Presenters:

Jerry Gurwitz, MD – UMass Chan Medical School

Helen Kales, MD – UC Davis Health

Lorella Palazzo, PhD – Kaiser Permanente Washington Health Research Institute

Robert Penfold, PhD – Kaiser Permanente Washington Health Research Institute

Elizabeth Phelan, MD, MS – University of Washington

Panelists:

Ariel Green, MD, MPH, PhD – Johns Hopkins University School of Medicine

Dae Hyun Kim, MD, MPH, ScD – Hebrew SeniorLife's Marcus Institute for Aging Research, Harvard Medical School

Marcel Salive, MD, MPH – National Institute on Aging



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MEDICAL SCHOOL

D-PRESCRIBE-AD

**Developing a Program to Educate and Sensitize Caregivers
to Reduce the Inappropriate Prescription Burden in Elderly
with Alzheimer's Disease (D-PRESCRIBE-AD)**

Jerry H. Gurwitz, MD
UMass Chan Medical School
Worcester, Massachusetts

NIA 4R33AG069794



D-PRESCRIBE-AD Overarching Aim

A large pragmatic trial to evaluate a health plan-based, mailed, patient/care partner educational intervention focused on deprescribing of high-risk medications in patients with AD/ADRD, using a randomized trial design.

Antipsychotics, sedative/hypnotics, and strong anticholinergics are the high-risk medications of interest.



D-PRESCRIBE-AD

- ▶ Pragmatic trial
- ▶ Health plan-based
- ▶ Mailed patient/care partner intervention
- ▶ Patients with AD/ADRD
- ▶ Deprescribing high-risk medications (antipsychotics; sedative/hypnotics; anticholinergics)
- ▶ Randomized trial design: randomization at the individual patient level



D-PRESCRIBE-AD: Eligibility Criteria

Inclusion : Diagnosis of AD/ADRD based on Chronic Conditions Warehouse codes, or treatment with a pharmacologic therapy used for AD (e.g., donepezil, rivastigmine, galantamine, or memantine)

1. *Use of targeted high-risk medications: antipsychotics; sedative-hypnotics; strong anticholinergics*
2. *Age ≥ 50 years of age as of cohort entry date.*

Exclusion. NH stay or missing contact information or information on prescriber.



D-PRESCRIBE-AD Design

- ▶ 14,442 subjects with 4,814 allocated to each of the three study arms
- ▶ Arm 1. Patient/Care Partner + Provider Arm: Patients and providers mailed letters and educational materials
- ▶ Arm 2. Provider only Arm: Only providers mailed letters and educational materials
- ▶ Arm 3. Usual Care Arm: No mailing, but data collection identical to intervention arms

Intervention Materials – Deprescribing.org

Patient Cover Letter

<Member First Name>, managing your medications is important to your health

[ANTHEM LOGO]

It's necessary to talk with your doctor regularly about your medications to ensure they are still right for you. To help you do that, we've included information about [drug name] which you are currently taking, so you can discuss this medication at your next doctor's visit.

Share this information

Show this letter and the enclosed information sheet to your doctor at your next visit.

If you have someone who helps you with your medications, share these materials with them, too.

For more information

Phone: 833-669-7650 (toll free)

Email: HealthResearch@healthcare.com

Website: knowmymeds.org

Important: Do not stop or change this medication without talking to your doctor.

Anthem and HealthCoos, Inc. have partnered to bring you this information. If you do not wish to receive any more materials like this, please email dnc@healthcare.com or call 844-203-3796.

— Your <Anthem> service team

Patient Information Sheet

Are your medications still right for you?

As life changes, your medication needs may change as well. Medications that were once good for you may not be the best choice for you today.

The medications in this box are sometimes used for anxiety or sleep:

- Alprazolam (Xanax*)
- Clonazepam (Klonopin*)
- Diazepam (Valium*)
- Eszopiclone (Lunesta*)
- Lorazepam (Ativan*)
- Temazepam (Restoril*)
- Zolpidem (Ambien*)

These medications can cause side effects including:

- falls and fractures
- dizziness
- worsened memory problems
- daytime fatigue
- dependence

As people age, they are more likely to experience side effects. Because of this, experts recommend that people on these medications talk to their healthcare provider about whether they should continue, reduce, or stop these medications.

Do not stop this medication before talking with your doctor. These medications must be reduced slowly. They should not be stopped suddenly. Stopping too quickly may cause problems.

Your doctor may suggest alternative medications or lifestyle changes that may help you.

What should you do?

- If someone helps you with your medications at home, share this information with them.
- Bring this information sheet to your doctor.**
- Ask your doctor whether reducing or stopping this medication is the right choice for you.

Pocket Card

Questions to ask your doctor

- Is this medication still right for me?
- Are there lifestyle changes that I could try instead?
- If I don't need this medication, can we make a plan to discontinue it?

knowmymeds

Always consult with your doctor before making any changes to your medications.

Website

knowmymeds HOME ABOUT PATIENTS/CAREGIVERS PROVIDERS FEEDBACK

Are My Medications Still Right For Me?

Provider Cover Letter

[Date]

Dear [Clinician Name],

This letter contains information that may assist you in caring for your patients. According to our records a patient of yours may be taking [medication name].

Sedative-hypnotic medications often have side effects including falls and fractures, dizziness, memory problems, and daytime fatigue. Experts recommend that these potentially inappropriate medications be avoided by older adults in most circumstances.¹

We have mailed a patient information sheet on sedative-hypnotic medications to the following patient (a copy is enclosed):

Name: [Patient Name]
 Date of Birth: [Patient Date of Birth]
 Medication: [Patient Medication]
 Date Initiated: [Date Medication Initiated]

We have enclosed an algorithm that may help you decide whether to reduce or discontinue this medication, and a tapering guide to help patients understand and track dose reductions. This, along with the patient information sheet, are available at knowmymeds.org.

We realize that our records may not reflect all clinically relevant information or may be incomplete. If you have questions or concerns about this letter, please contact us at Letters.Perfetti@anthem.com or 910-916-1000.

Sincerely,

Chief Medical Office
 [Health Plan]

Tapering Guide

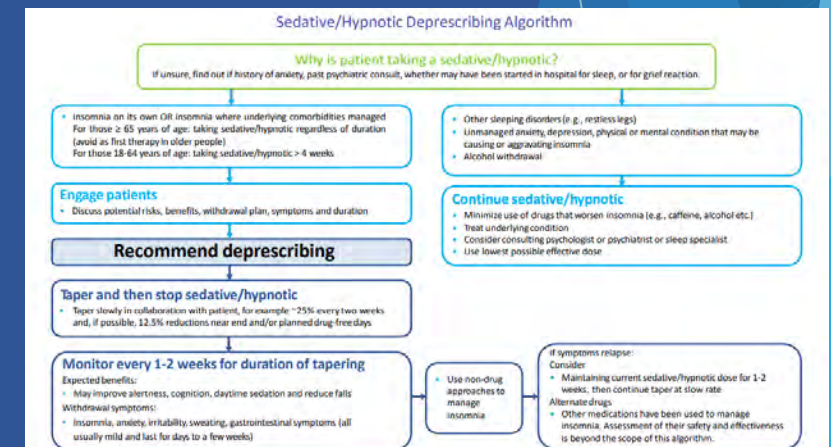
Medication Tapering Plan

Talk to your doctor, nurse or pharmacist before making any changes to your medication.

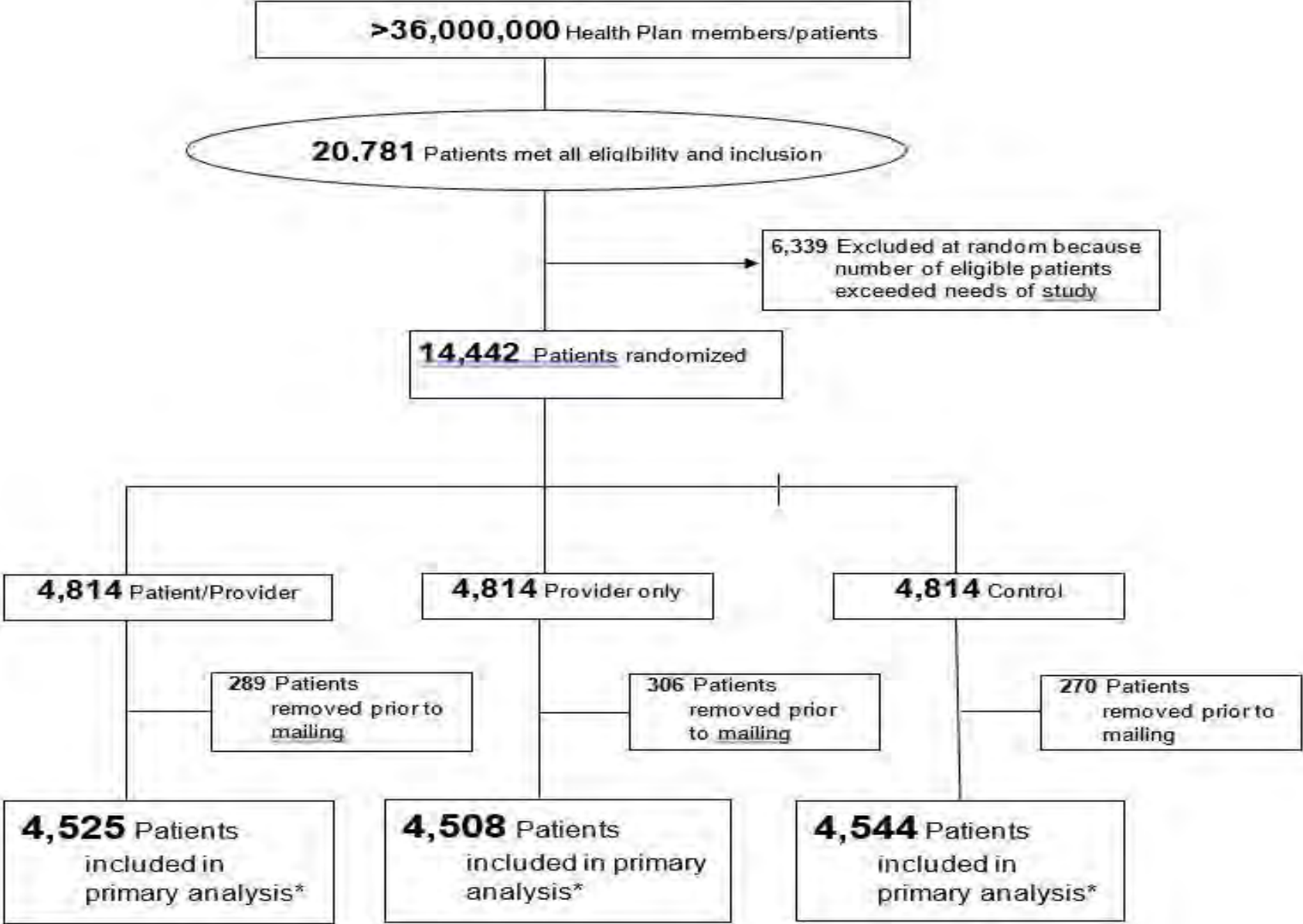
Patient Name: _____ Doctor: _____ Medication: _____

WEEK OF:	SU	MO	TU	WE	TH	FR	SA
1.	☐	☐	☐	☐	☐	☐	☐
2.	☐	☐	☐	☐	☐	☐	☐
3.	☐	☐	☐	☐	☐	☐	☐
4.	☐	☐	☐	☐	☐	☐	☐
5.	☐	☐	☐	☐	☐	☐	☐
6.	☐	☐	☐	☐	☐	☐	☐
7.	☐	☐	☐	☐	☐	☐	☐
8.	☐	☐	☐	☐	☐	☐	☐
9.	☐	☐	☐	☐	☐	☐	☐
10.	☐	☐	☐	☐	☐	☐	☐
11.	☐	☐	☐	☐	☐	☐	☐
12.	☐	☐	☐	☐	☐	☐	☐
13.	☐	☐	☐	☐	☐	☐	☐

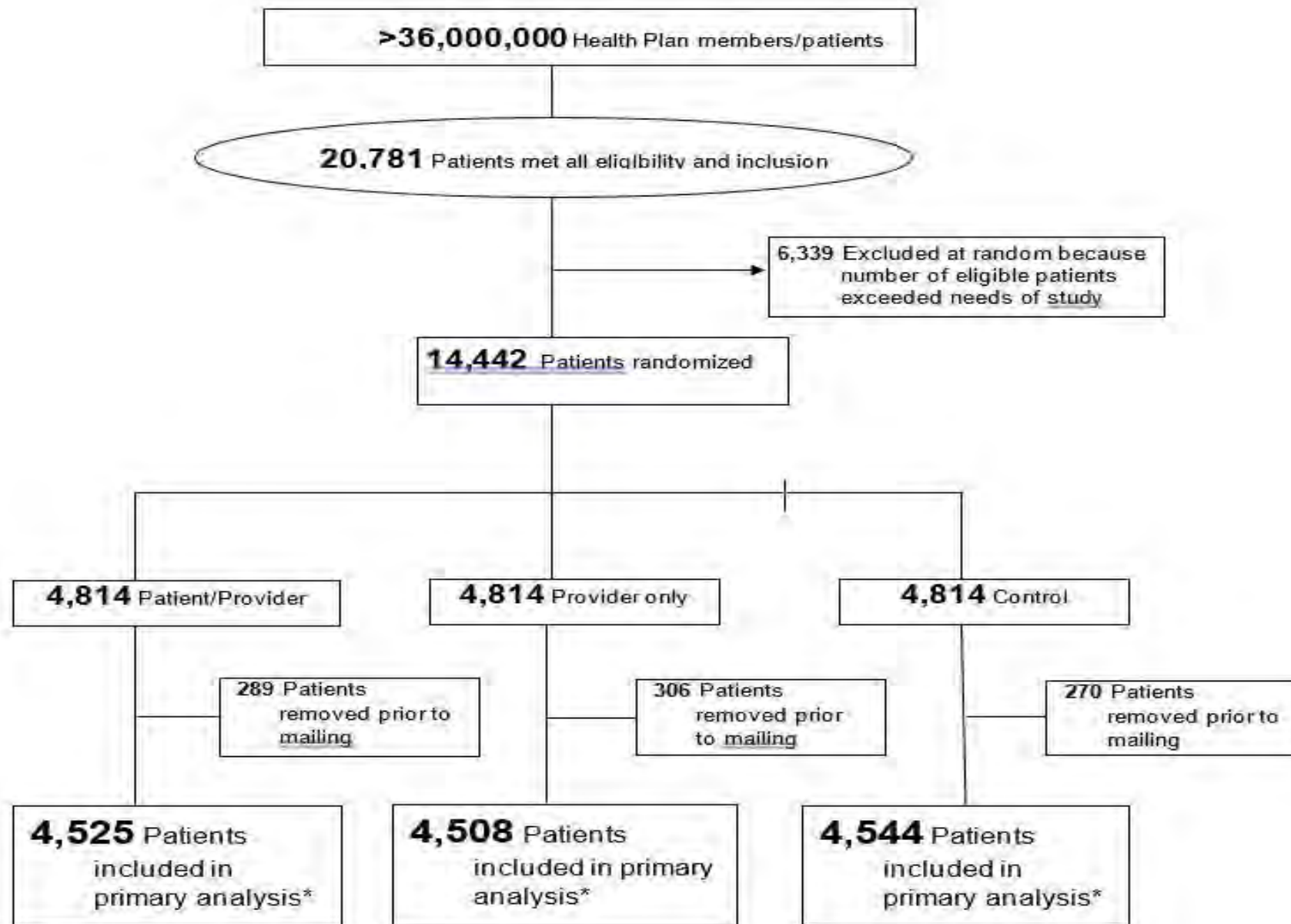
Algorithm



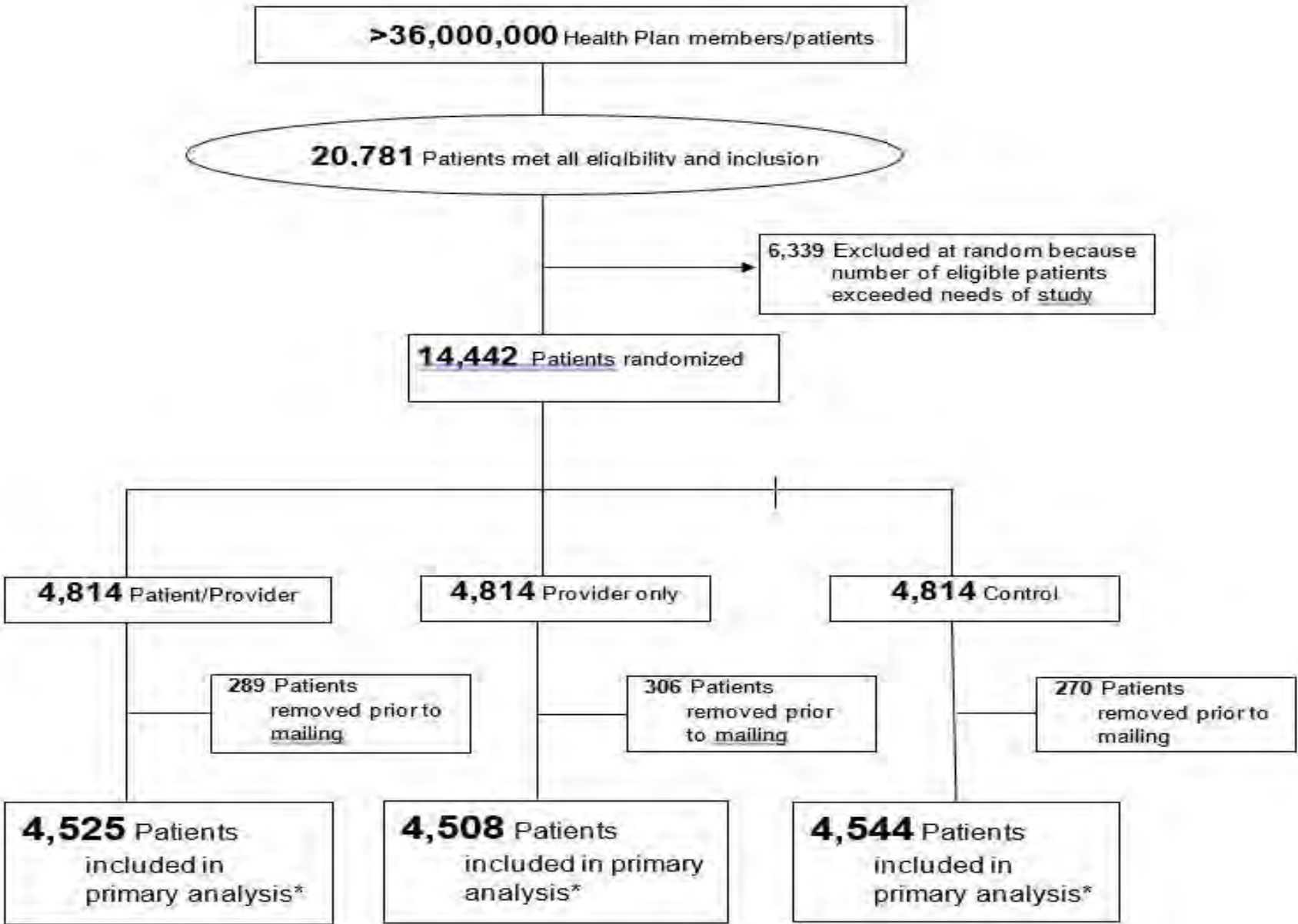
Flow Diagram of Primary Analysis Population



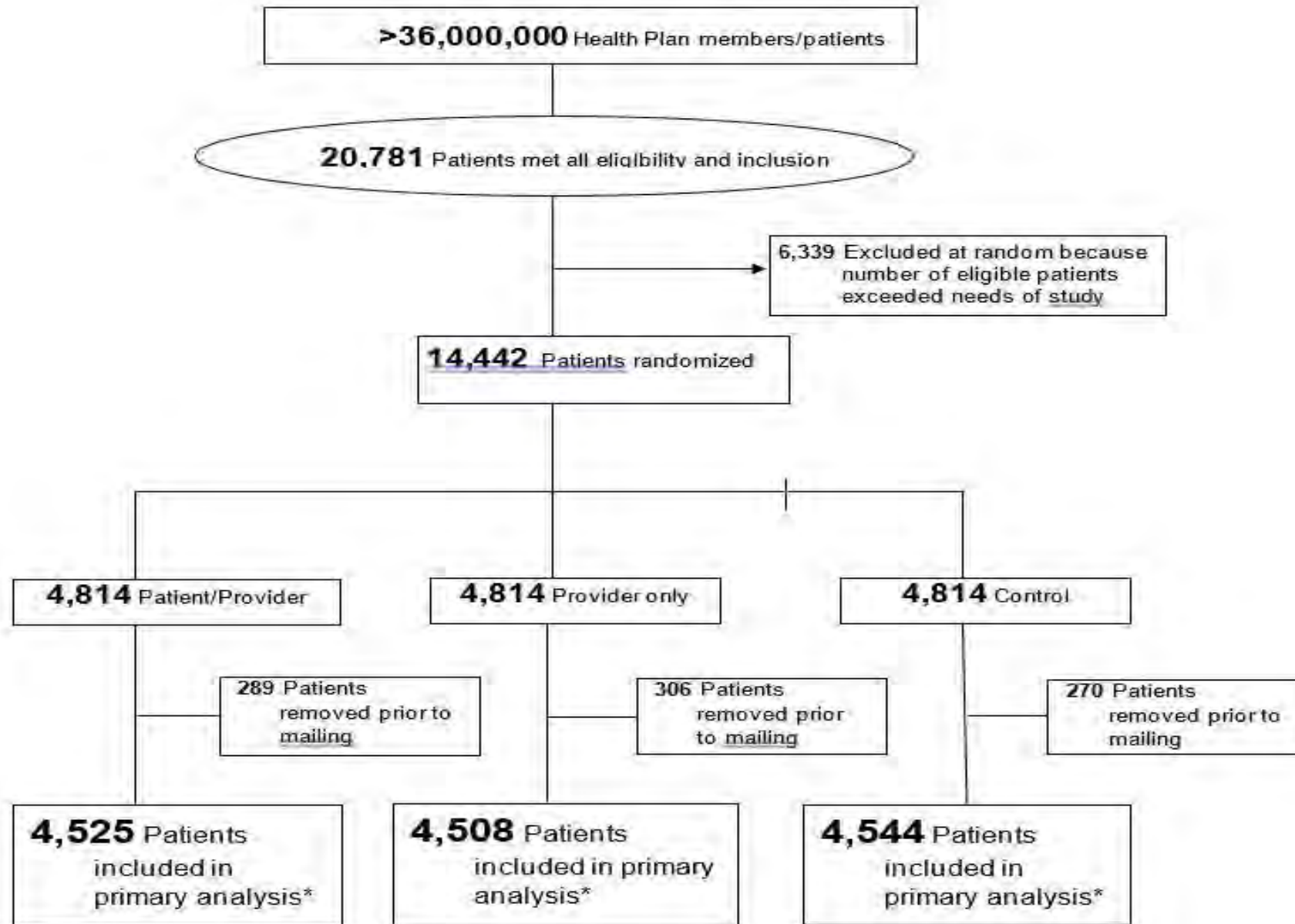
Flow Diagram of Primary Analysis Population



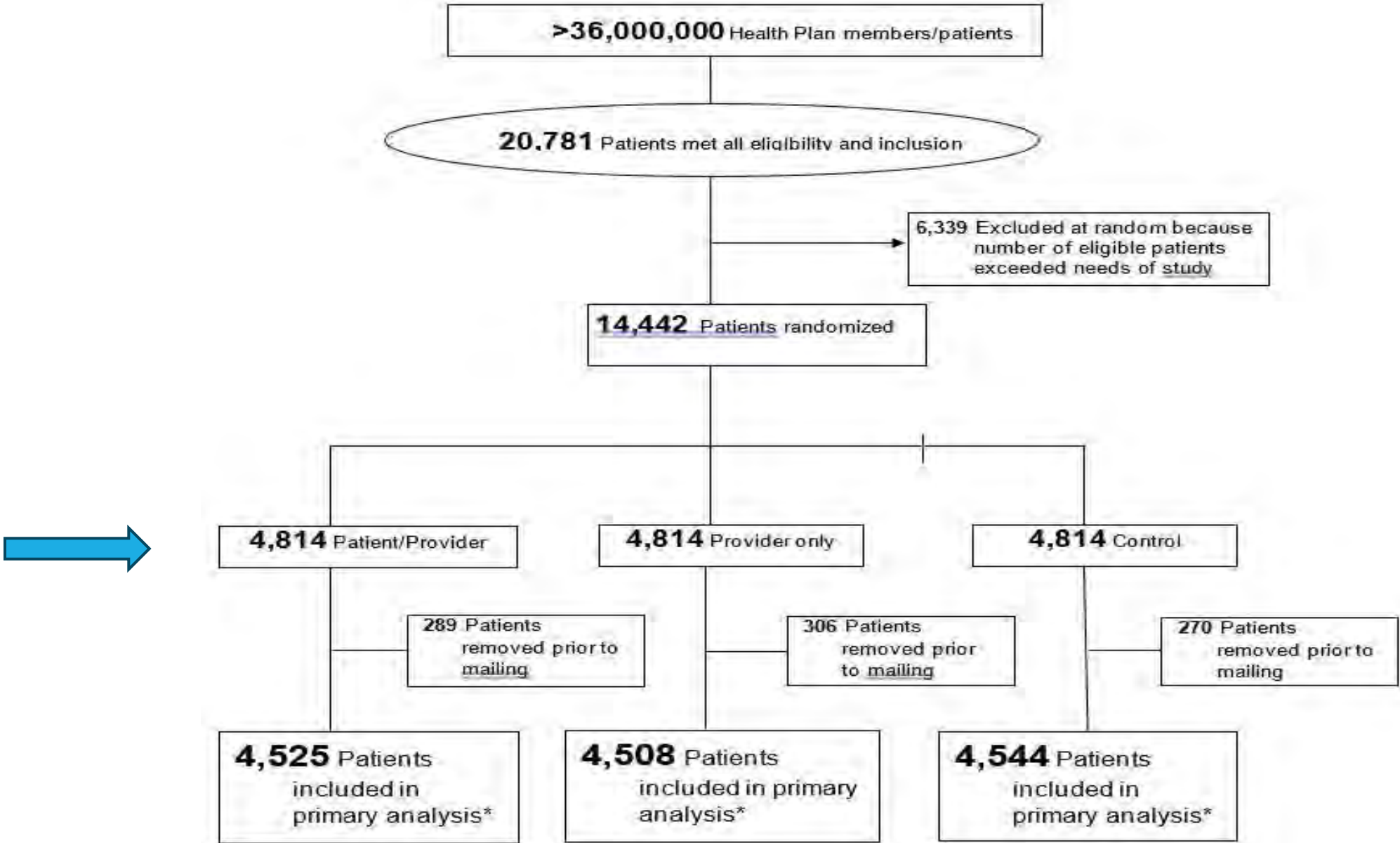
Flow Diagram of Primary Analysis Population



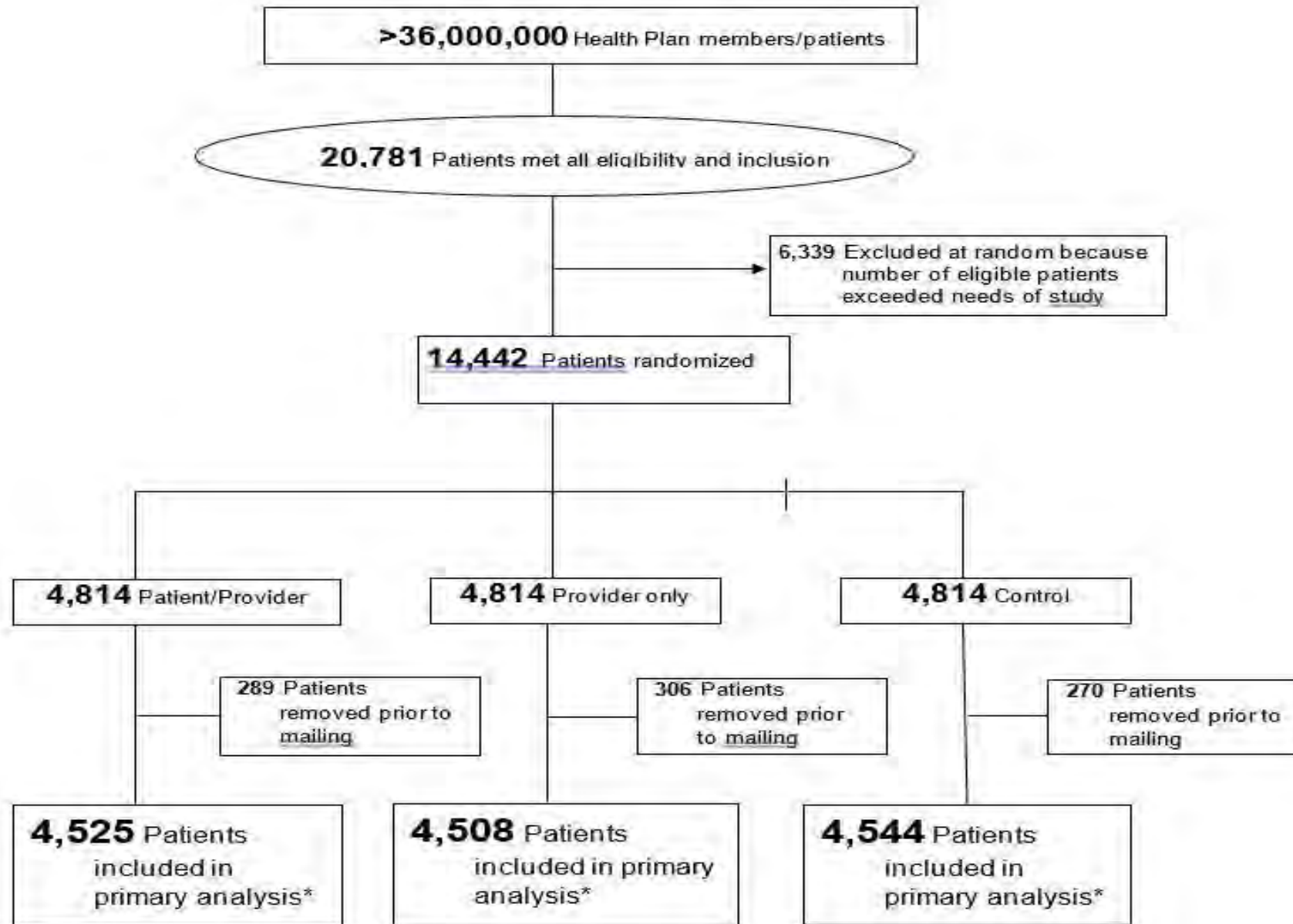
Flow Diagram of Primary Analysis Population



Flow Diagram of Primary Analysis Population



Flow Diagram of Primary Analysis Population





Baseline Demographics



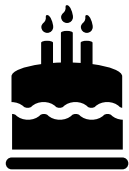
68% Female



2% Hispanic

11% Black or African American

24% Race/Ethnicity unknown



90% age 65+

24% age 85+

Breakdown of Targeted Drug Classes



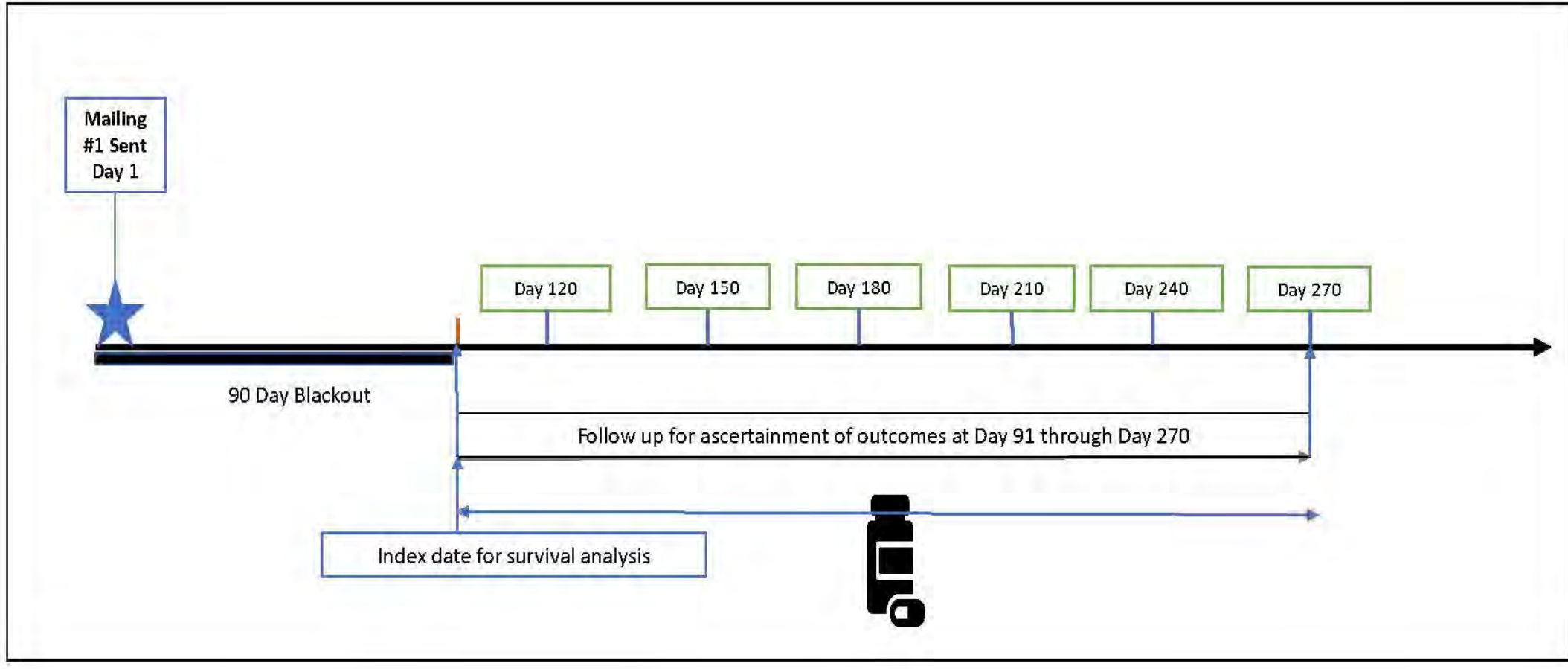
44% Antipsychotics
19% Sedative-Hypnotics
38% Anticholinergics



UMass Chan
MEDICAL SCHOOL



Intervention Design





Outcomes

Primary Outcome: Absence of any dispensing of the targeted medication from day 91 through day 270 during the 9 months following the mailing.

Secondary Outcomes (not to be presented today):

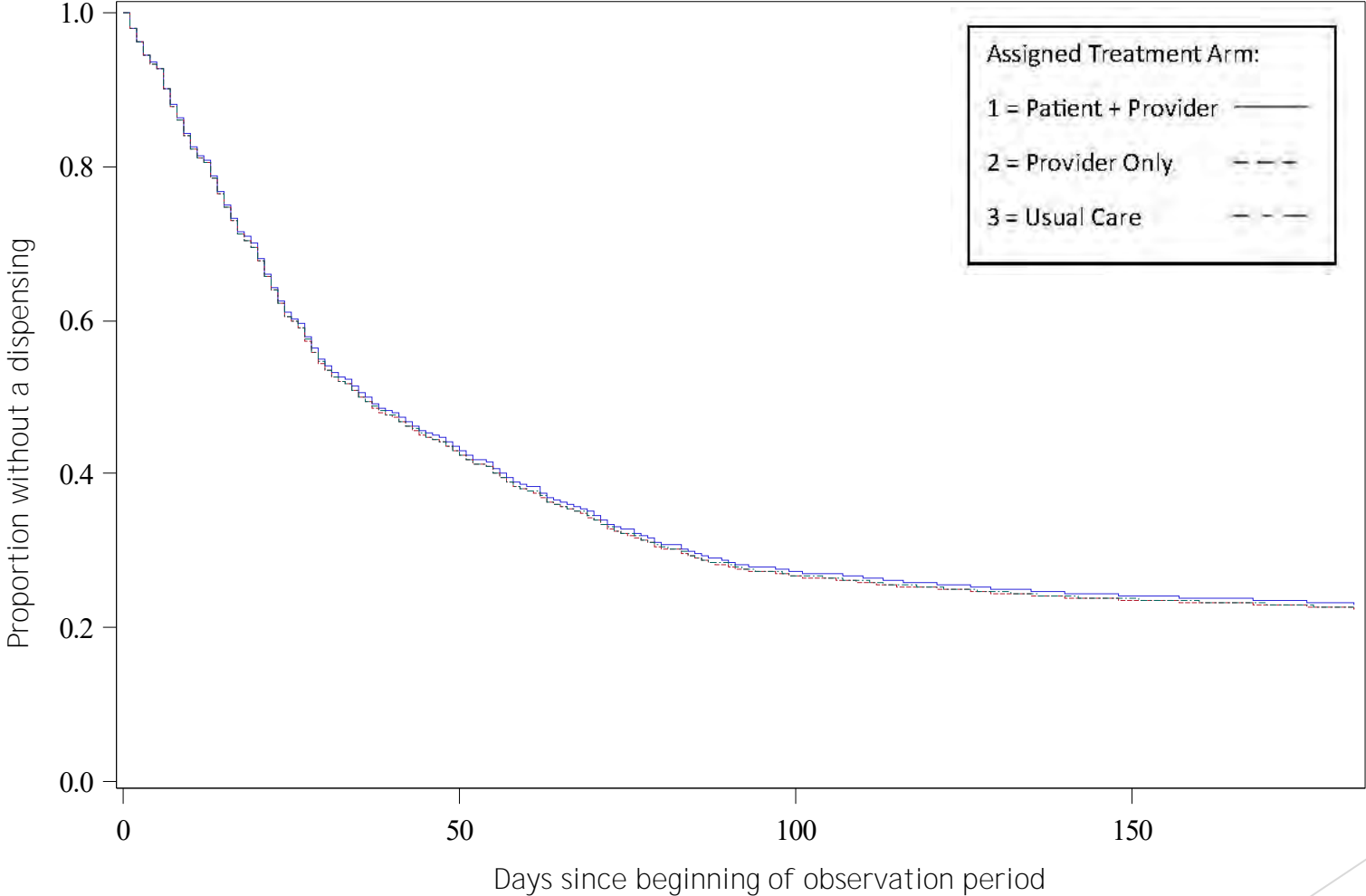
- a) Any dose reduction (defined as $\geq 50\%$ reduction in dose of the targeted medication)
- b) Percentage of patients with polypharmacy (>5 active prescriptions for different oral agents)
- c) Health care utilization: emergency room visits; hospitalizations; non-acute institutional stays (e.g., skilled nursing facilities)
- d) In-hospital all-cause mortality



Percentage not dispensed the medication targeted for deprescribing during follow-up period

	Arm 1: Patient + Provider		Arm 2: Provider Only		Arm 3: Usual Care	
	N	%	N	%	N	%
<i>Primary outcome</i>						
Patients without dispensing	1,355	29.9	1,335	29.6	1,350	29.7

Results - All Medication Categories Combined – Probability of not getting dispensed the targeted medication

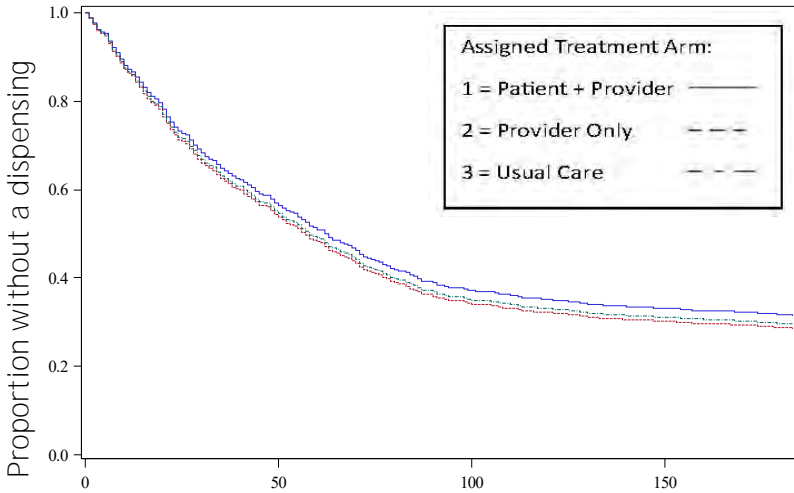


Results – By Drug Class



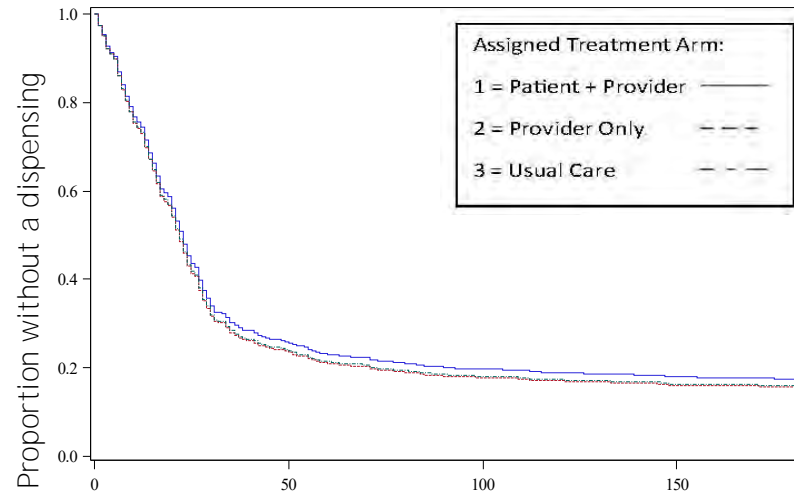
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Anticholinergics



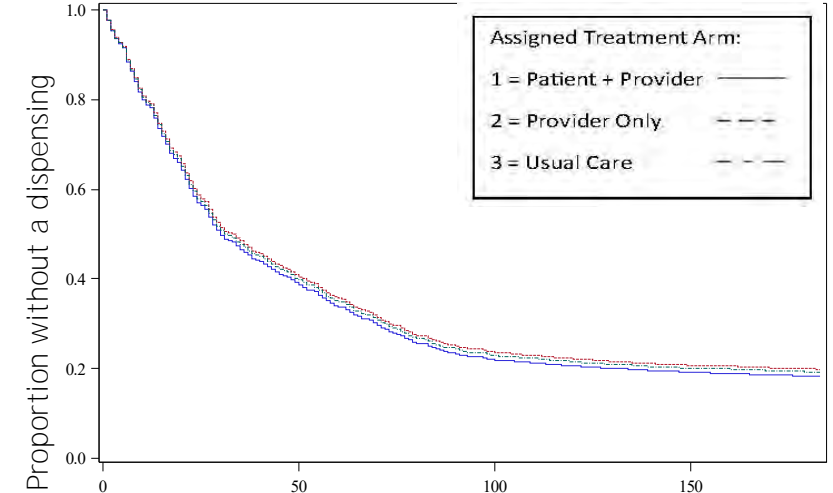
Days since beginning of observation period

Sedative/Hypnotics



Days since beginning of observation period

Antipsychotics



Days since beginning of observation period

If all goes well

Identify pts on target drugs

Mail to pt address on record

Patient reviews materials

Patient passes materials on to
care partner

Care partner reviews materials

Materials understood, seen as
important, need for action

Patient/care partner initiate
conversation with provider

Provider deprescribes

Where things might go wrong

Patient not on drug

Patient not at address (SNF,
deceased, moved)

Letter not opened; misplaced;
ignored

Patient does not share; has no
care partner

Materials not understood,
dismissed, or ignored

Provider not accessed (no
appointment, no call)

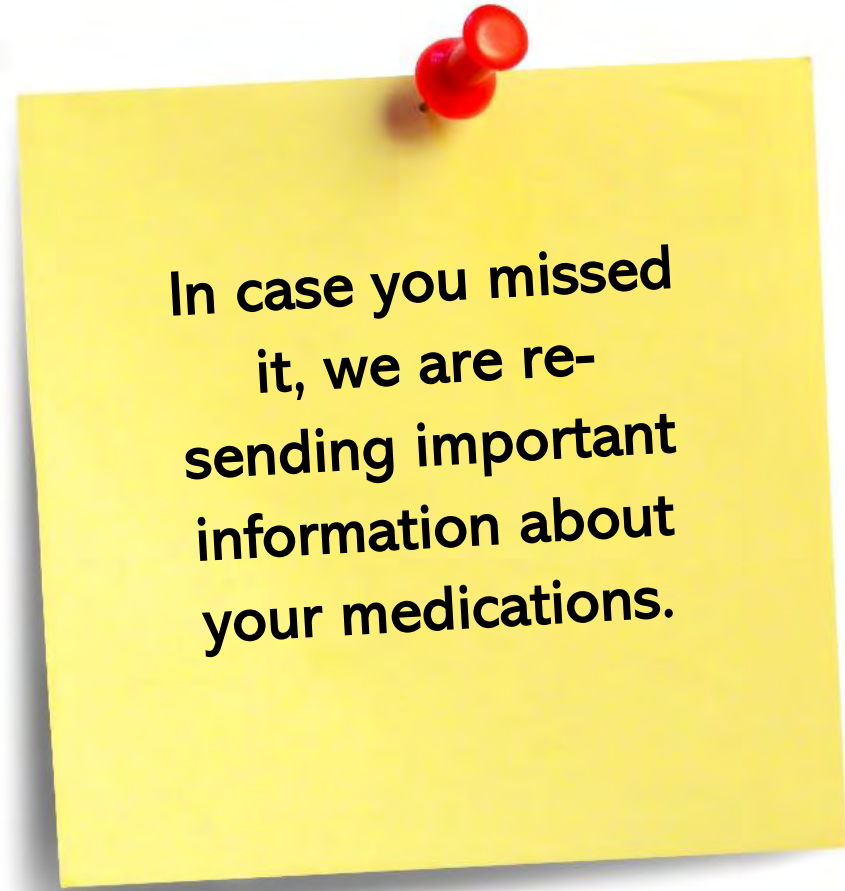
Provider disagrees with
recommendation



rial #2: Chance for a “do-over”

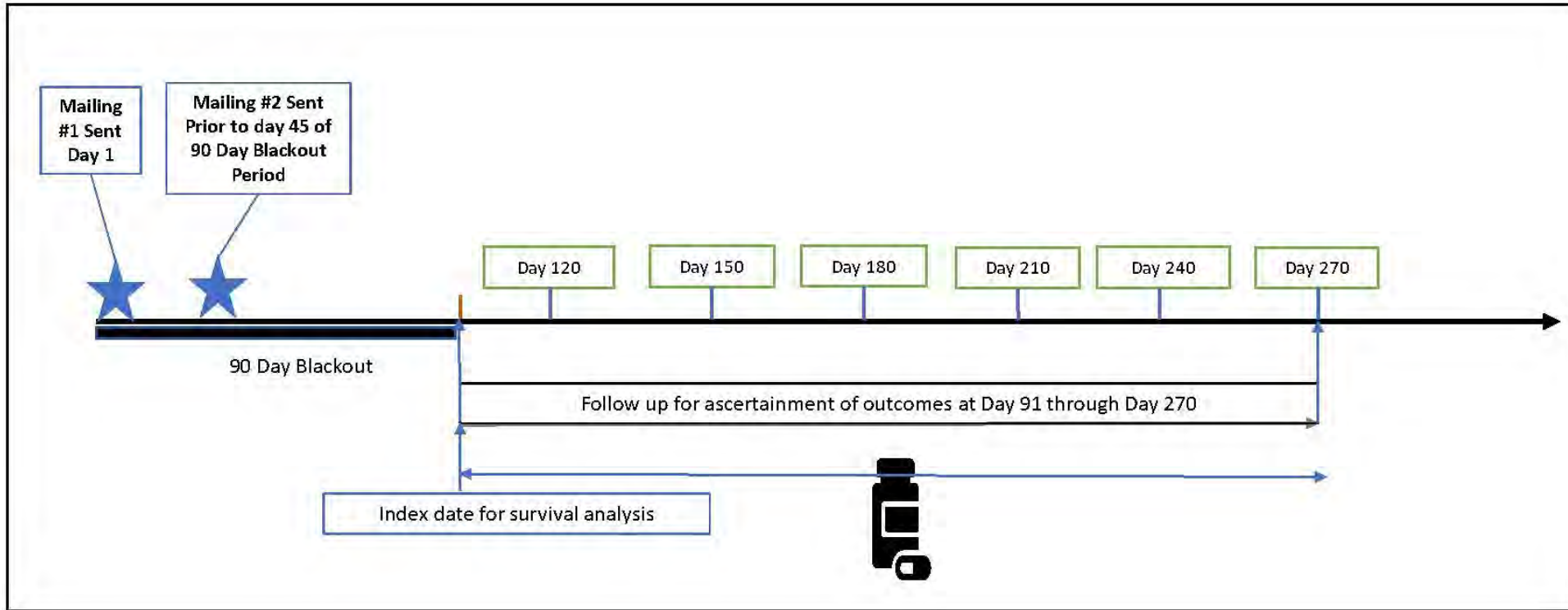
- ▶ Results of Trial #1
- ▶ Feasibility and timing – mailing by end of June 2024
- ▶ Cannot increase costs
- ▶ Must stay true to principles of “light-touch” intervention and essence of intervention employed in Trial #1
- ▶ Policy implications...

Reminder

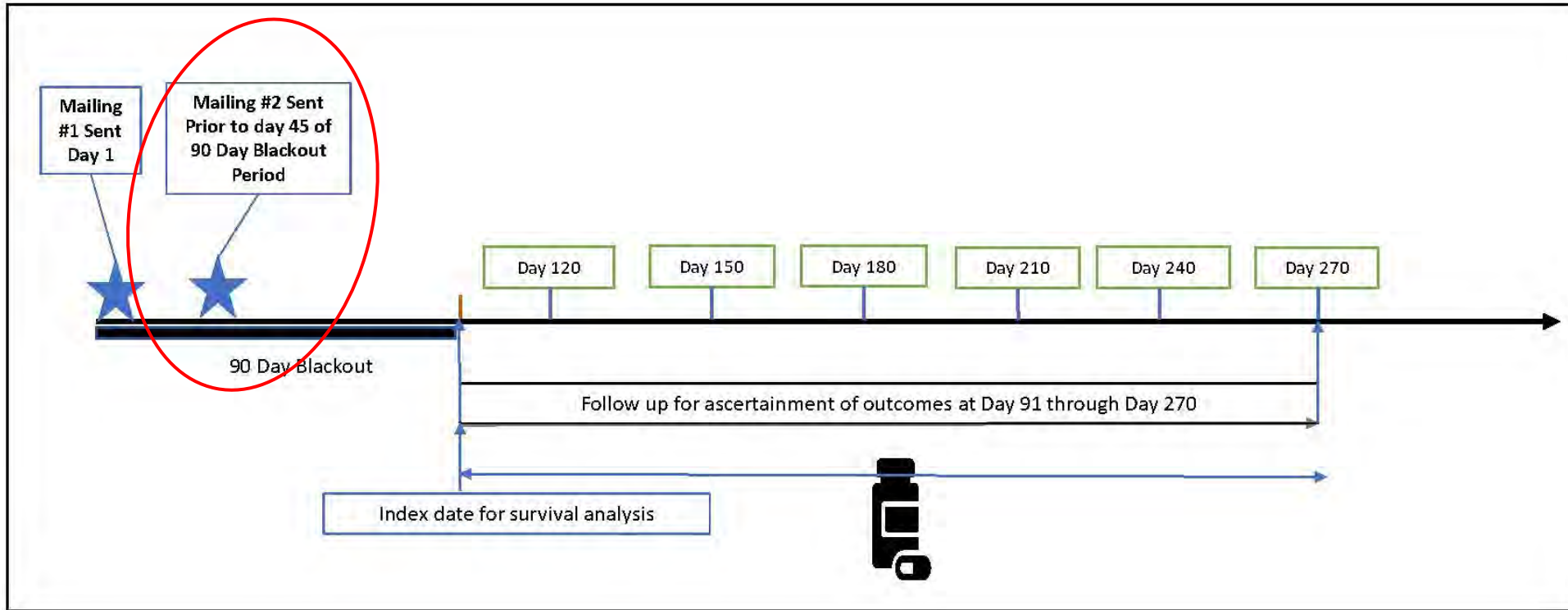


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Trial #2 Proposal: Test the benefits of a second (reminder) mailing



Trial #2 Proposal: Test the benefits of a second (reminder) mailing





D-PRESCRIBE-AD Design - Trial #2

Remains a prospective, randomized design with:

- ▶ Target drug classes: antipsychotics, sedative-hypnotics, and strong anticholinergics
- ▶ Randomization at the individual patient level

Modifications:

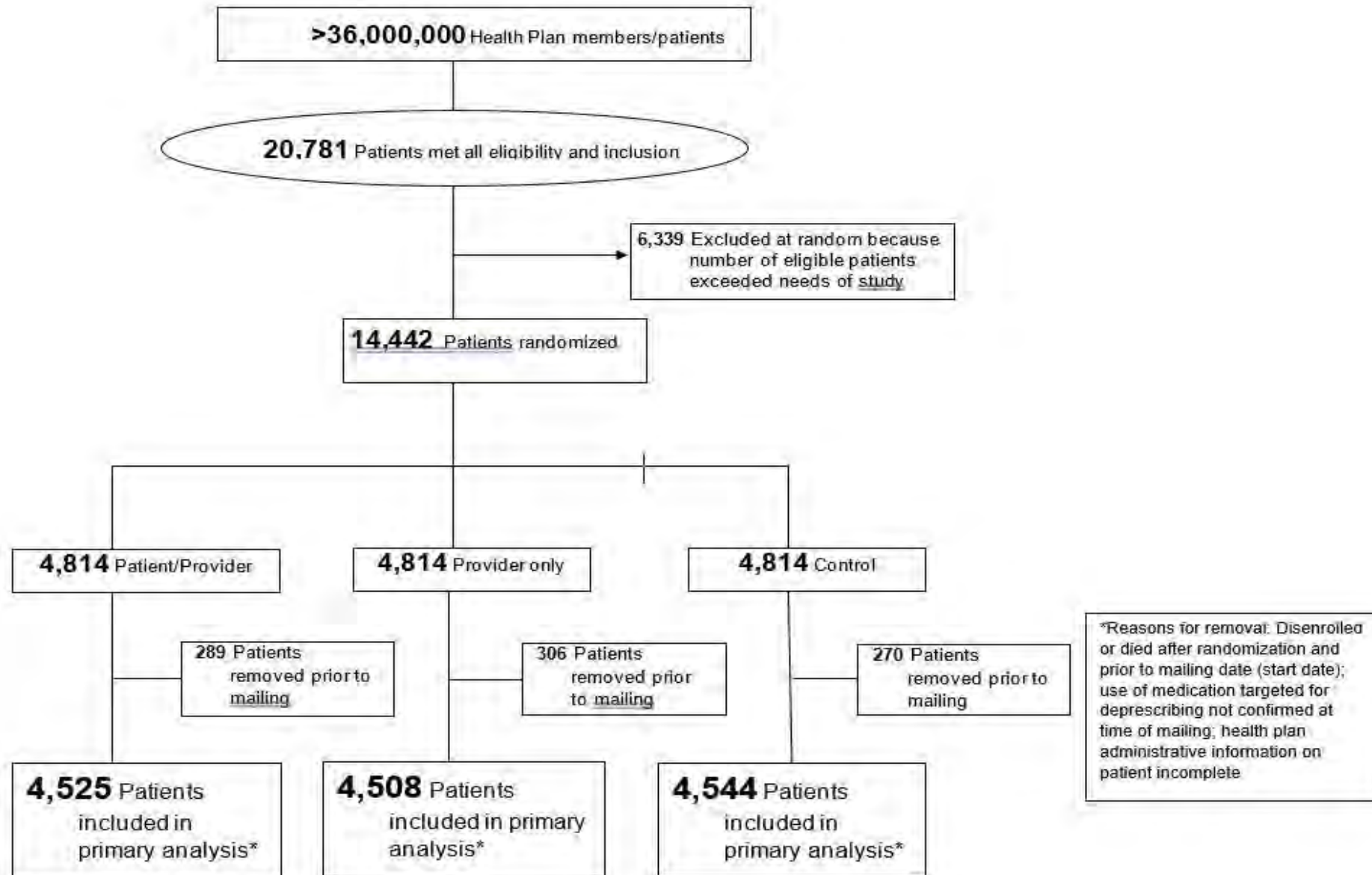
- ▶ Three arms:
 - ▶ **two mailings to patient + provider,**
 - ▶ single mailing to patient + provider,
 - ▶ usual care
- ▶ No provider only arm
- ▶ 7,221 subjects with 2,407 allocated to each of the three study arms



Discussion and Questions



Flow Diagram of Primary Analysis Population



UC DAVIS HEALTH

NIA IMPACT COLLABORATORY 2024 SCIENTIFIC CONFERENCE

Reducing Inappropriate Medication Use and Improving Health Outcomes for Behavioral and Psychological Symptoms of Dementia

Helen C. Kales MD
Chair of Psychiatry and Behavioral Sciences
Joe P. Tupin Endowed Professor
University of California Davis



Behavioral and Psychological Symptoms of Dementia

- Devastating syndrome affecting 5 million people in US, 16 million by 2050
- **Non-cognitive behavioral and psychological symptoms of dementia (BPSD)** are universal (>98%)
 - Can occur at any disease stage
 - Occur with every type of dementia
 - Often dominate the disease course
 - Associated with poor outcomes
 - Role of the family caregiver is critical

- Depression
- Anxiety
- Apathy
- Psychosis
- Agitation
- Aggression
- And “many more”

**Kales, Gitlin, Lyketsos
British Medical Journal
2015**

Dementia Care: Three big problems

- **Big problem #1=Inability to access relevant resources precisely when needed**
- **Big problem #2=Current dementia care is neither personalized nor precise**
- **Big problem #3=Behaviors remain the day to day focus of management, the medications we use to treat them are not very effective and the focus is on sedation**

Maust, Kales et al
JAMA Psychiatry
2015

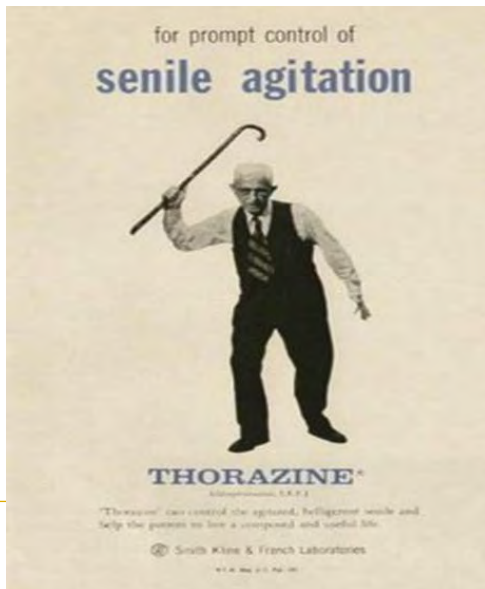
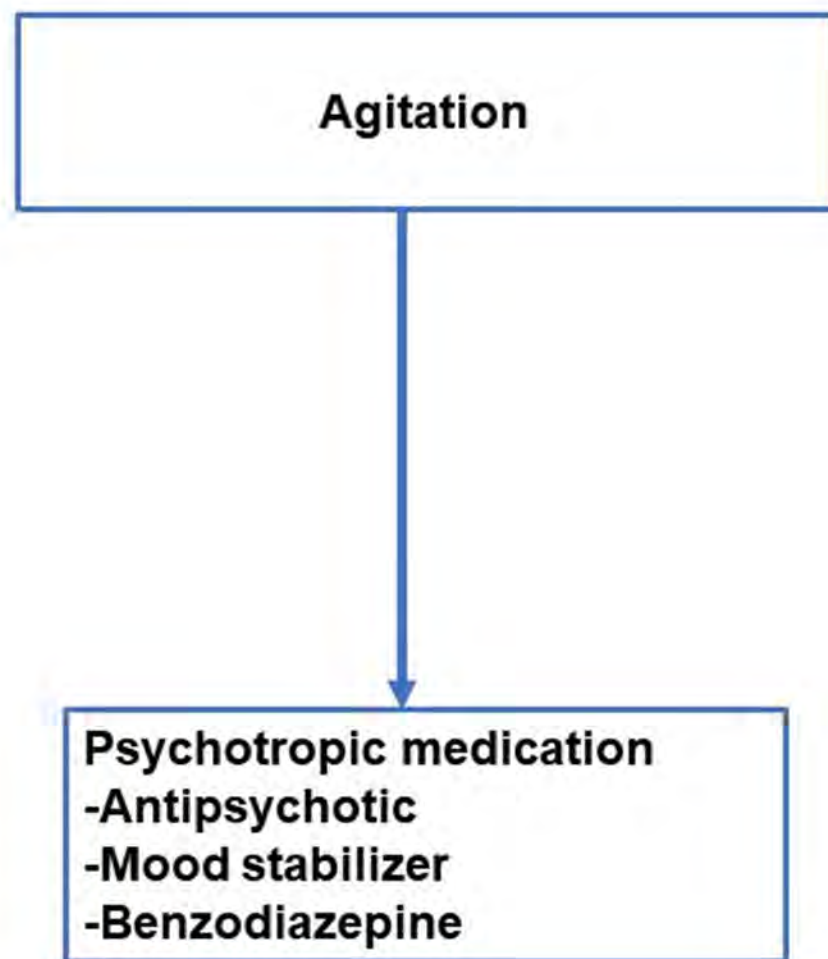


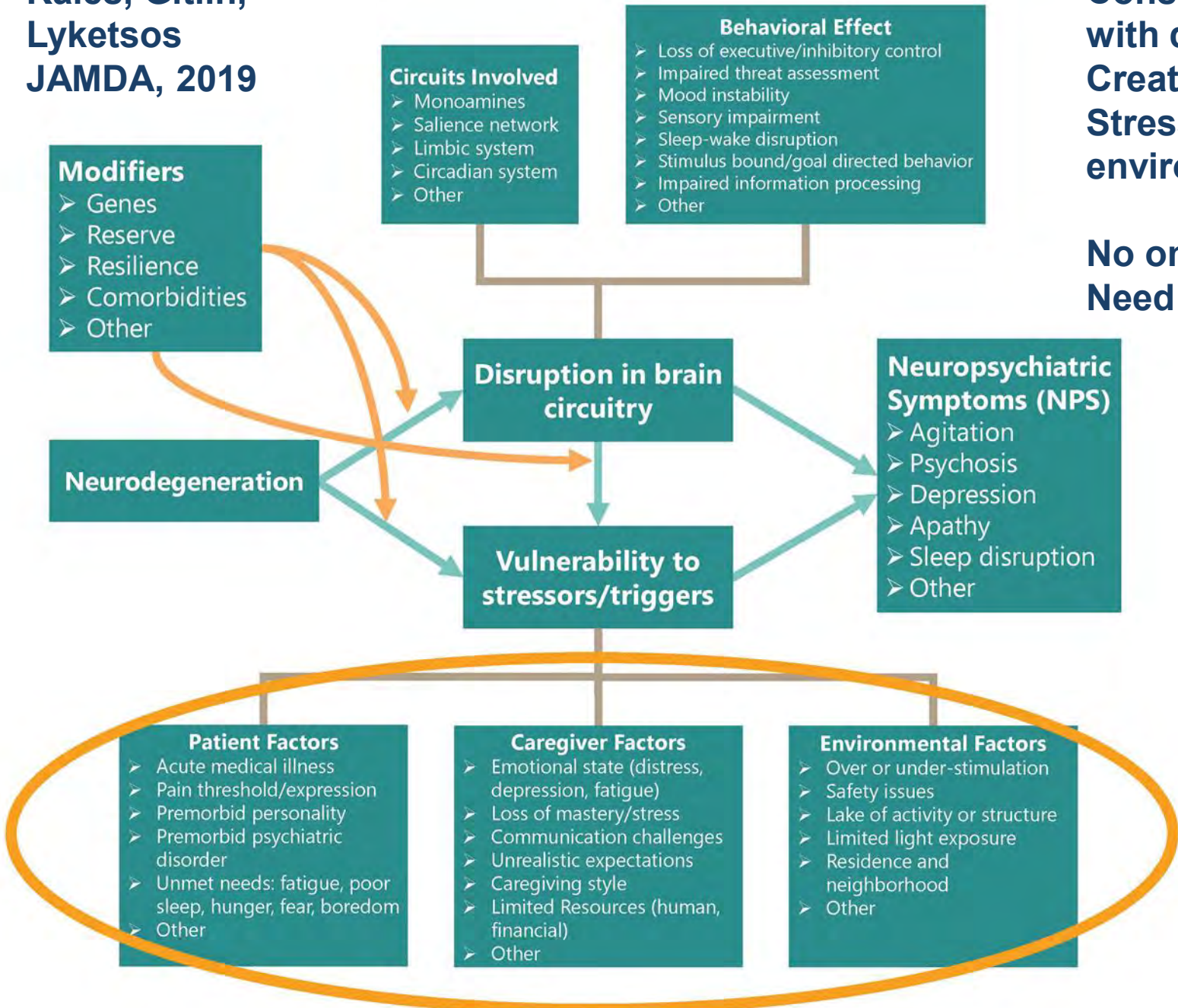
Table 3. Adjusted Mortality Risk Differences in Death Rates During the 180-Day Observation Period Between Medication Users and Antidepressant Users^a

Medication	Risk Difference, % (95% CI)	NNH (95% CI)
Antidepressant	[Reference]	NA
Haloperidol	12.3 (8.6-16.0) ^b	8 (6-12)
Olanzapine	7.0 (4.2-9.8) ^b	14 (10-24)
Quetiapine	3.2 (1.6-4.9) ^b	31 (21-62)
Risperidone	6.1 (4.1-8.2) ^b	16 (12-25)
Valproic acid	5.1 (1.8-8.4) ^b	20 (12-56)

Current Real-World “Assessment” of Behavioral and Psychological Symptoms of Dementia



**Kales, Gitlin,
Lyketsos
JAMDA, 2019**



Consequence of neurodegeneration associated with dementia

Creates an increased vulnerability to stressors
Stressors include patient, caregiver and environmental factors

No one-size-fits all solution
Need for personalization and precision

Big Problem #3



- **Big problem #3: Lack of training among caregivers (or providers) on how to use proven non-pharmacological strategies to manage behavioral symptoms**

Molinari et al, 2010;
Cohen-Mansfield et al, 2013

– Brodaty Meta-analysis



OR

**CHOLINESTERASE
INHIBITORS**



Brodaty et al, Am J Psychiatry, 2012

What outcomes result from BPSD?

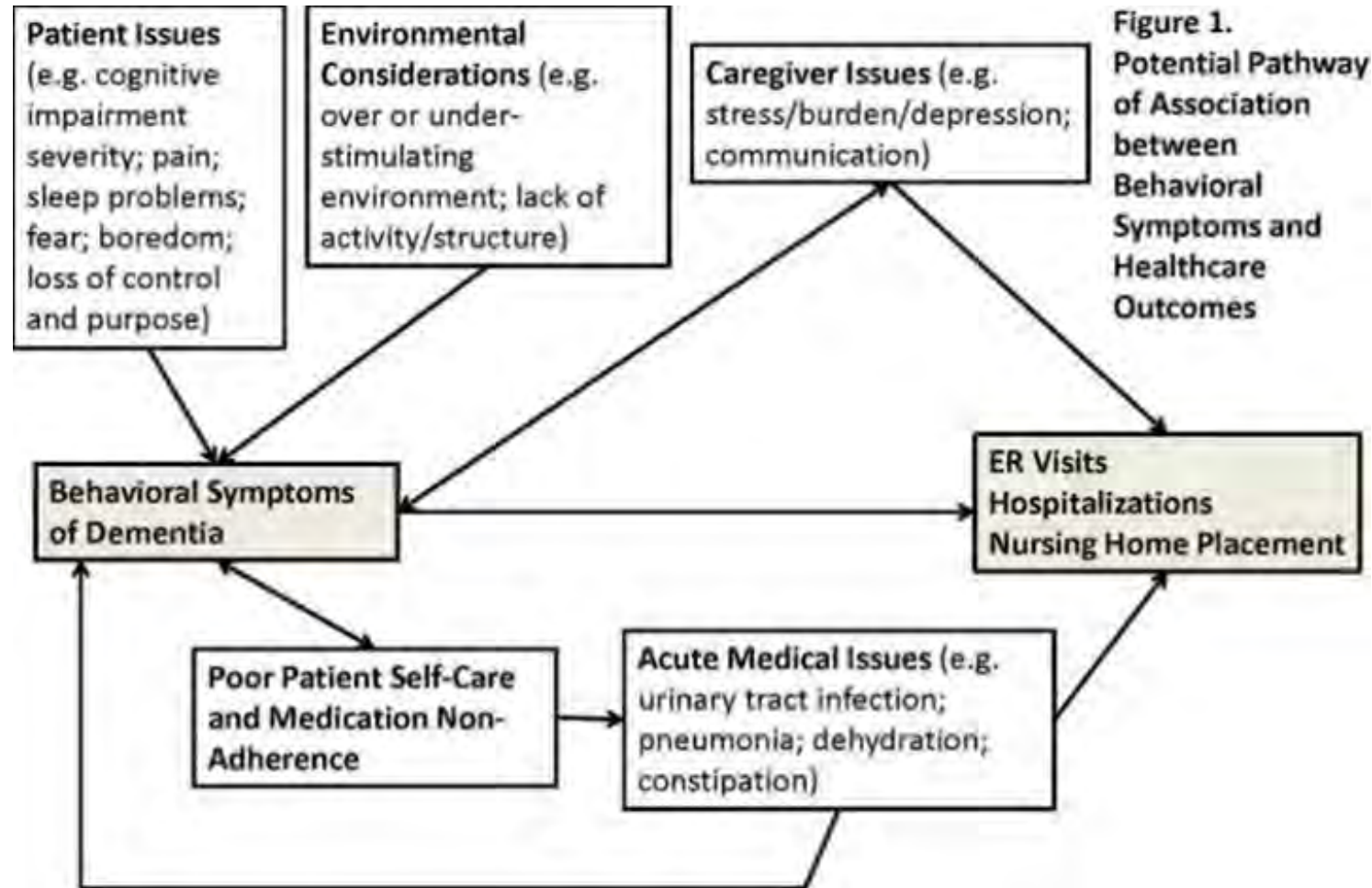
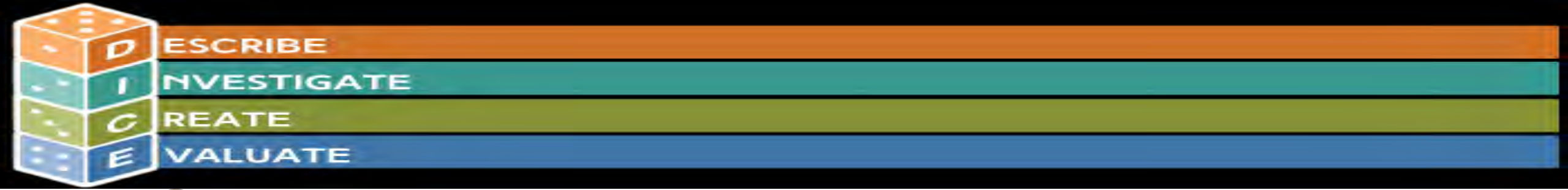


Figure 1.
Potential Pathway
of Association
between
Behavioral
Symptoms and
Healthcare
Outcomes



- **Describe** a behavior that challenges; who, what, where, when, and how the behavior occurs
- **Investigate** thinking like a detective and explore the person with dementia, the caregivers, and environment for possible clues to triggers underlying possible causes of behavior
- **Create** a prescription in collaboration with your team to help prevent and manage behaviors
- **Evaluate** and review prescription effectiveness, and modify or restart the process as needed

Kales, Gitlin, Lyketsos
Journal of the American Geriatrics
Society
2014

Regular Research Article

Moving Evidence-Informed Assessment and Management of Behavioral and Psychological Symptoms of Dementia into the Real World: Training Family and Staff Caregivers in the DICE Approach

Helen C. Kales, MD, Vincent Kern, BA, H. Myra Kim, ScD, Mary C. Blazek, MD MED

ARTICLE INFO

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Key Words:

Dementia
BPSD
caregiving

ABSTRACT

Objective: To investigate the impact of a one-day training program on caregivers' confidence and knowledge in managing aspects of dementia care. **Design:** One-day caregiver training program featuring: 1) an interactive, multi-media format; 2) a companion manual; and 3) a "brain-storming" session at the end of the day that utilized attendees' real-world cases where the use of the DICE (Describe, Investigate, Create, and Evaluate) approach was illustrated "live." **Setting:** Three different geographical sites in Michigan. **Participants:** Family ($n = 40$) and professional (paid; $n = 140$) caregivers (total $n = 180$) for people with dementia. **Measures:** Pre- and post self-ratings related to confidence in aspects of dementia care management before and directly after the training. **Results:** Comparing self-ratings pre- and post-training, more than 50% of family caregivers showed improvement in confidence post-training on 11 of 12 items with significant improvement in 4 items. Among professionals, more than 50% of caregivers showed improved confidence on 3 of 12 items, with 4 items showing significant improvement. Family caregivers were significantly more likely than professionals to show improved confidence on 6 of 12 items. **Conclusions:** The number of people with dementia and their family caregivers is large and growing every day with the aging of the population. Living well with dementia is the goal. Current care systems are inadequate and lead to multiple poor outcomes. Innovative solutions like the DICE

Featured Article

Training dementia care professionals to help caregivers improve the management of behavioral and psychological symptoms of dementia using the DICE Approach: A pilot study

[Tammi Albrecht DNP^a](#), [Molly Schroeder CSW^a](#),
[Tamara LeCaire MS, PhD^a](#), [Sarah Endicott DNP^c](#),
[Katelyn Marschall MPH^d](#), [Kristen Felten MSW^d](#),
[Noelia Sayavedra MS^e](#), [Sydney Russmann BA^a](#),
[Vince Kern BS^f](#), [Mary C. Blazek MD, MEHP^g](#),
[Helen C. Kales MD^f](#), [Cynthia M Carlsson MD, MS^{a b}](#),
[Jane Mahoney MD^b](#), [Art Walaszek MD^{a b}](#)  

[Show more](#) 

DICE Website

The DICE Approach Online Training Program

Are you a caregiver of a person with dementia?

Are you trying to manage behavioral symptoms such as agitation, wandering, aggression, anxiety (and so many others)?

Welcome to your one-stop location for evidence-informed training for assessing and managing the behavioral symptoms of dementia!

Years of research, hands-on experience and feedback are the foundation of this customized video training program and detailed manual to provide caregivers the education, expertise, confidence and strategies needed to better assess and manage the behavioral symptoms that so frequently accompany dementia.



[LEARN MORE](#)

A grid of six video thumbnails. The top row contains three thumbnails for 'DEMENTIA OVERVIEW' (Step 1 of the DICE approach). The bottom row contains three thumbnails for 'MODULE 3' (INVESTIGATE, Step 2 of the DICE approach) and 'MODULE 4' (CREATE, Step 3 of the DICE approach). Each thumbnail includes a 'PLAY VIDEO' button.

Describe: First step in DICE

It is **CRUCIAL** to **DESCRIBE** the problem behavior thoroughly and clearly



eSimulation Videos

Ready to take the next step? Test your skills with e-simulation

Home/Family Caregiver



[PLAY VIDEO](#)

Professional Caregiver



[PLAY VIDEO](#)

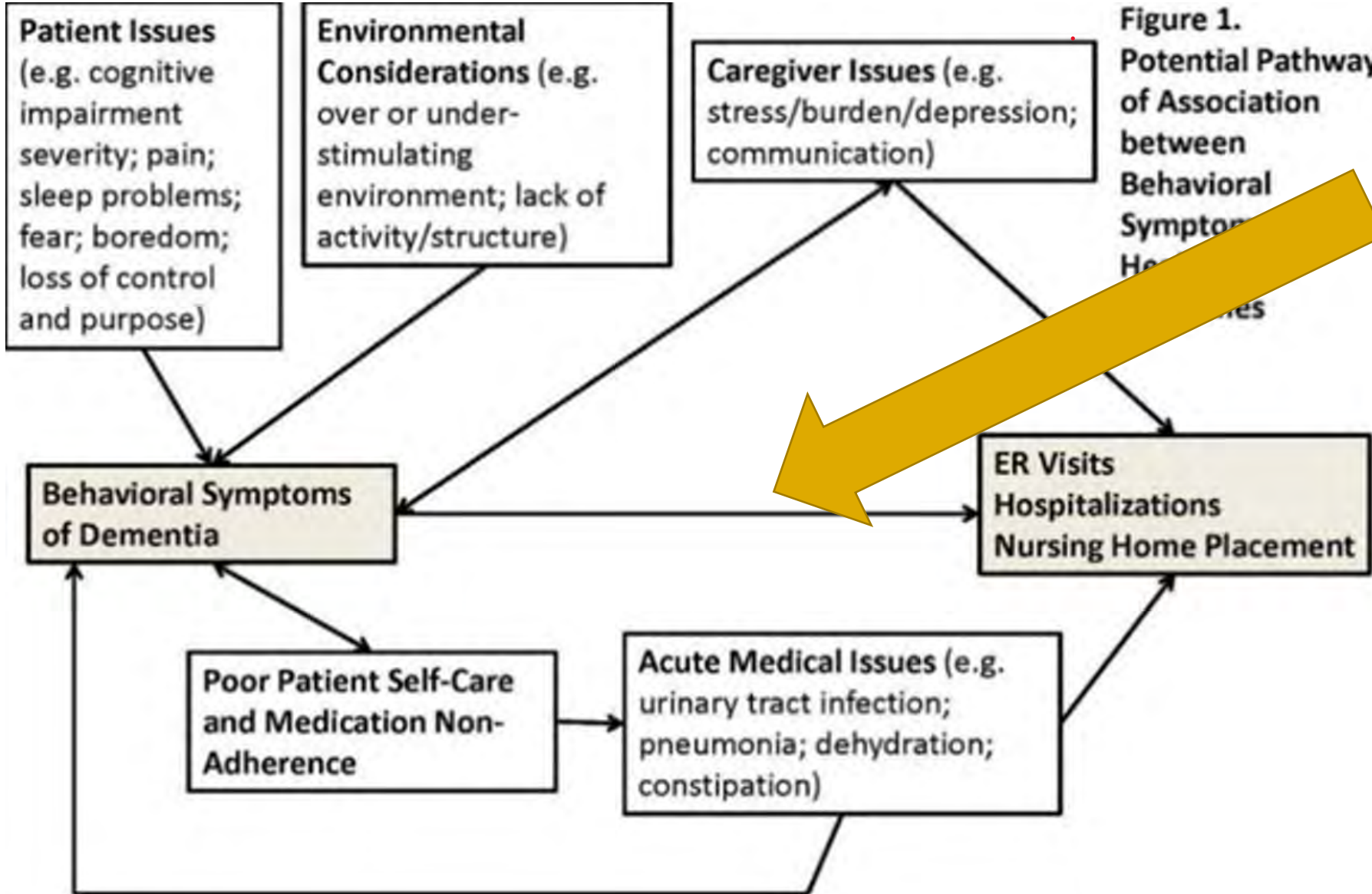


Figure 1. Potential Pathway of Association between Behavioral Symptoms of Dementia and ER Visits, Hospitalizations, and Nursing Home Placement



YOU using the DICE Approach!



IMPACT Pilot Grant

Training of LVNs and Social Workers

- Buy in from supervisors
- 3 hours in person with lunch
- #26

Complete

Booster sessions every four months

- Held with 2 geriatric psychiatrists
- Support, brainstorm, get input

In Process

Augment approach

- Train new staff with website (#12)
- Creation of “dot phrase” in EP C


In Process

Track outcomes using the medical record

- Number of dyads
- Medication use
- Health services use

In Process

Lessons learned so far

- Reorganizations of staff
- Turnover of staff (#12 new and #7 who left)
- Great examples from booster sessions of approach empowering front-line staff
 - Garden story 
- Utilization of staff input to tweak approach
 - Creation of dot phrase
- Working with supervisors key to ensure buy-in and allocate staff time

Questions?

<https://diceapproach.com/>

Can Value Champions Reduce Inappropriate Prescribing for People with Dementia?

Lorella Palazzo, PhD, Robert Penfold, PhD, Masami Tabata Kelly, MA, Sherry Peppercorn, Jennifer Perloff, PhD, Linda Kiel, MA, Michael L. Parchman, MD, MPH

Lorella.G.Palazzo@kp.org
Robert.B.Penfold@kp.org



SCHOOL OF PUBLIC HEALTH
UNIVERSITY of WASHINGTON



Background: Potentially Inappropriate Medications

- The problem: Overuse of Potentially Inappropriate Medications (PIMs) for People Living with Dementia (PLWD)
- PIMs are medications for which the potential for harm outweighs benefit among PLWD
 - Antipsychotics
 - Benzodiazepines
 - Hypoglycemics
 - Sulfonylureas
 - Insulin



Hamilton HJ, Gallagher PF, O'Mahony D. Inappropriate prescribing and adverse drug events in older people. *BMC Geriatr* 2009;9:1-4. 10.1186/1471-2318-9-5. Wallace E, McDowell R, Bennett K, et al. . Impact of potentially inappropriate prescribing on adverse drug events, health related quality of life and emergency Hospital attendance in older people attending general practice: a prospective cohort study. *J Gerontol Ser A Biol Sci Med Sci [Internet]* 2016;00:glw140.



Background: Clinician Champions

- Effective trusted source of scientific evidence regarding potential benefits and harms of specific services
- Facilitate reflective practice with their colleagues
 - Provide feedback
 - Ask reflective questions regarding treatment and testing decisions: “sense-making conversations”
- Create a supportive environment by serving as a role models of high-value care delivery

Stammen LA, Stalmeijer RE, Paternotte E, Oudkerk Pool A, Driessen EW, Scheele F, Stassen LP. Training physicians to provide high-value, cost-conscious care: a systematic review. JAMA. 2015;314:2384-400.



Specific Aims

- **Aim 1:** Assess the effectiveness of a clinician champion on de-implementing three classes of PIMs among PLWD
- **Aim 2:** Determine if the intervention is associated with a reduction in Emergency Department visits and hospitalizations with documentation of a fall
- **Aim 3:** Examine five de-implementation outcomes critical to the success of the de-implementation efforts: appropriateness, feasibility, fidelity, penetration, and equity.



Study design

- A 24-month Cluster-Randomized Pragmatic Trial
- Two Accountable Care Organizations (ACOs)
 - Harmony Cares (formerly U.S. Medical Management)
 - Ochsner Health (Louisiana)
- Primary care clinics randomized to intervention or control (matched pairs in each ACO based on number of patients with dementia in each clinic location)
- One clinician from each intervention clinic recruited by ACO leadership (N=17)
 - Nurses, physicians, pharmacists
- 6-months training, then 9 monthly check-ins to support champions



Patient Cohort

- Harmony Cares, Ochsner
- ACO members aged ≥ 65 years
- Diagnosis of ADRD
- Prescription rates for:
 - antipsychotics, benzodiazepines, insulin, sulfonylureas
- N = 1794 patients (intervention)
- N = 2077 patients (control)



Mixed Method Approach

- Quantitative
- Assessed changes in the rates of prescription fills in the 7 months prior to training clinicians and 14 months following (24 months total)
 - Interrupted time series analyses (DiD where appropriate)
 - Interruptions at
 - January 2022 (start of training)
 - April 2022 (intervention at full strength)
- Qualitative
 - Data sources included interviews with champions and one medical director of pharmacy (N = 7) and monthly check-in calls (N = 5)
 - Coding was informed by the de-implementation outcomes, and followed by thematic analysis



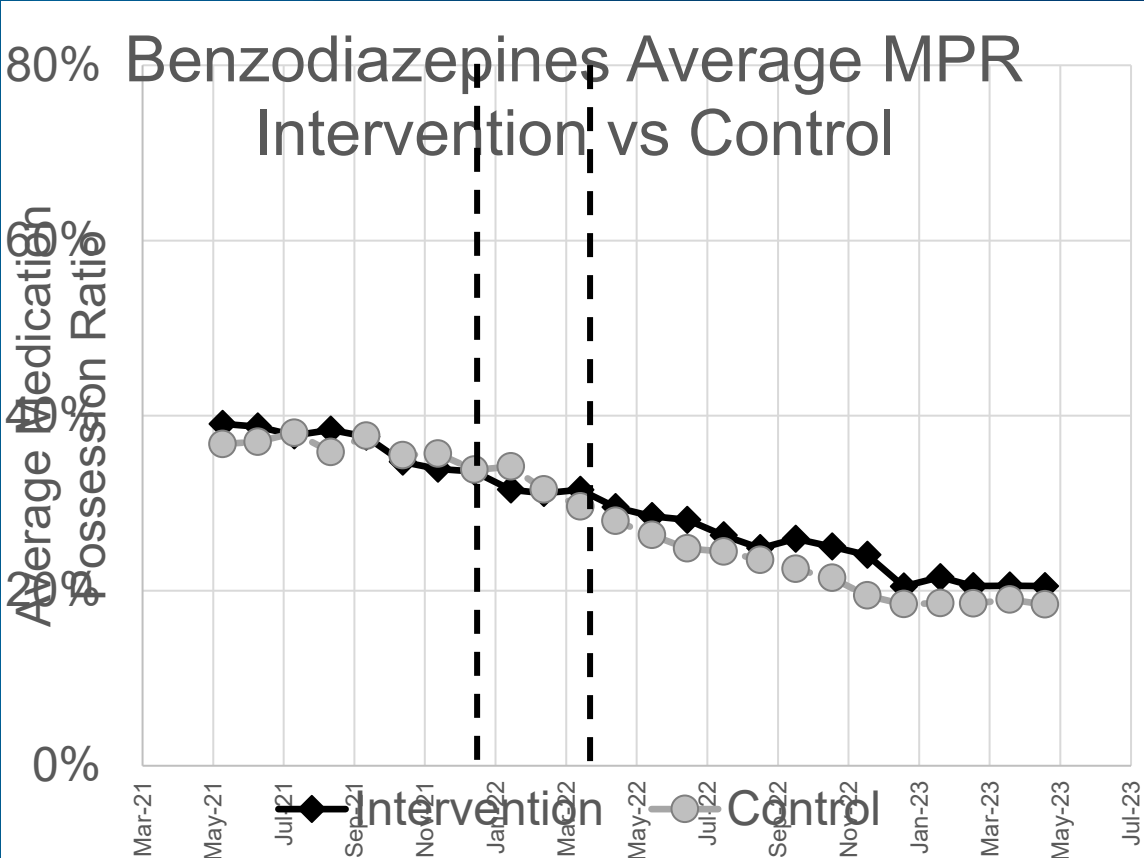
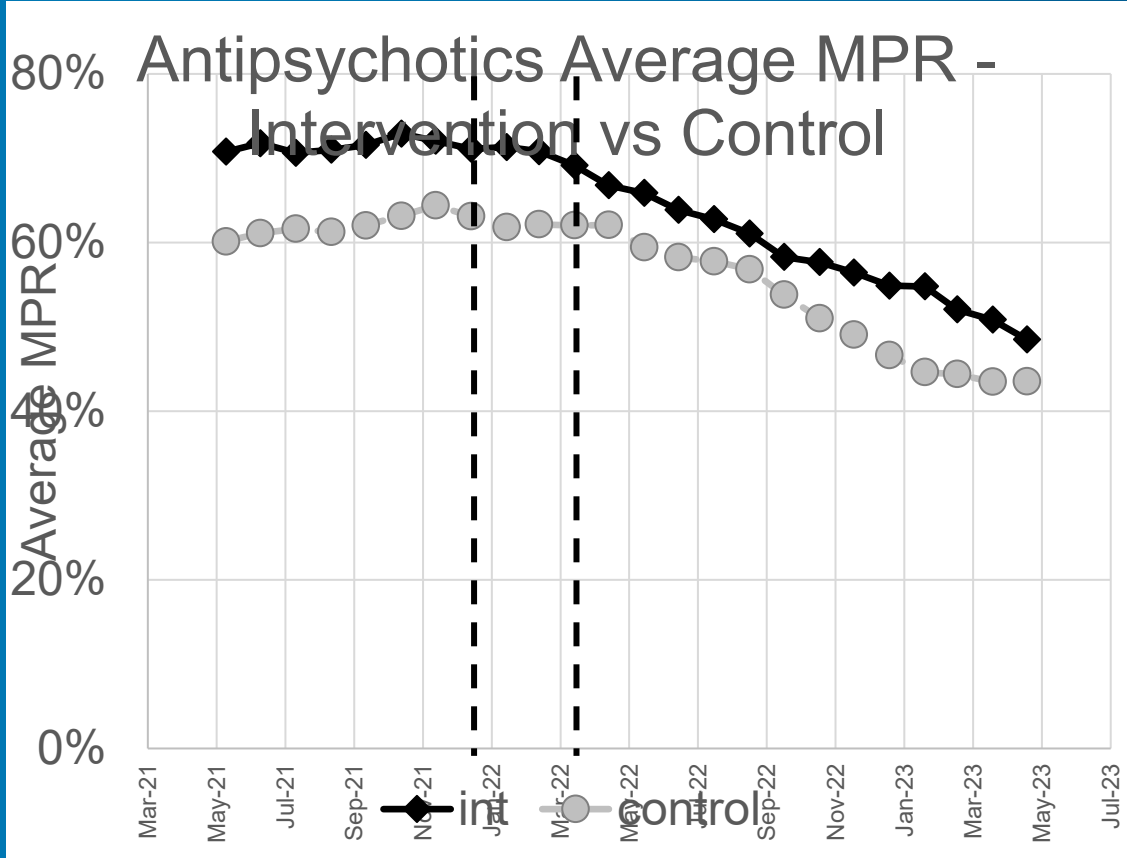
QUANTITATIVE FINDINGS

Table 1.

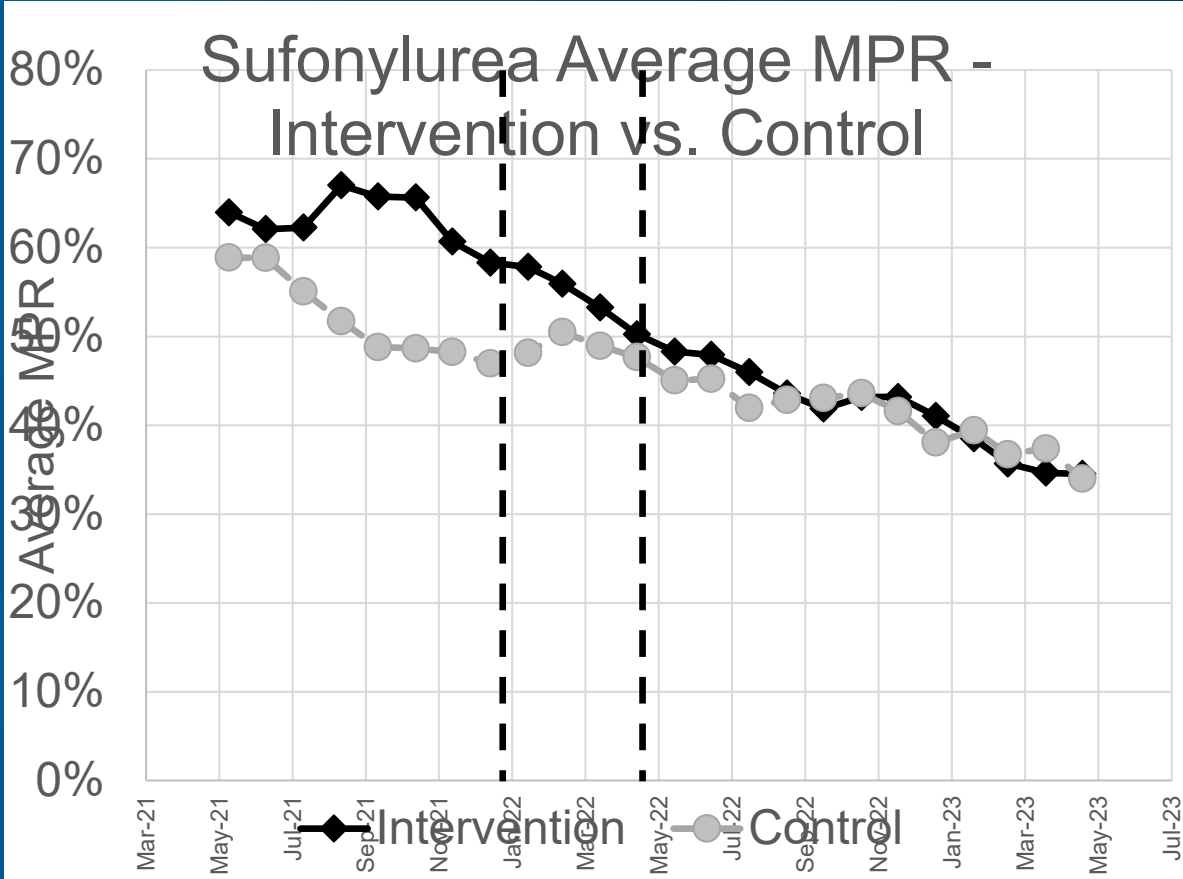
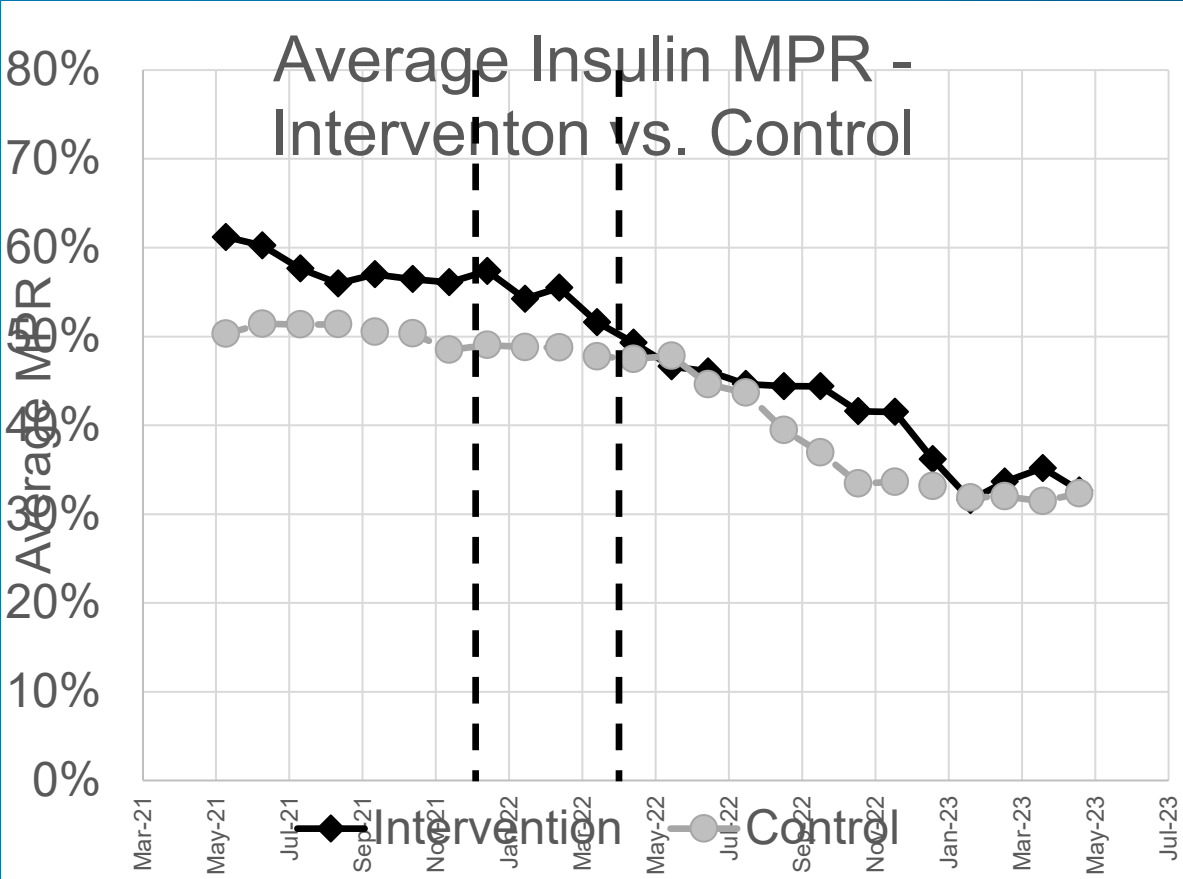
	Harmony Cares (USMM) ACO			
	Intervention Arm		Control Arm	
	Full Dementia Cohort	Dementia Cohort w/ Part D Coverage	Full Dementia Cohort	Dementia Cohort w/ Part D Coverage
Number	1794	1570 (88%)	2077	1612 (78%)
Age				
65-74	570 (32%)	534 (34%)	428 (21%)	378 (23%)
75-84	602 (34%)	537 (34%)	775 (37%)	612 (38%)
85+	622 (35%)	499 (32%)	874 (42%)	622 (39%)
Female	1218 (68%)	1055 (67%)	1512 (73%)	1182 (73%)
Race and Ethnicity				
American Indian/Alaskan Native	***	***	***	***
Asian/Pacific Islander	22 (1%)	21 (1%)	57 (3%)	51 (3%)
Black or African American	335 (19%)	305 (19%)	454 (22%)	372 (23%)
Hispanic	41 (2%)	37 (2%)	47 (2%)	46 (3%)
Non-Hispanic White	1358 (76%)	1171 (75%)	1453 (70%)	1091 (68%)
Other/Unknown	34 (2%)	32 (2%)	61 (3%)	47 (3%)
Entitlement				
Aged-nondual	609 (34%)	426 (27%)	1100 (53%)	682 (42%)
Aged-dual	579 (32%)	570 (36%)	576 (28%)	564 (35%)
Disabled	602 (34%)	570 (36%)	398 (19%)	363 (23%)
ESRD	***	***	***	***



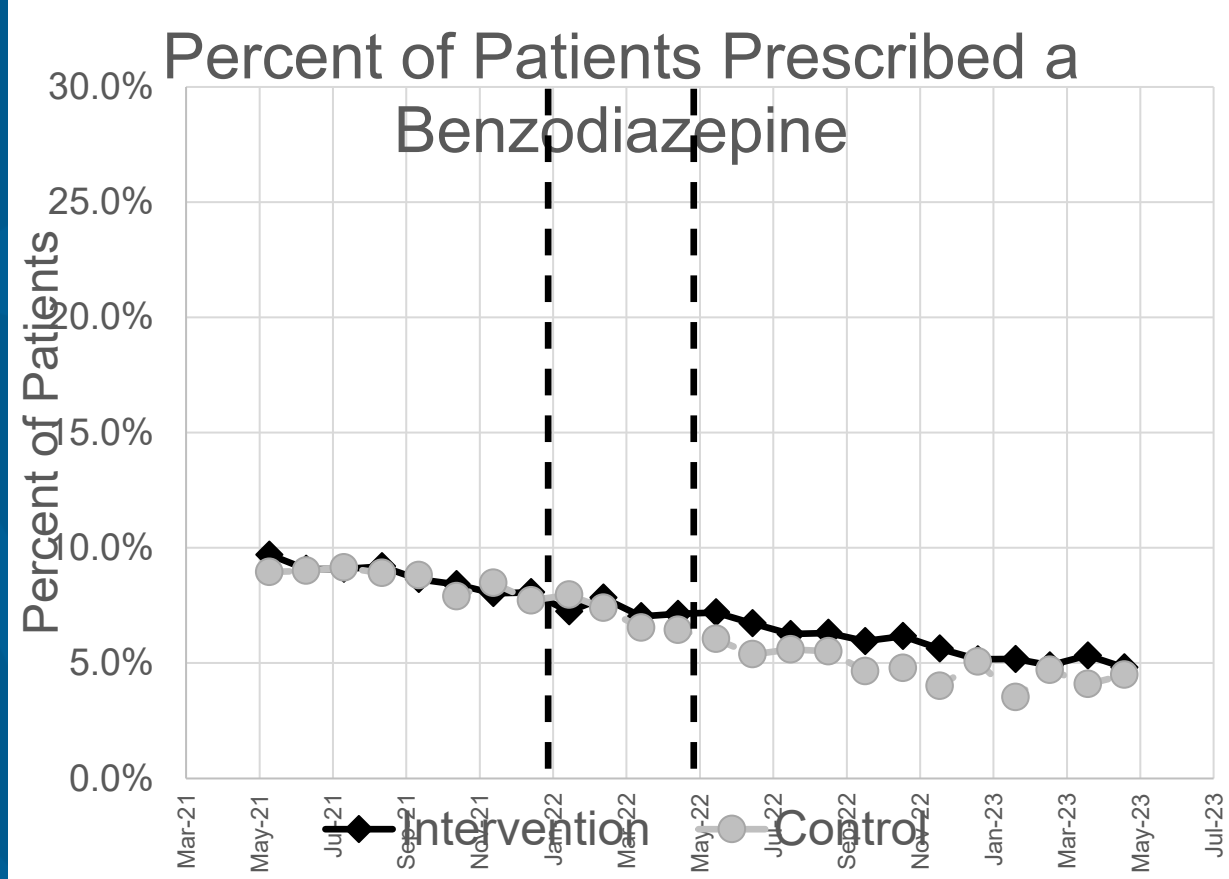
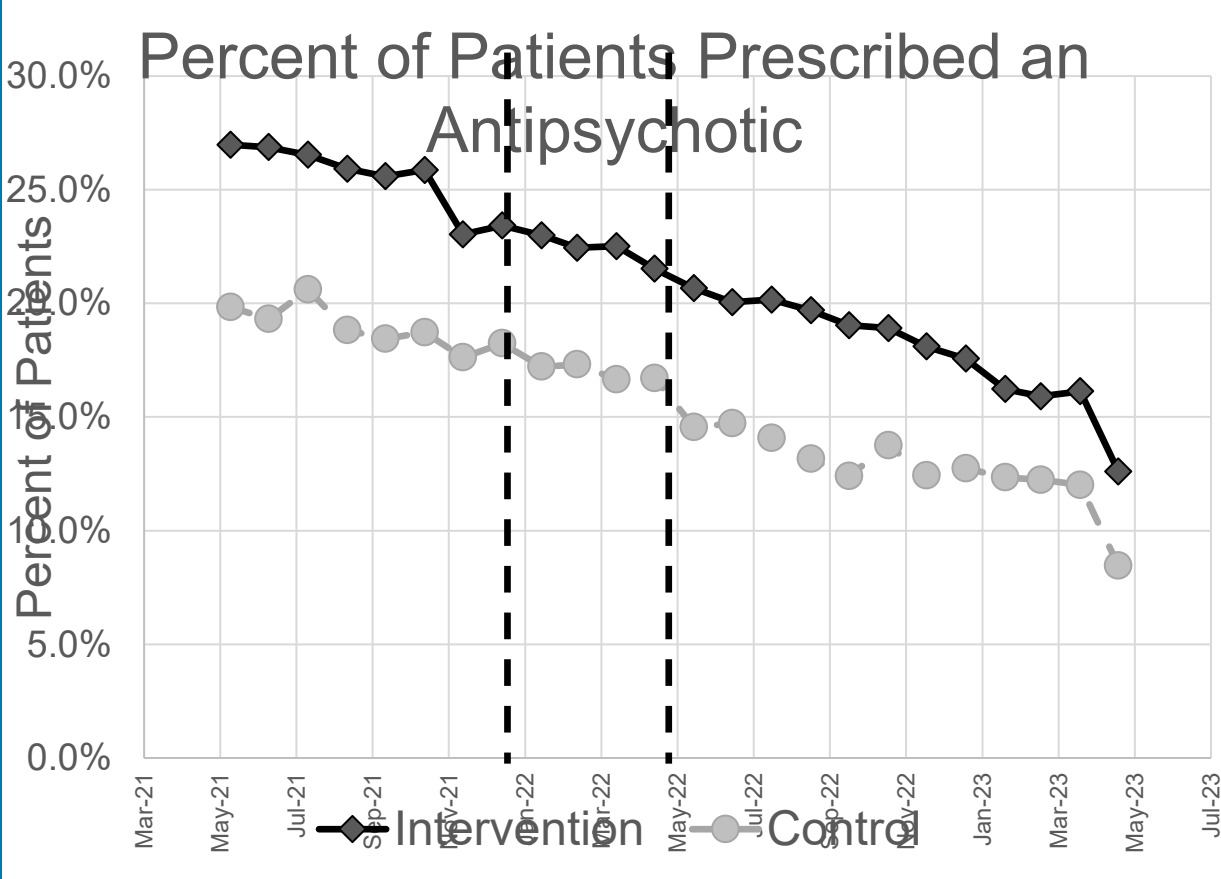
Results – Changes in Medication Possession Ratio (MPR)



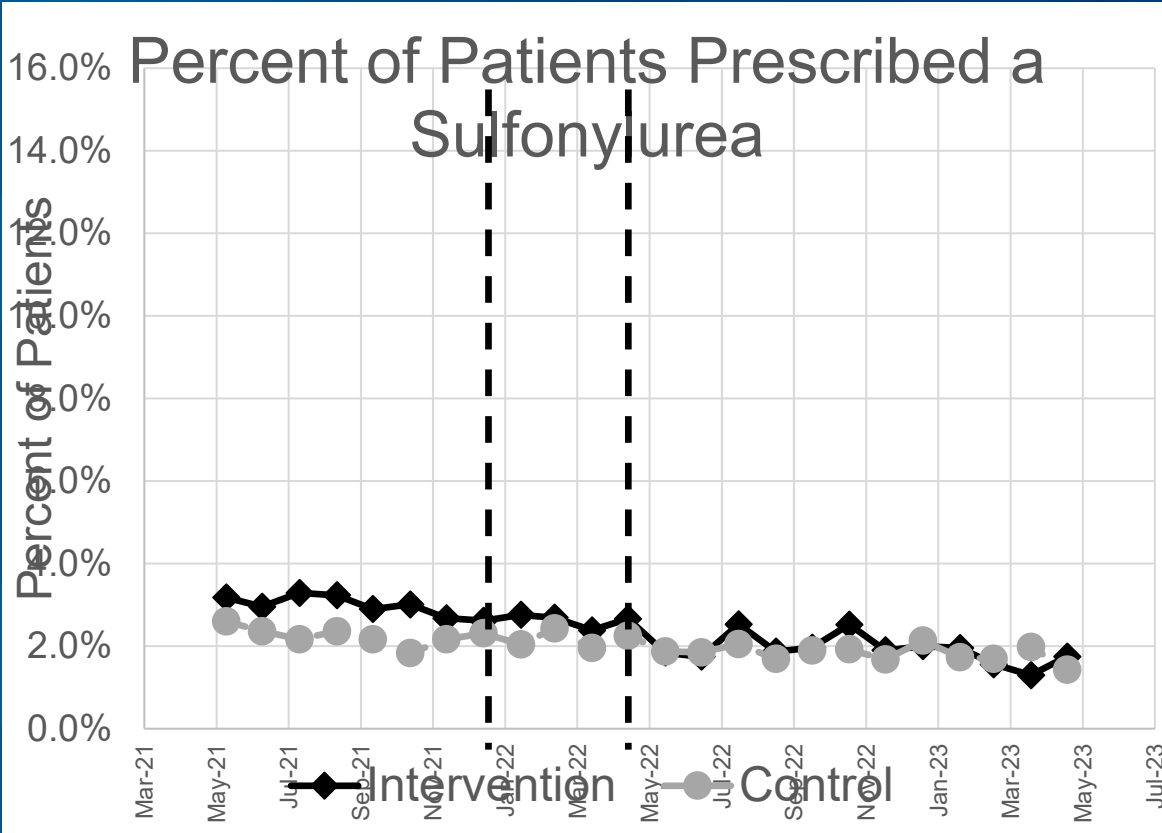
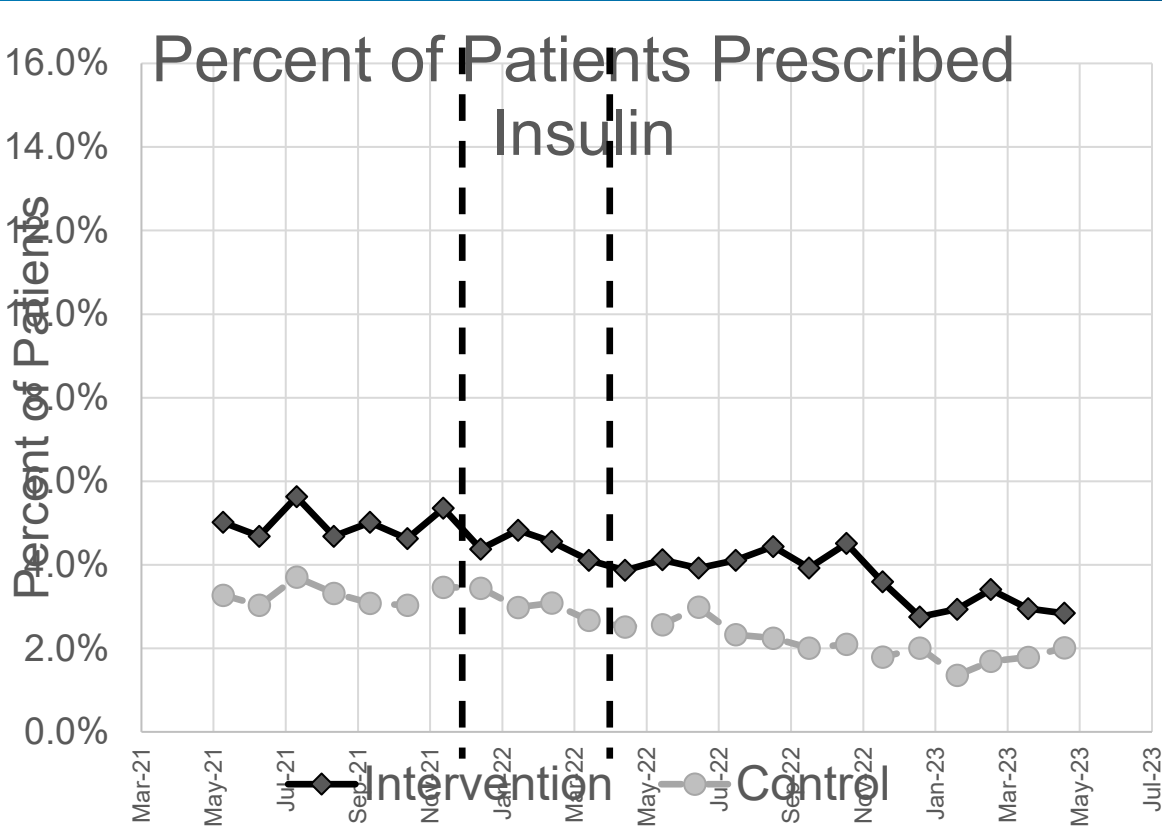
Results – Changes in MPR



Results – Changes in Percent of Patients Prescribed Medication



Results – Changes in Percent of Patients Prescribed Medication



QUALITATIVE FINDINGS

Qualitative Themes

- Six multilevel themes, with focus on themes 1 - 3
 1. External influences on feasibility and fidelity of de-implementation in the clinic
 2. Organizational factors affecting champions' de-implementation work
 3. De-implementation success stories
 4. Caregiver and patient-level determinants of feasibility and equity
 5. Clinical champions' tailored strategies to mitigate challenges
 6. The role of relationships and communication in the champions' efforts



Theme 1: External Influences on Feasibility and Fidelity of De-implementation

- The COVID 19 pandemic and extreme weather events disrupted de-implementation efforts. In addition, market-driven company restructuring and rebranding undermined the champions' role and their ability to carry out the intervention as planned.



"We were supposed to do this in February 2022, so I started the conversations in February, and I was told no, '[hurricane] Delta's killing us, now is not a good time.' We came back in April-May and they were like, 'we're just catching our breath, we're doing some other things, just wait.' And then I came back in June-July, and they're like, 'Omicron's killing us now.'" –Pharmacist, ACO 1



Theme 2: Organizational Factors Affecting Champions' De-implementation Work

- Organization-level challenges undermined the feasibility and fidelity of de-implementation. These challenges included high staff turnover, time constraints, constant change (e.g., scheduling, workflow), and availability of user-friendly data.



“They have had a lot of turnover.... change management has never been more important because of the speed that change is occurring, but I've never seen turnover like this in my career...One of the things that I've learned is, you engage the nurse practitioners and the RNs you train them, we provide the education, and then they leave.” – Pharmacist, ACO 1



“When I've asked our data analyst to please only put in [PIM], she tells me 'well, if you click this box and click this you can open this up and unclick the medications you don't want to see.' So it's basically falling back on me to manage all of that data myself, and I don't have the time to do that.” – Nurse practitioner, ACO 2



Theme 3: De-implementation Success Stories

- Despite many challenges, Value Champions described being able to de-prescribe PIM to some patients through persuading caregivers and using lessons from the Value Champions training.
 - Champions had to buy into the intervention and try it for themselves before they could engage peers.



“There was one patient [with whom] we really did have a lot of success. She had been on a benzo [Lorazepam], and we were finding that buspirone was working better. Over a number of visits, speaking with the staff, speaking with the daughter, we got her a little more Buspar, very minimal Lorazepam. But it took a lot of work and a lot of tracking people down.”—Physician, ACO 2



“I have another example of a patient; an elderly woman being taken care of by her son in a home. She was also getting [benzodiazepine]Ativan as needed. She wasn't having any falls or nothing, but just knowing what I've learned during this study, I just brought up the subject [of deprescribing Ativan] with the son, and he was very open to the idea.”—Nurse, ACO 2



Conclusion

- The intervention had no impact on average MPR or percent of patients prescribed PIMs
- Clinical champions might be effective in promoting de-implementation of PIM for PLWD, but need system-level supports, including a robust IT infrastructure, to be successful
- Targeted training that provides knowledge and skills to respond to challenges and manage change could be helpful to champions involved in de-implementation.
- Study limitations included declining champion participation as the study progressed. Future research should explore how to engage clinicians in care redesign in the midst of busy practice
- Our findings underscore the challenge of care redesign in complex practices, and suggest assessing organizational readiness and capacity for change before interventions are launched



Describing to Reduce Injurious Falls among Older Adults with Dementia

Elizabeth A. Phelan, MD MS

IMPACT 2024 Scientific Conference

Background and Significance

- Older people with dementia (OPWD) are at high risk of falls and less likely than those without dementia to recover from a fall-related injury
- Medications that affect the central nervous system (CNS) are an important modifiable risk factor for falls and often prescribed for OPWD
- Few deprescribing interventions have targeted OPWD and examined the effect of deprescribing CNS-active medications on fall injuries

Objective

To determine the feasibility of conducting a health-system-embedded, pragmatic clinical trial to evaluate the effectiveness of an evidence-based, person-centered deprescribing intervention (“S OP-FALLS”) to reduce use of central nervous system (CNS)-active medications among older people with dementia (OPWD)

Relevance

This pilot study will set the foundation for a full-scale ePCT evaluating the effectiveness of STOP-FALLS for OPWD. This work has the potential to improve the safety of medication regimens for OPWD and reduce their risk of falls. It may also benefit care partners by reducing stress of managing complex medication regimens and fall risk for their care recipient.

Study Aims

Aim 1. Adapt an evidence-based deprescribing intervention^a for OPWD and their care partner(s)

Aim 2. Conduct a one-arm pilot trial of the adapted intervention to determine

- Feasibility of reaching OPWD and their care partners
- Acceptability of the intervention
- Whether the intervention was implemented as intended (implementation success)

Aim 3. Establish feasibility of using pragmatic methods to ascertain clinical outcomes

- Primary outcome: Medically treated falls
- Secondary outcomes:
 - All-cause emergency department visits and hospitalizations
 - Nursing home placement
 - Medication discontinuation^b

^a Balderson et al. *Trials* 2023.

^b Defined as no evidence of a pharmacy fill between 5-6 months of follow-up.

Design, Setting and Participants

One-arm pilot study

Kaiser Permanente Washington (KPWA)

- 25 primary care clinics state-wide
- 100,000 Medicare enrollees
- Epic electronic medical record

Participants

- OPWD^a aged 60+, prescribed one or more CNS-active medications on a chronic (≥ 3 consecutive months) basis
- Care partners and primary care providers of the OPWD

^a Dementia ascertained based on dementia diagnosis code or prescription for dementia medication.

Intervention and Implementation

- Deprescribing intervention
 - Educational materials for OPWD and care partners
 - Decision support for PCPs
- Implementation
 - Mailing to OPWD
 - Staff message (within Epic) to PCPs

Measures, Data Source, and Timing

Measure	Data Source	Timing
Feasibility and acceptability of intervention	Mailed questionnaire	1 month
Implementation success ^a	Electronic health record	6 months
Outcomes	KPWA virtual data warehouse	6 months

^a Defined as evidence of a medication taper plan for medications that require tapering (antipsychotics, opioids, sedative-hypnotics).

Demographic and Health Characteristics of OPWD (N=114^a)

	Mean (SD) or N (%)
Age, mean (SD)	80 (9)
Female, n (%)	82 (72)
Non-white, n (%)	15 (13)
Frail, n (%)	34 (30)
Chronic condition, n (%)	
Depression	51 (45)
Diabetes	24 (21)
Hypertension	64 (56)
Insomnia	29 (25)
Musculoskeletal pain	38 (33)
Osteoporosis	15 (13)
Peripheral neuropathy	8 (7)
History of stroke	8 (7)

^a Initial sample N=116; 2 participants excluded after PCP deemed them as inappropriate for intervention.

Prescription Medications of OPWD (N=114)

	N (%)
Target medication prescription	
Antipsychotic	89 (78)
Opioid	13 (11)
Tricyclic antidepressant	11 (10)
Sedative-hypnotic ^a	3 (3)
Skeletal muscle relaxant	3 (3)
Antihistamine	0
Two concomitant target medication prescriptions	5 (4)
Other CNS-active medication prescriptions	
Antidepressant	93 (82)
Gabapentinoid	21 (18)
Other sedative-hypnotics ^b	1 (2)

^a All sedative-hypnotic prescriptions were for a benzodiazepine (no Z-drug prescriptions).

^b Includes chloral hydrate, meprobamate, ramelteon, trazodone, and low-dose (3 mg, 6 mg) doxepin.

Implementation Endpoints

Endpoint	Measure	Result
Feasibility	Intervention materials reach OWPD (<30% “returned to sender”)	<input checked="" type="checkbox"/>
Acceptability	Acceptability of Intervention ^{a,b}	3.5 / 5
Implementation success	Medication taper plan ^c	0

^a Assessed via the 4-item Acceptability of Intervention (AIM) instrument; see Weiner BJ et al. *Implement Sci* 2017. Response option range for each item is 1–5, with higher scores indicating higher acceptability.

^b Open-ended feedback:

“We are taking the letter to the next appointment to talk to the psychiatrist about it.”

“Why give this to an elderly woman with dementia? Why was she given this?”

^c Assessed via examination of signetur (“sig”) fields in the electronic health record; see Boudreau D et al. *J Gen Intern Med* 2020.

Clinical Outcomes of OPWD (N=114)

Outcome	Baseline N (%) ^a	Follow-up N (%) ^a
Medically treated falls	25 (22)	24 (21)
All-cause ED visits and hospitalizations	26 (23)	29 (25)
Nursing home placement	N/A	5 (4)
Medication use		
Antipsychotic	89 (78)	51 (44)
Opioid	13 (11)	12 (11)
Tricyclic antidepressant	11 (10)	6 (5)
Sedative-hypnotic	3 (3)	3 (3)
Skeletal muscle relaxant	3 (3)	1 (1)

^a Calculated based on number with event / total N. Baseline and follow-up time periods each six months.

Strengths and Limitations

Strengths

- Complete capture of prescription data and healthcare utilization (no missing data)

Limitations

- Predominantly white study sample
- No pragmatic method to identify dementia care partners

Conclusions and Next Steps

The deprescribing intervention is feasible and may achieve meaningful reduction in antipsychotic prescribing

- Care partner identification is not necessary to deliver the intervention

Findings lend support for a controlled trial with sufficient power to assess effects on relevant clinical outcomes

Session 4:

ePCT of Intervention for Early Detection of Dementia



Moderator:

Jason Karlawish, MD – University of Pennsylvania

Presenters:

Darlene Floden, PhD, ABPP – Cleveland Clinic

Maria Edelen, PhD – Brigham and Women's Hospital, Harvard Medical School

Leah Hanson, PhD – HealthPartners Institute

Michael Wolf, PhD, MPH, MA – Northwestern Feinberg School of Medicine

Panelists:

Jason Karlawish, MD

Julie Bynum, MD, MPH – University of Michigan

Deborah Barnes, PhD, MPH – University of California, San Francisco

A Cognitive Risk Calculator and Screening Tool for Primary Care Settings

Darlene Floden, PhD ABPP-CN

NIA IMPACT Collaboratory
2024 Scientific Conference
Bethesda, MD



Study Team

MPI Team



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Healthcare Delivery & Implementation Science Center



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Geriatrics



Saket Saxena

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Biostatistics



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Alex Milinovich

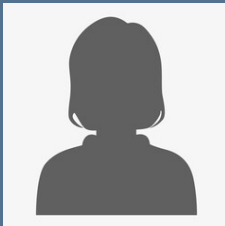
RESEARCH TEAM



Megan Zelinsky



Erika Weik



Jamie Gatesman

Funding



R61AG069729



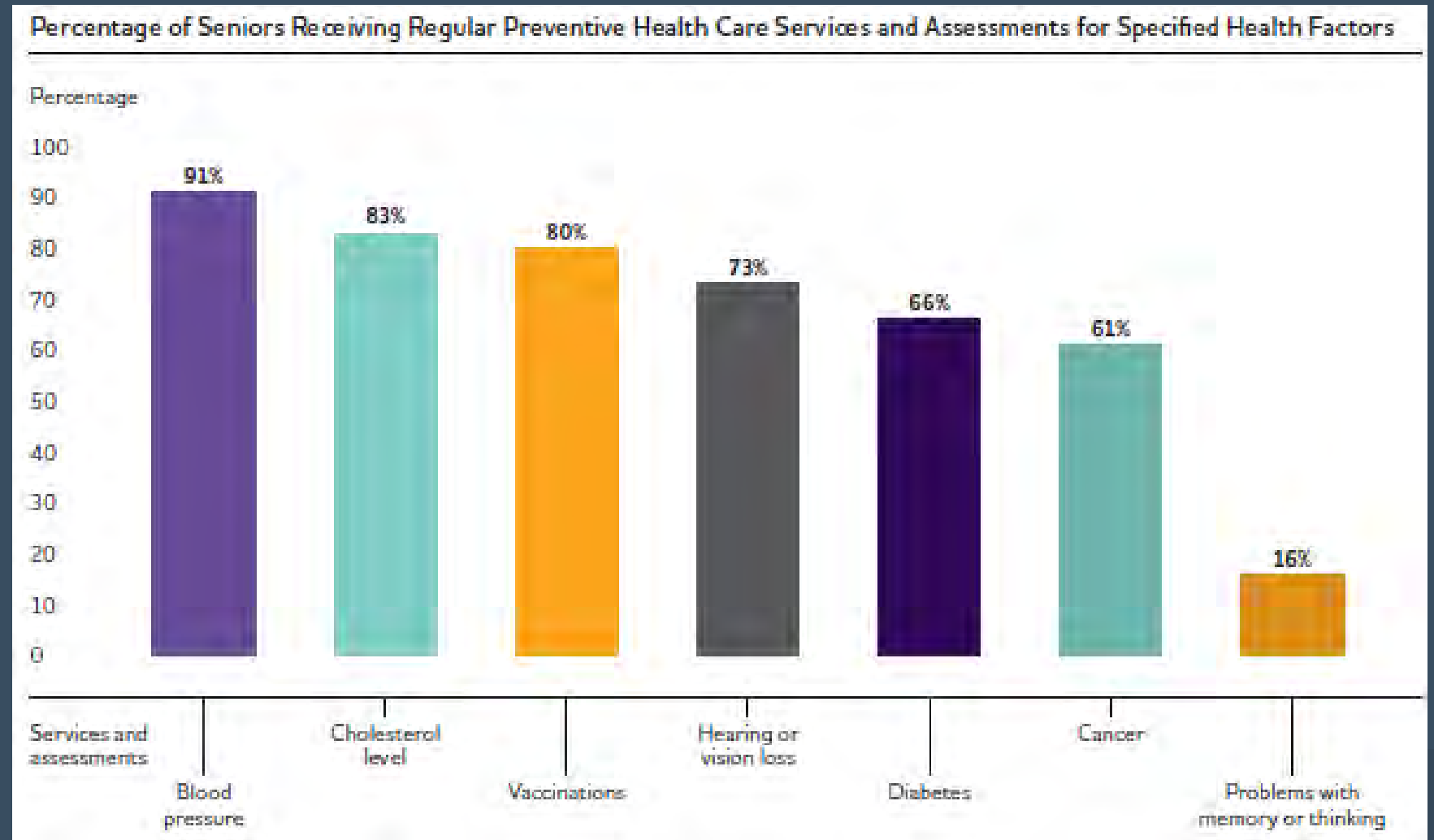
R33AG069729



Disclosures

Ceraxis Health, Inc. - potential future distributions as inventor (Brief Assessment of Cognitive Health)

The Problem:



Special Report — Alzheimer's Detection in the Primary Care Setting
Alzheimer's Association, Alzheimer's & Dementia, 2019

Barriers to Cognitive Screening

Patient Selection



Estimate Risk

Time



Automate
Screening

No Treatments



Reversible
Factors

Solution 1: Cognitive Risk Calculator

Passive EHR calculator to flag high-risk patients

1. Age
2. Race
3. Systolic blood pressure
4. Pulse rate
5. NSAID use
6. Hx mood disorder
7. FHx neurological disease

C-statistic = 0.72

Cognitive Risk Calculator EHR Workflow

Female, 75 year old, 1948
MRN: [REDACTED]
eMRN: [REDACTED]
Cur Location: P57 - PSYL NEURPSY TEST
Code: Full Code by Default
ACP/Adv Dir: AD

COVID-19: No Recent Tests
⚠ Cognitive Risk
🧑🏻‍🔬 Research Participant

Date	Complaint	Diagnosis	Type	Department	Provider
7/22/20			Admission (Discharged)	ORTWIN	Weber, Luke
7/18/19		Carpal tunnel syndrome, bilateral	Admission (Discharged)	ORTWIN	J. Hendrickson, Mark F.
1/18/17			Admission (Discharged)	ORTWIN	Long, Donald E.
6/4/14	Blood Test Abnormality	Acute abdominal pain ...	ED to Hosp-Admission (ADMIT)	HLOBV	Sangani, Bindu P.; Douglass, Karen...
2/20/09			Admission (Discharged)	HPH070	Moore, Courtenay K.
7/12/07			Admission (Discharged)	hpb010	Long, Donald E.
1/4/07			Admission (Discharged)	HL4AOR	Anouchi, Yoel S (Hist)
10/4/05			Admission (Discharged)	hpb010	Salama, Sheriff
9/26/05			Admission (Discharged)	hpshoo	Salama, Sheriff
9/19/05			Admission (Discharged)	hpb010	Salama, Sheriff

Problem List (48 items)

- Renal mass, right
- Diverticulosis of colon (sigmoid and descending colon) - with possible acute diverticulitis (as per CT report)
- DJD OF KNEES
- Spinal stenosis, lumbar region, without neurogenic claudication
- Other chronic sinusitis
- CHRONIC OBESITY, (s/p lap banding in 09/06)
- Emotional depression
- Other and unspecified mitral valve diseases
- Deformity of toe
- Hypothyroidism

COVID-19: No Recent Tests
⚠ Cognitive Risk
🧑🏻‍🔬 Research Participant

⚠ Cognitive Risk

The patient is at high risk for cognitive impairment. BACH testing is recommended.
Prior screening tests:

	03/21/22
MoCA	26

Order Do Not Order 🏠 BACH Screening Test

✔ Accept Cancel

Solution 2: Brief Assessment of Cognitive Health

Automate screening through the EHR



Components:

- History Questionnaire
- Depression Screen
- Cognitive testing

Self-Administered:

- 15 minutes
- Web-based at home or in clinic



Output:

- Estimates probability of cognitive impairment
- Screens for common, reversible etiologies - sleep disorder, depression, and high stress

BACH EHR Workflow

My Note

Note Details

Date of Service: 6/13/2023 12:30 PM

Cosign Required?

Summary:

Arial 11 B I U S A 100%

The patient endorsed minimal depression symptoms on PHQ-8¹.
The patient endorsed a moderate level of stress.
The patient reported 7 hours of sleep per night, which falls in the Recommended category based on National Sleep Foundation Guidelines². They endorsed no recent sleep problems.
BACH probability of cognitive impairment³: 88%



Synopsis

BACH Vitals Diabetes HTN/Lipids CHF Thyroid Depression Weight Graph CKD Asthma/C

Days 12/1/2023 Most Recent Value
All 1/11/2023 - 1/11/2024

^ Patient Spotlight
No data to display.

^ BACH

<input type="checkbox"/> Probability of cognitive impairment	88	88	12/1/2023
Stress rating	moderate	moderate	12/1/2023
<input type="checkbox"/> Stress Level (0-100)	56.5	56.5	12/1/2023
<input type="checkbox"/> Average hours of sleep	7	7	12/1/2023
Sleep recommendation	Recommended	Recommended	12/1/2023
Sleep problem rating	no	no	12/1/2023
<input type="checkbox"/> Sleep Score (0-3)	0	0	12/1/2023
Depression rating	minimal	minimal	12/1/2023
<input type="checkbox"/> PHQ-8 score	1	1	12/1/2023
English as native language	yes	yes	12/1/2023



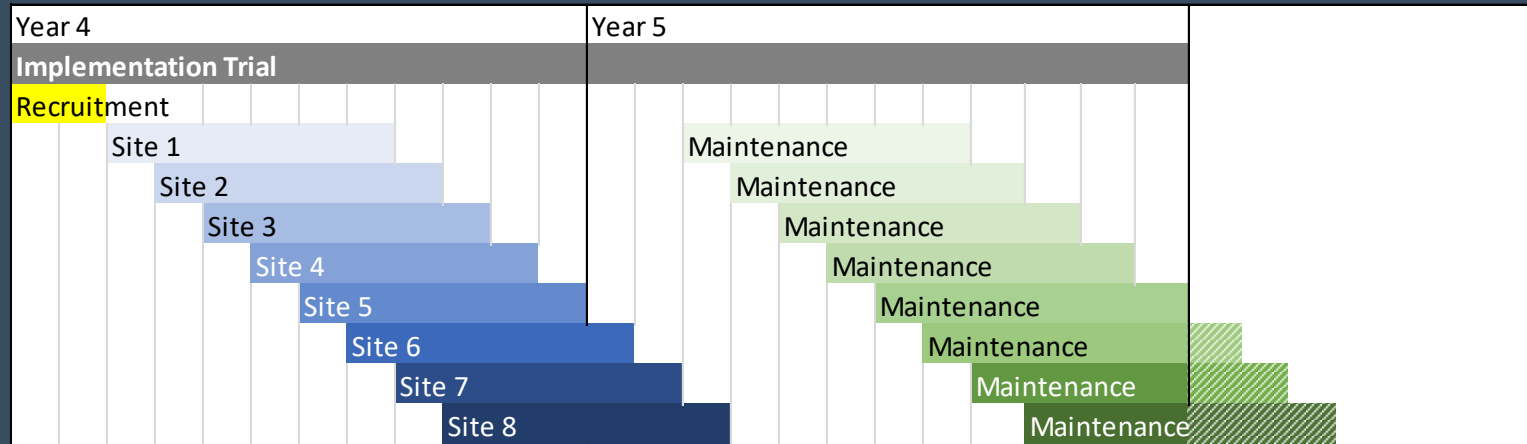
Pragmatic Clinical Trial and Replication Trial

Implementation Trial

- Stepped Wedge, mixed methods
- Cluster Randomize 5 providers in 8 clinics to start time
- Adaptive implementation strategy

Replication Trial

- Randomize 2 additional clinics
- Static implementation strategy based on best practice from first 8 clinics



Primary Outcome Measures: RE-AIM

1. Adoption

Increased frequency of
cognitive screening events in
high risk patients

Number of BACH orders
placed

C
R
C

B
A
C
H

Secondary Outcome Measures: RE-AIM

3. Maintenance

C
R
C

Sustained change in frequency
of cognitive screening events

B
A
C
H

Sustained Rate of BACH
orders placed

Qualitative Secondary Metrics

Provider Surveys

Cognitive Screening Practices
Experience with CRC and BACH

Provider Interviews

In-depth feedback on implementation
Opinions and preferences
Clinical culture

Acceptability

Patient Surveys

Experience with BACH

Patient Interviews

Attitudes about cognitive screening
In-depth feedback on BACH or other test

Using the PROMIS Cognition Item Bank for Early Detection of Cognitive Decline in Primary Care (NIA R61)

NIA IMPACT COLLABORATORY SCIENTIFIC CONFERENCE ON
EMBEDDED PRAGMATIC CLINICAL TRIALS (ePCTs) IN DEMENTIA

APRIL 2-4, 2024



Acknowledgements

Study team:

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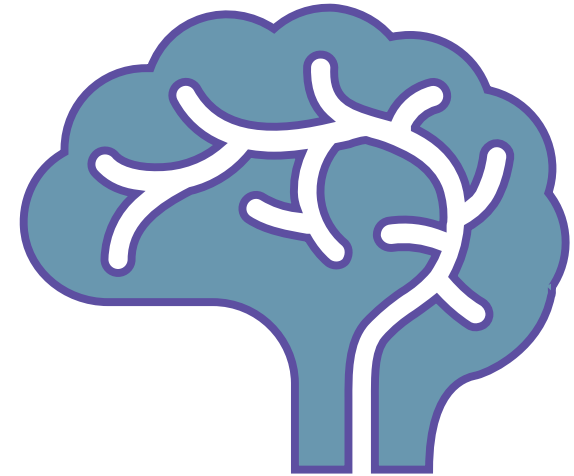
Partha Thirumala (UPMC School of Medicine)

Funded by NIA grant R61AG069776

Using the PROMIS Cognition Item Bank for Early Detection of Cognitive Decline in Primary Care

Background

- Early diagnosis of Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) through detection of cognitive impairment (CI) would facilitate intervention early in the disease trajectory when patients are still able to communicate their wishes
- Screening for CI is a required component of the Medicare Annual Wellness Visit (AWV) and represents an excellent opportunity for early detection
- A measure of CI that is brief, reliable, validated, self-administered by the patient, and easily integrated into the electronic health record (EHR) could serve as a low burden standardized screening tool for use in the AWV



Project Objective

To:

identify a small set of PROMIS Cognitive Function items to screen for cognitive impairment during the Medicare Annual Wellness Visit (AWV);

and

evaluate the feasibility, acceptability, and initial validity of the item set using a 'real-world setting' system-wide implementation in AWVs across a large health system

Approach



We gathered input from patients, caregivers, providers and experts to identify cognitive domains most important to include in a screening tool and selected the best 4-item set from the PROMIS Cognitive Function item bank



We partnered with a large health system (University of Pittsburgh Medical Center [UPMC]) to implement the EHR-integrated tool (the PROMIS Cognitive Screener, or PRO-CS) into their AWW workflow



Feasibility was assessed with completion rates, acceptability with provider interviews and scale of adoption, initial validity with descriptive statistics and associations with clinical variables and outcomes

Cognitive Domains

Memory; Change in function

Multi-tasking

Working memory

Verbal fluency

Stakeholder input

Focus groups with patients (n=18), family caregivers (n=5), and primary care providers (n=11) supported the idea of a self-assessment cognitive screening tool

We shared feedback from focus groups with our expert advisory board (n=5) to identify the most relevant cognitive domains to be included in the screener

And selected items from the PROMIS cognitive function item bank to reflect these domains

Initially based on focus group feedback, positively worded items were selected (*I have been able to...*)

but in the clinical context, patients and providers both preferred negatively worded statements (*I have had trouble...*)

The PROMIS Cognitive Screener (PRO-CS)

Positively worded PRO-CS (Abilities)					Negatively worded PRO-CS (Concerns)				
My memory has been as good as usual					I have had trouble remembering whether I did things I was supposed to do, like taking a medicine or buying something I needed				
I have been able to keep track of what I am doing, even if I am interrupted					I have had trouble shifting back and forth between different activities that require thinking				
I have been able to learn new things easily, like telephone numbers or instructions					I have had trouble remembering new information, like phone numbers or simple instructions				
I have been able to bring to mind words that I wanted to use while talking to someone					I have had trouble recalling the name of an object while talking to someone				
Not at all	A little bit	Somewhat	Quite a bit	Very much	Never	Rarely (once)	Sometimes (2 or 3 times)	Often (about once a day)	Very often (several times a day)

Implementation

- UPMC updated AWW form in 2021-2022 and added the PRO-CS
- Approximately 200 primary care sites in over 400 departments across UPMC system
- Use of AWW form is 'highly recommended' and widely used, but not always integrated
- The form can be administered and entered electronically into EHR in several ways
 - Form is available through the patient portal, patient answers at home or via tablet in clinic
 - Form is completed via live questioning by rooming staff or clinician and answers are entered directly into fillable form within EHR
 - Form is completed via printed copy (either directly by patient or by staff) and is either transcribed to electronic fillable form after the visit or attached as a 'note'
- Info about PRO-CS embedded within info about new form, which is available in known resource space (InfoNet)

Interpretive guidance for providers: PRO-CS

PRO-CS Score	Concern for Impairment	Treatment Recommendation
<6	High	Reflex exam, referral, most likely treatment
6-9	Moderate	Reflex exam, possible treatment
10-12	Low	Possible reflex exam, monitor
>12	Very low	Monitor

Screening for cognitive impairment during the Annual Wellness Visit can be done using the Patient Reported Outcome Measurement Information System (PROMIS®) Cognition Screener (PRO-CS). This is a brief, patient reported screening tool used to facilitate early detection of cognitive decline. It is evidence based, standardized, easy to administer for both patient and provider.

**notice a higher score is better, opposite to GAD and PHQ scores*

- Can be used to compare scores overtime*
- If brief screen is positive, should reflex to more comprehensive neuropsychological screening tool like Mini-Mental Status Exam (MMSE), St. Louis University Mental Status Examination (SLUMS Exam) or Montreal Cognitive Assessment (MoCA). In the Annual Wellness Visit SmartSet, under Cognitive Changes tab, you can place some diagnoses which may be appropriate and place orders for referrals (i.e - for neuropsychiatric testing or neurology).*

Feasibility and Acceptability

66,393 – total # of AWWs during study period
(June 6, 2022 – January 19, 2023)

6,070 – # of electronically completed AWWs (9.14%)

1,049 – # of providers who conducted AWWs during
study period

602 – # of providers who submitted at least one
AWV form electronically (57%)

Average # of electronically submitted AWWs:
Mean=10, Median=5, Mode=1

Provider interviews supported acceptability of PRO-
CS Concerns version for both providers and patients

Characteristic	Level	N (%)
Gender	Female	3316 (58%)
Race	White	5461 (96%)
Ethnicity	Hispanic	20 (0.4%)
Age group	65-74	3776 (66%)
	75-89	1839 (32%)
	90+	87 (2%)
Charlson Index	0	3730 (65%)
	1	839 (15%)
	2 or more	1133 (20%)
Cognitive Impairment Group	None recorded	4982 (87%)
	Possible	625 (11%)
	Definite	95 (2%)

Demographic and Clinical Characteristics of PRO-CS Respondents (N=5702)

PRO-CS screening results (N=5702)

Score range	Concern for Impairment	N (%)
<6	High	35 (0.6%)
6-9	Moderate	125 (2.2%)
10-12	Low	306 (5.4%)
>12	Very low	5236 (91.8%)

Initial Validity

PRO-CS scores varied as expected according to clinical groups

PRO-CS scores were related as expected with other patient-reported outcomes

		PRO-CS Score (N=5702)
Overall		53.8 (7.7)
Cognitive Impairment	None (n=4982)	54.1 (7.4)
	Possible (n=625)	52.3 (8.1)
	Definite (n=95)	43.1 (9.9)
	$F_{(df)} (p)$	112.3 _(2,5699) (p<.0001)
Help needed with IADLs	No (n=5090)	54.5 (7.2)
	Yes (n=612)	47.9 (9.1)
		$t_{(df)} (p)$
Taking cognitive enhancing medications	No (n=5641)	53.9 (7.6)
	Yes (n=61)	42.1 (8.7)
		$t_{(df)} (p)$

PRO-CS scores varied as expected by clinical groups

Pearson Correlations (N=5659)	
	PRO-CS
Self-rated health (single item)	0.30
Depression (PHQ-2)	-0.31
Anxiety (GAD-2)	-0.28

PRO-CS scores were related as expected with other patient-reported outcome variables

Conclusions

- PRO-CS items were feasible to implement into the AWW of a large health system
- Our findings provide initial validity evidence for the PRO-CS for cognitive assessment in the Medicare AWW
- PRO-CS scores are related to clinical variables and outcomes as hypothesized
- The PRO-CS screener represents a promising, low burden standardized first step screening tool for cognitive impairment in the AWW
- PRO-CS scores may be helpful in promoting patient-provider discussions about cognitive decline, indicating need for referral or medication, and tracking changes in cognition over time in the AWW

Next Steps

Future work will examine:

- Change in scores over time and correlates of change (i.e., over two or more AWWs)
- Comparison of scores to a gold standard to validate thresholds for recommended provider action (e.g., referral, further testing, medication)
- Controlled (as opposed to real-world) PRO-CS implementation to evaluate impact of PRO-CS on provider behavior and patient satisfaction with clinical encounter

Thank you!

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A Technology-Driven Intervention to Improve Early Detection and Management of Cognitive Impairment (CI Wizard)

R61/R33AG069770

Leah Hanson, PhD
Rebecca Rossom, MD, MS

 HealthPartners[®] Institute



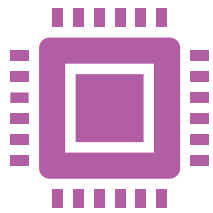
Rationale



- Estimated that over 47 million individuals have dementia worldwide
 - Unrecognized in 27-81% of affected patients
- The Medicare Annual Wellness Visit (AWV) includes a cognitive impairment screen
 - Our health system uses the Mini-Cog
 - Relevant physician action only occurred in 17% of patient with a positive mini-cog screen in primary care
- Additional tools are needed to bridge the gap between screening and diagnosis

Primary Objective

Increase detection of cognitive impairment in primary care by leveraging an existing clinical decision support tool, **Priority Wizard**



What is Priority Wizard?

- ❖ Web-based, EHR-linked shared decision making/clinical decision support system
- ❖ Informs patients and clinicians of important care opportunities
- ❖ Current content focuses on modifying cardiovascular risk



Who uses Priority Wizard?

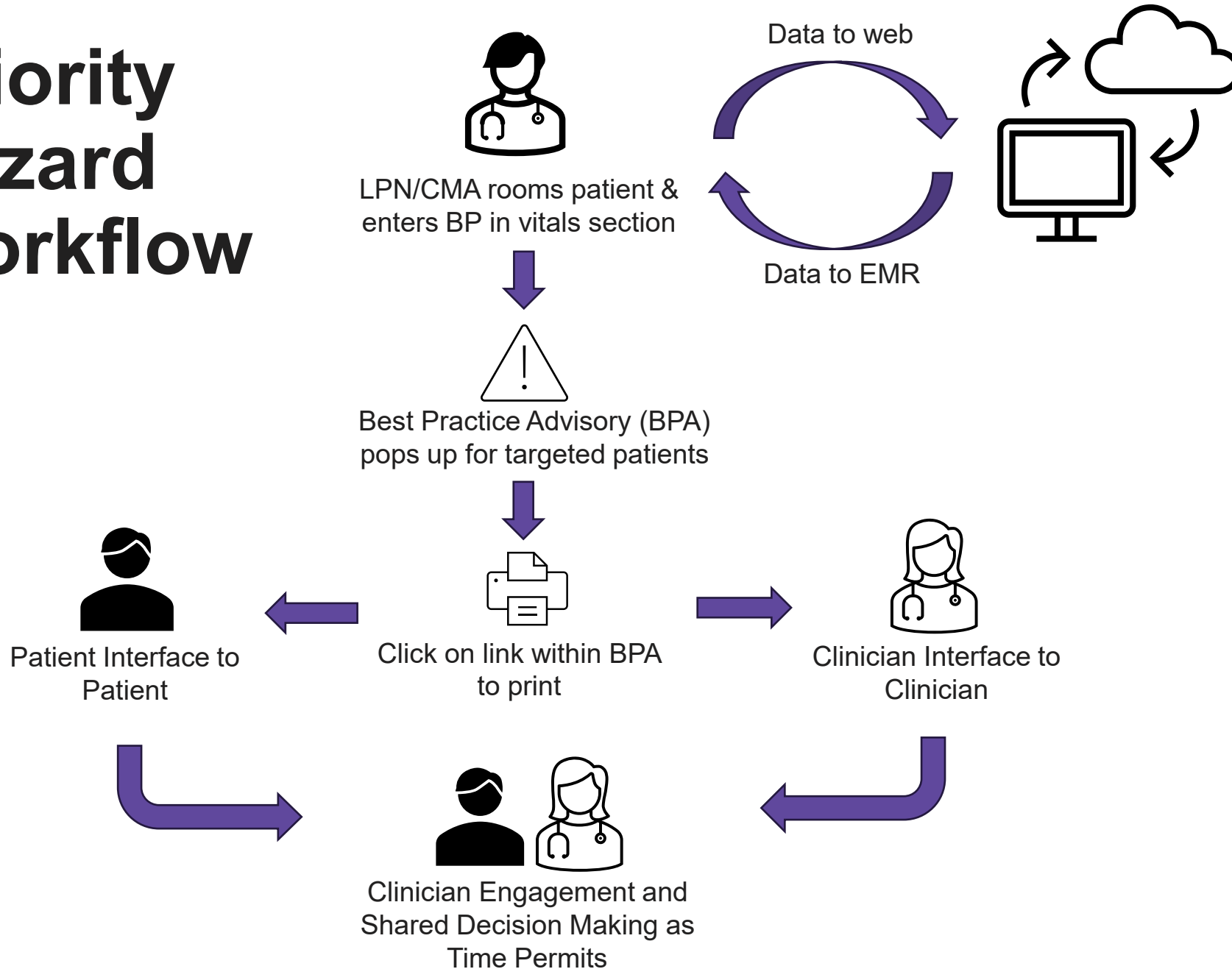
- ❖ 10 states
- ❖ 3 million patients
- ❖ 70 safety net clinics



Does Priority Wizard work?

- ❖ Improved glucose control (A1C levels) and BP in people with diabetes
- ❖ Reduced CV risk in patients with serious mental illness
- ❖ Improved BP and Lipid medication adherence

Priority Wizard Workflow



Web Service Runs Algorithms

- Identifies targeted conditions with opportunity for actionable care improvement
- Prioritizes clinical conditions and determine order of display
- Suggests treatment and actions
- Provides safety considerations

Priority Wizard Patient Handout

TALK TO YOUR DOCTOR ABOUT HOW YOU CAN IMPROVE YOUR HEALTH













Start the conversation! Use the priorities below as a guide to take action to better your health.

 Important	 Consider Action	 Doing well
---	---	--

 Medications can be costly. We encourage you to talk with your care team about the cost of your medications.

New CI Wizard
Content

Current Priority
Wizard Content

 MEMORY HEALTH		Consider scheduling a visit to talk to your doctor about memory health. If there is a problem with memory beyond what is expected with normal aging, they can help you understand what it means, address possible treatable causes, and plan for the future.
 WEIGHT	 Your Weight: 240	Weight management options (shown on the next page) can reduce your weight up to 24 lbs (10%)
 CHOLESTEROL	 Your LDL: 74	Your Goal: A cholesterol lowering medication may be beneficial for you. Talk to your doctor.
 BLOOD SUGAR	 Your A1C: 5.5	You may be due for diabetes screening.
 BLOOD PRESSURE	 Your Blood Pressure : (119/72)	BP is less than 130/80
 TOBACCO		Good Work!

Priority Wizard Clinician Handout



Clinical Priorities **Cognitive Health**

Provider Patient Print

Relevant Conditions: Hypertension

10-year Cardiovascular Risk : 17.8% (Risk of stroke or heart attack over the next 10 years)

New CI Wizard
Content

Current Priority
Wizard Content

#1 COGNITIVE HEALTH	Results	
Treatment Considerations <ul style="list-style-type: none"> Patient screened positive for potential cognitive impairment on the MiniCog (score less than 3). Consider completing a cognitive health evaluation, such as the MoCA. See the Wizard Tools Cognitive Health tab for more information. 	TSH 1.15 PHQ9 0 MINICOG (nl >=3) 2 ⓘ (nl = normal)	No relevant medications
#2 BMI (WEIGHT)	Results	
Treatment Considerations <ul style="list-style-type: none"> Consider structured lifestyle program to achieve weight reduction of up to 7% (16 lbs) (see QR code on next page of print out). Consider using medications to achieve weight loss of about 24 lbs. 	Weight(lbs) 240 Last Weight(lbs) 240 BMI 39.9	No relevant medications
#3 LIPID	Results	
Goal: Consider statin initiation. Treatment Considerations <ul style="list-style-type: none"> Consider statin initiation or intensification per ACC/AHA guidelines due to 10-year cardiovascular risk of 7.5% up to 20%, favoring moderate to high intensity statins in the presence of cardiovascular risk enhancers. Other Alerts <ul style="list-style-type: none"> The last lipid labs were more than a year ago. Consider ordering lipid tests to ensure that CV risk and statin recommendations are up-to-date. The following drugs or conditions were identified that could influence your choice of statin or limit the dosage intensity recommended to moderate or less: * Niacin 	LDL (mg/dl) 74 HDL (mg/dl) 45 TRIG (mg/dl) 73 TC (mg/dl) 134 ALT (mg/dl) 16	No relevant medications

Home Screen and Assessments Tab

Clinical Priorities **⚠ Cognitive Health**

Reason(s) for displaying: Positive Mini-Cog screen for cognitive impairment

Relevant Evaluation TSH (normal 0.30-4.50 uIU/mL) 1.15 PHQ9 (depression>=5) 0	Relevant Screening Mini-Cog 2 3-5 ⓘ	Quick Actions OT cognitive eval. E-Consult Neurology Refer to Neurology
--	---	---

Assessments Additional Evaluation Diagnostic Criteria Care & Support

Mini Cog Comprehensive Assessments Functional Assessments

Consider further assessment of cognitive function recommended using one of the following:

MoCA (preferred test)	Previous Screen Date:	Previous Score:	-
Step 1: Click here to launch MoCA assessment.			
SLUMS	Previous Screen Date:	Previous Score:	+
MMSE	Previous Screen Date:	Previous Score:	+
Mayo Mini Mental	Previous Screen Date:	Previous Score:	+

Diagnostic Criteria Tab

[Assessments](#)

[Additional Evaluation](#)

Diagnostic Criteria

[Care & Support](#)

Here are several common and less common cognitive impairment diagnoses:

Common Cognitive Impairment Diagnoses

- **Mild cognitive impairment (MCI) (G31.84)**
 - Mild deficits in memory, executive, visuospatial, language, and/or attention that do not interfere with functioning (i.e., does not meet criteria for dementia)
- **Alzheimer's disease (G30.0 – Alzheimer's disease with early onset (<65 years old), G30.1 – Alzheimer's disease with late onset (>=65 years old))**
 - Most common type of dementia
 - Memory loss, confusion, disorientation, trouble with names or words

Less Common Dementia Diagnoses

- **Dementia with Lewy bodies (G31.83)**
 - Second most common type of dementia
 - Visual hallucinations, REM sleep disorder, parkinsonism, fluctuations in cognition
- **Frontotemporal dementia (G31.09)**
 - Third most common type of dementia; primarily affects individuals in their 50s and 60s
 - EITHER marked changes in behavior/personality OR language (speaking or understanding) with relative sparing of memory
- **Vascular Dementia (F01.50 – vascular dementia without behavioral disturbance, F01.51 – vascular dementia with behavioral disturbance)**
 - Relatively rare in pure form
 - Symptoms often overlap with those of Alzheimer's disease but patients have evidence of stroke or microvascular events
- **Unspecified dementia (F03.90 – without behavioral disturbance; F03.91 – with behavioral disturbance)**
 - Cause of dementia is unknown.

Non-Dementia Causes of Impaired Cognition

Care and Support Tab

Assessments	Additional Evaluation	Diagnostic Criteria	Care & Support
<h3>Pharmacologic Support</h3> <p>Mild-Moderate Alzheimer's disease</p> <ul style="list-style-type: none">+ Donepezil (oral)+ Galantamine (oral)+ Rivastigmine (patch) <p>Moderate-Severe Alzheimer's disease</p> <ul style="list-style-type: none">+ Memantine <p>Depression/Anxiety</p> <ul style="list-style-type: none">+ Sertraline+ Escitalopram <p>Insomnia</p> <ul style="list-style-type: none">+ Melatonin+ Trazodone+ Sleep Services Referral <p>Agitation</p> <ul style="list-style-type: none">+ Quetiapine+ Sertraline	<h3>Lifestyle</h3> <ul style="list-style-type: none">Living Well with Dementia GuidePatient educationHealthy brain diet <h3>Caregiver Support</h3> <ul style="list-style-type: none">+ Refer to Care CoordinationCaregiver educationTypes of DementiaDealing with challenging behaviors <h3>Patient Safety</h3> <ul style="list-style-type: none">+ Driving evaluation referral+ Home safety and medication compliance	<h3>Medication Management</h3> <p>Medication adherence</p> <ul style="list-style-type: none">+ MTM referral (not covered by insurance) <p>New Alzheimer's treatments</p> <ul style="list-style-type: none">Lecanemab/Aducanumab (Leqembi/Aduhelm) FAQ <h3>Future Planning Information</h3> <ul style="list-style-type: none">Power of attorneyRelease of informationPOLST (Physician's Orders for Life-Sustaining Treatment) <h3>Resources in Spanish</h3> <ul style="list-style-type: none">What is dementia?After diagnosis -- now what?Alzheimer's Association resourcesTips for managing stress as a caregiverDealing with challenging behaviorsKeeping home safe	

Eligibility for CI Wizard

Primary care office visit at a randomized clinic during the accrual period

AND

Patient is age 65 or over

AND

Patient has no CI diagnosis documented in the EHR prior to the visit

AND

Patient has

Any abnormal score on a comprehensive cognitive assessment (MoCA, MMSE or SLUMS) in the prior 18 months

OR

MiniCog score <3 in the prior 18 months and there is no evidence of a subsequent comprehensive cognitive assessment (MoCA, MMSE, SLUMS)

OR

No cognitive assessment in the past 18 months and risk of a dementia diagnosis in the next 3 years $\geq 15\%$ as calculated by the MC-PLUS algorithm developed in the R61 phase

R61: Model development and pilot testing

Dementia Prediction Model

- identifies patients at $\geq 15\%$ risk of a dementia diagnosis in the subsequent 3 years
- Validated in one healthcare system

	With Mini-Cog	Full Population
AUC	0.832	0.801
Specificity	96.49%	92.82%
Sensitivity	31.11%	38.09%
PPV	24.95%	25.01%

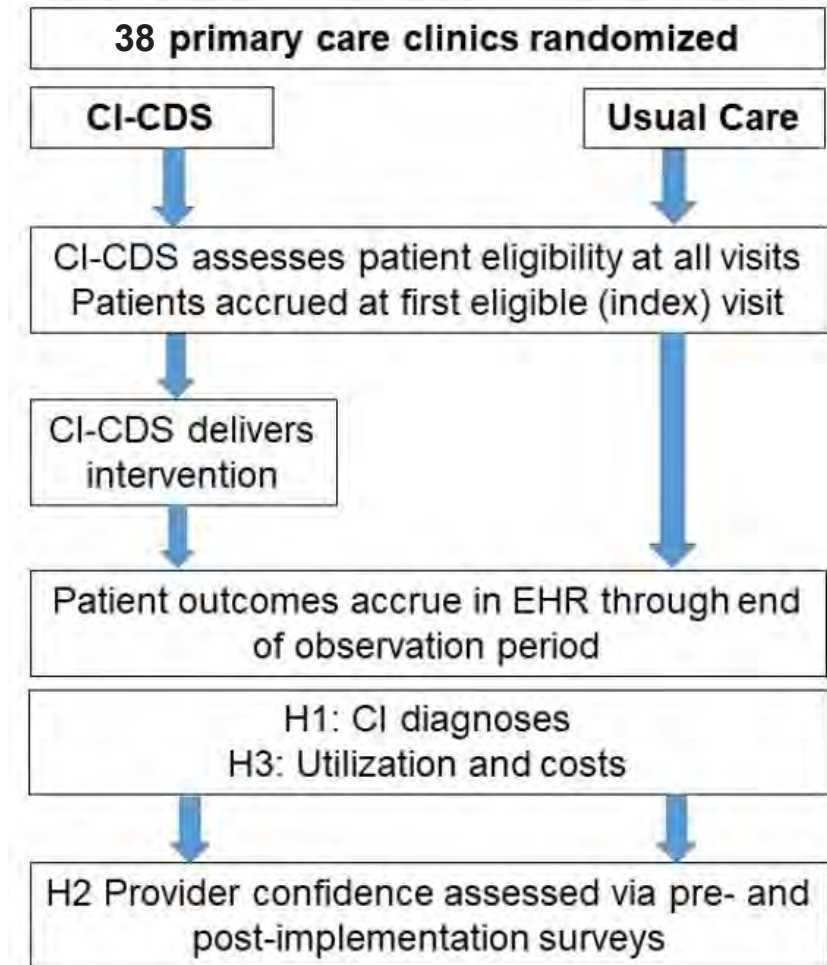
Included Variables:

- Annual Wellness Questionnaire
- Cognitive Screens
- Diagnoses and problem list
- Encounters
- Health Modifiers
- Labs
- Vitals
- Medication list
- Procedures
- Patient reported outcomes (e.g., PHQ-9)
- Social history (e.g. drug and alcohol use)
- Vaccinations

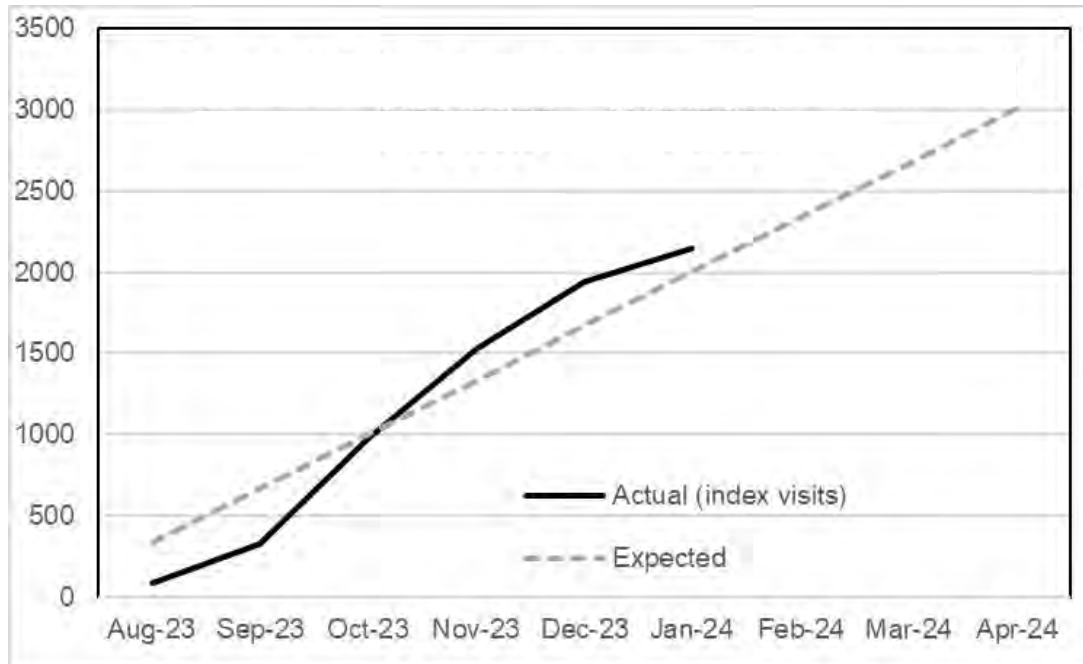
Pilot tested model and UI at 3 primary care sites

R33: randomized, pragmatic clinical trial

- Settings:
 - HealthPartners (Main Site): a large, integrated care organization with over 70 primary care facilities in Minnesota and Wisconsin
 - OCHIN (Replication Site): network of over 2,000 community healthcare delivery sites in 39 states
- Clinic Randomized
 - Addition of Cognitive Impairment Module (CI-CDS) vs Usual Care (UC)
- Embedded within the clinic workflow
- Primary outcome will be assessed through EHR documentation
 - Patients with elevated CI risk at index visits in CI-CDS compared to UC clinics will have significantly higher rates of CI detection as indicated by EHR documentation of CI in up to 24 months of follow up.



Recruitment & Enrollment



- 38 primary care clinics randomized (n=19 per arm)
- Patient accrual began August 2023
- Total accrued as of 03/02/2024: 2754

Recruitment & Enrollment: Replication Site

14 service areas approached to participate in the study

Service area = group of related clinics within the same geographic area



3 service areas (7 clinics) have agreed to participate in the intervention arm



5 service areas (26 clinics) have agreed to participate in the control arm



Patient accrual to begin April 2024

Recruitment goal: 2000 patients

Study Team

HealthPartners

Leah Hanson

Rebecca Rossom

Patrick O'Connor

Mike Maciosek

Lauren Crain

Meghan JaKa

Deepa Appana

Ann Werner

Heidi Ekstrom

Bethany Crouse

Aleta Svitak

Sally Gustafson

Rashmi Sharma

Kay Kromrey

Brian Laroque

Gopi Kunisetty

Cyndi Luedtke

Vijay Thirumalai

Sam O'Blenes

Laura Jacobson

OCHIN

Connie Owens

Rachel Gold

Maura Pisciotta

Joanna Georgescu

Mary Middendorf

Shelby Watkins

Andrew Weresch

Jenny Hauschildt

Dan Budney

Thank you!
Questions?



Primary Care Detection of Cognitive Impairment and Dementia: The Toolbox Detect Trial



a clinical application of the NIH
Toolbox

Michael Wolf, PhD MPH MA

James R. Webster, Jr. Professor of Medicine

Director, Center for Applied Health Research on Aging (CAHRA)

Director, Northwestern Pepper Center

M Northwestern Medicine[®]
Feinberg School of Medicine

NIH National Institute of
Neurological Disorders
and Stroke

NIH National Institute
on Aging

Overview.

- I. Introduction to the NINDS Consortium for Detecting Cognitive Impairment, Including Dementia
- II. MyCog: A Cognitive Screening Paradigm Leveraging the NIH Toolbox
- III. Toolbox Detect Trial
- IV. Expanding the MyCog Suite of Tools

DetectCID

The Consortium for Detecting Cognitive Impairment, Including Dementia

<https://www.detectcid.org>



National Institute of
Neurological Disorders
and Stroke

Rebecca Hommer, MD
Roderick Corriveau, PhD



- Since 2017, a collaborative network of research programs validating paradigms that include cognitive, functional assessment tools and protocols
- Overall Goal: increase the frequency and improve the quality of patient evaluations for detecting cognitive impairment in primary care and other everyday clinical settings, as well as community screenings
- Address barriers to detecting cognitive impairment associated with health disparities

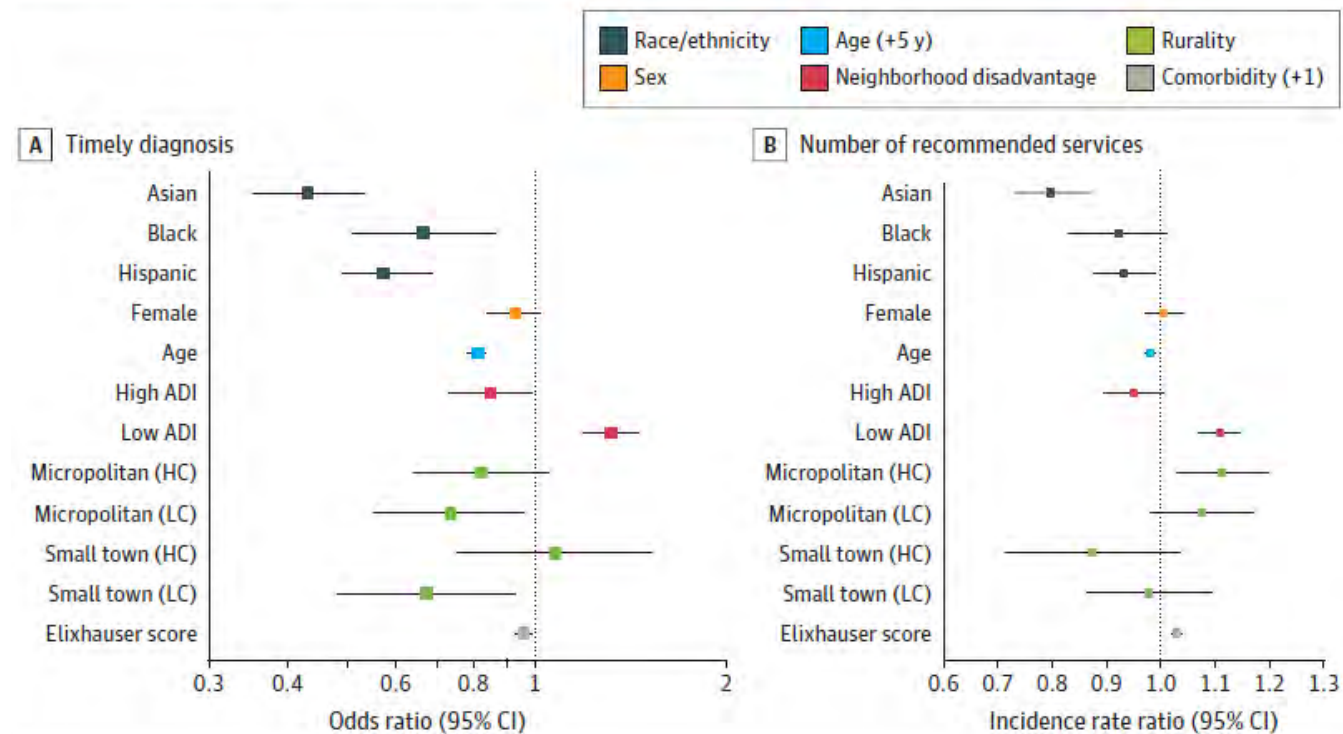
Need to Address Known Disparities

JAMA Neurology | Original Investigation

Assessment of Racial/Ethnic Disparities in Timeliness and Comprehensiveness of Dementia Diagnosis in California

Elena Tsoy, PhD; Rachel E. Kiekhofler, BA; Elan L. Guterman, MD; Boon Lead Tee, MD; Charles C. Windon, MD; Karen A. Dorsman, BA; Sergio C. Lanata, MD; Gil D. Rabinovici, MD; Bruce L. Miller, MD; Amy J. H. Kind, MD, PhD; Katherine L. Possin, PhD

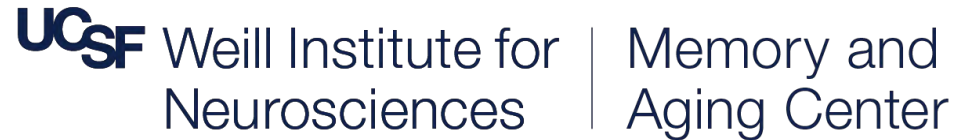
Figure. Adjusted Odds Ratios and Incidence Rate Ratios of Timely Diagnosis and Number of Recommended Diagnostic Services by Race/Ethnicity, Individual Factors, and Contextual Factors



- Medicare data from 2013-15 (California); N=10,472
- Asian, Black, and Latino adults less likely to receive a timely dementia diagnosis (MCI)
- Asian adults received fewer diagnostic evaluation elements

Dotted line indicates the reference group estimate (White, male, mid-area deprivation index [ADI], and metropolitan). HC indicates high commute; LC, low commute.

Site-Specific Approaches.



5-Cog

3 components:

1. picture-based memory impairment screen (PMIS)
2. timed walk
3. match test

<5 min. to complete

Brain Health Assessment

2 required tests:

1. favorites (associative memory)
2. match test

2 optional tests:

1. line orientation
2. animal fluency

optional informant survey

7 min. to complete tests, 3 min
for key informant survey

MyCog

2 NIHTB tests:

1. picture sequence memory
2. dimensional change card sort

<7 min. to complete
(self-administered)



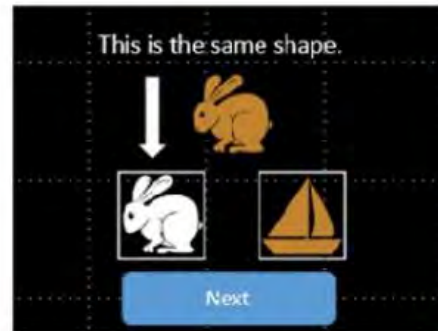
Leveraging the NIH Toolbox.

UG3/UH3NS105562

Executive Function

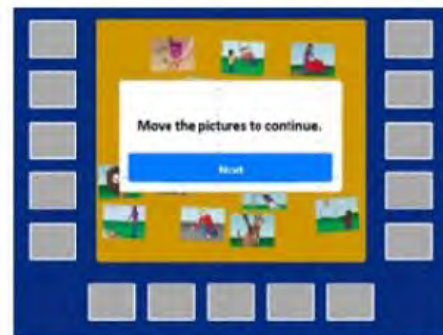


Figure 1. NIHTB MyCog Assessments



Dimensional Change Card Sort

Episodic Memory



Picture Sequence Memory



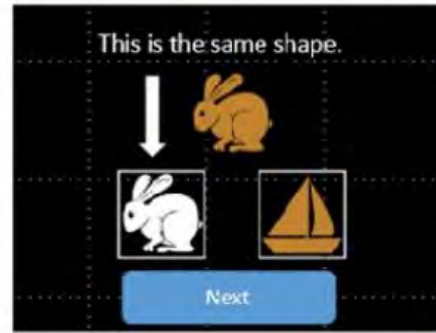
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UG3/UH3NS105562

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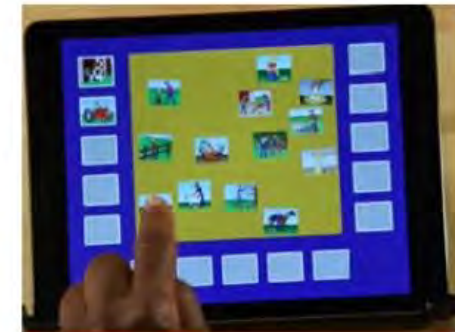
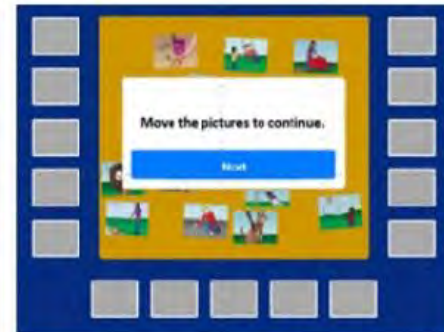


Figure 1. NIHTB MyCog Assessments



Dimensional Change Card Sort

Episodic Memory



Picture Sequence Memory

Table 1. Fully Corrected T-Scores for Armada General Population Sample

NIHTB Test	NC 65	MCI	AD	p
Cognition Crystallized Composite	58.2	52.7	49.7	<.0001
Cognition Fluid Composite	51.3	41.5	30.4	<.0001
Cognition Total Composite	55.5	46.8	38.5	<.0001
Dimensional Change Card Sort	55.2	49.5	42.0	<.0001
Flanker Inhibitory Control and Attention	45.6	42.0	33.2	<.0001
List Sorting Working Memory	53.7	44.5	35.5	<.0001
Oral Reading Recognition	55.4	51.9	49.1	<.0001
Pattern Comparison Processing Speed	48.1	42.4	30.8	<.0001
Picture Sequence Memory	52.1	42.4	36.0	<.0001
Picture Vocabulary	59.5	53.1	50.4	<.0001



Features.

- User-centered, iterative design – involving clinicians, administrators, patients



Features.

- User-centered, iterative design – involving clinicians, administrators, patients
- iPad-based



Features.

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- Self-administered



Features.

- User-centered, iterative design – involving clinicians, administrators, patients
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- Self-administered
- Tethered to the electronic health record (EHR)
 - bar/QR code linkage
 - auto-populated results with 'red light/green light' impairment determination



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- Provision of clinic-tailored 'turnkey' recommendations (e.g. Epic 'smartset')



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 - auto-populated results with 'red light/green light' impairment determination
- Provision of clinic-tailored 'turnkey' recommendations (e.g. Epic 'smartset')
- Ability to track relative vs. normative decline over time with EHR flowsheets

MyCog Scores

Mycog Battery V1.1

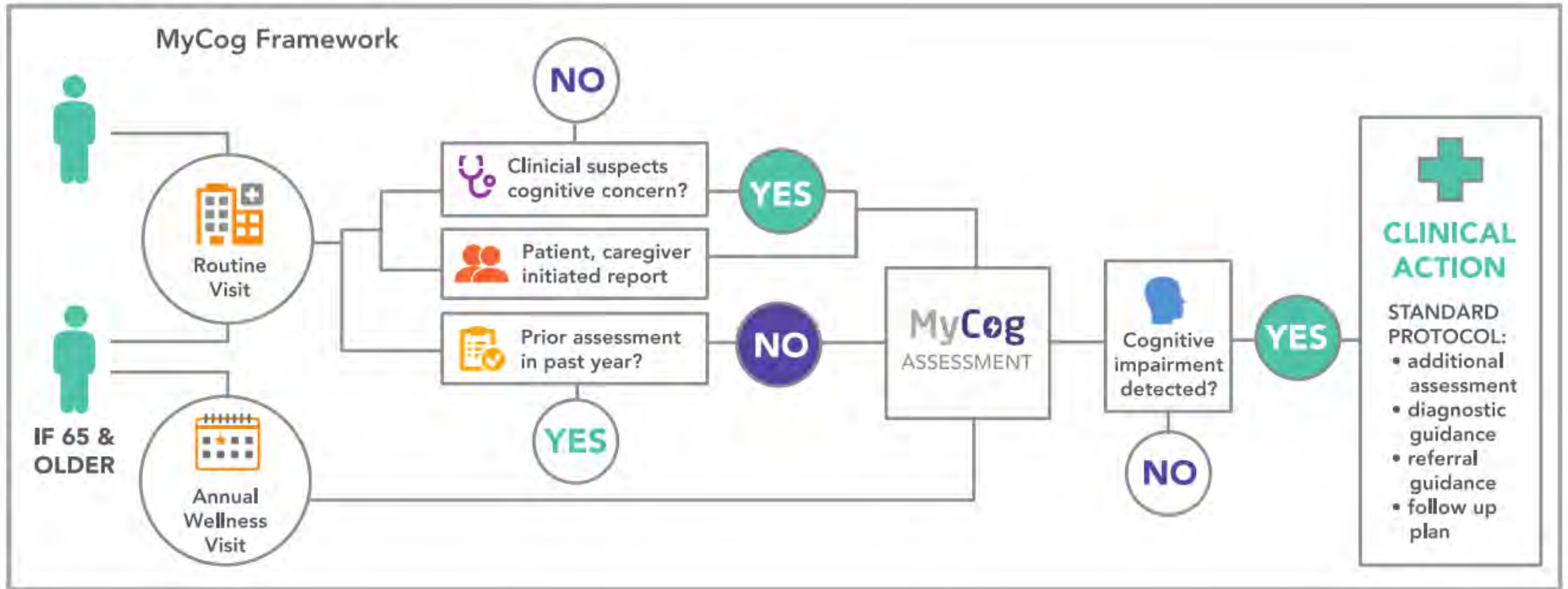
Question	5/30/2023 3:42 PM CDT - Filed by Background, Enterprise Data Architecture Interconnect
MyCog Dimensional Change Card Sort (range: 0 - 30)	14
MyCog Picture Sequence Memory (range: 0 - 12)	0
MyCog Battery Score (range: 0 - 100)	88 (High likelihood of impairment) !!

MyCog Scores

Mycog Battery V1.1

Question	5/30/2023 3:33 PM CDT - Filed by Background, Enterprise Data Architecture Interconnect
MyCog Dimensional Change Card Sort (range: 0 - 30)	30
MyCog Picture Sequence Memory (range: 0 - 12)	12
MyCog Battery Score (range: 0 - 100)	3 (Low likelihood of impairment)

A Primary Care Paradigm



Ongoing: Real World Studies and Further Adaptation

- 2-arm, clinic-randomized trial (40 academic practices, 20 FQHC replication sites)
 - 12 to 36 month follow-up implementation period
- Primary outcomes:
 - rates of detected CI, proportion MCI, disparities reduction
- Secondary outcomes:
 - referrals, diagnosis, caregiver involvement
- Fidelity outcomes:
 - cognitive screening rates, costs, workflow impact, referral acceptance



Toolbox Detect Update

R01AG09762

- 30 clinics randomized (15 intervention, 15 usual care)
- As of February 2024, 16,880 participants enrolled
- 72% of AWWs in intervention arm completed MyCog
 - rates vary by clinician (40-90%)

Challenges to date: patient technology literacy, patient cognitive screener refusal, time, variable clinician EHR workflows

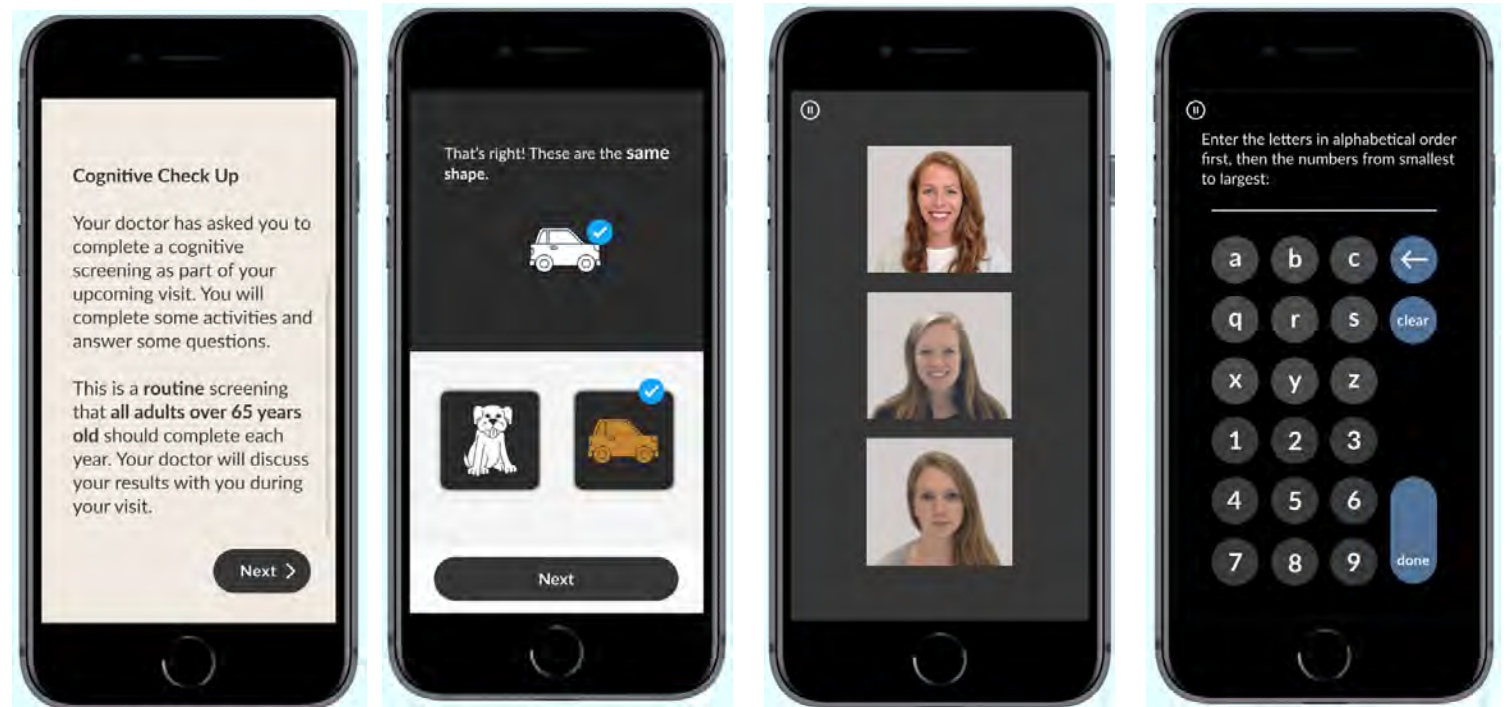


‘MyCog Trial’ to Address Disparities.

- DetectCID v2: Pragmatic Trials launched in 2022 to target communities experiencing health disparities
- Trial launched January 2024 (5 states, 24 sites)
- Partnership with Oak Street Health  OAK STREET HEALTH
- Dissemination to a new EHR platform (Greenway)
- Goal: to reduce disparities in early CID detection among Black, Latino communities

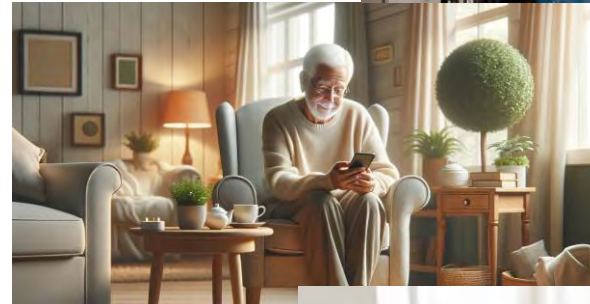
Adapting to Primary Care.

- MyCog Mobile: smart phone version in development (R01AG074245)
 - unproctored, pre-visit, smartphone-based assessment tethered to the EHR



Seeking a Coordinated System of Products.

- Multiple platforms
- Multiple devices
- Pre-visit or at visit
- Multiple languages
- Consideration of other tests



NORTHWESTERN
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CAHRA
Center for Applied Health Research on Aging

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