



NEXT STEPS

Advancing Nursing Home
Care Through Research

Housekeeping



- All participants will be muted
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
- Visit impactcollaboratory.org
- Follow us on LinkedIn



Building the NEXT STEPs Network

Kathleen Unroe, MD, MHA, MS

Disclosures

NEXT STEPs is funded by the National Institute on Aging (U24AG087939).

Dr. Unroe is the founder and CEO of Probari, Inc., a healthcare start-up designed to improve clinical care of nursing home residents.

Overview

- Evidence needed to improve nursing home care
- Building the NEXT STEPs Network
- Upcoming opportunities with NEXT STEPs!

Nursing homes

- >15,000 facilities
- Rehabilitation and Long-Term Care
- Average of 106 beds; 1.7 million beds
- Nearly all Medicare-Medicaid certified
- 70% for profit
- ~\$85-100K per year
- Medicaid payer for 60%



Nursing home residents

- Over 80% of residents need help with 3 or more Activities of Daily Living
- ~90% require supervision
- 50-70% have cognitive impairment



Research in nursing homes

- The 1.4 million people who receive care in nursing homes (NHs) are largely excluded from explanatory clinical trials, despite significant need
- Concerns and challenges regarding care and outcomes in NHs necessitate rigorous clinical trials designed for the NH setting
- There is consensus that NHs are a challenging setting for research
- Existing infrastructure and collaborations can be leveraged to address barriers to NH research. This is the next step!

NEXT STEPs U24 RFA Purpose

- To establish a **national consortium of interdisciplinary nursing home researchers**
- To **address critical knowledge gaps and generate high-quality evidence** to inform medical decision making and enhance quality of care for nursing home residents
- To create a **centralized research infrastructure** with essential core functions



Elements of a High-Quality Clinical Trials in the Nursing Home Setting

Journal of the American Geriatrics Society
September 2024 issue (Volume 72, Issue 9)

NEXT STEPs Specific Aims

Aim 1: Provide integrated support for investigators to conduct equitable, explanatory trials in NHs.

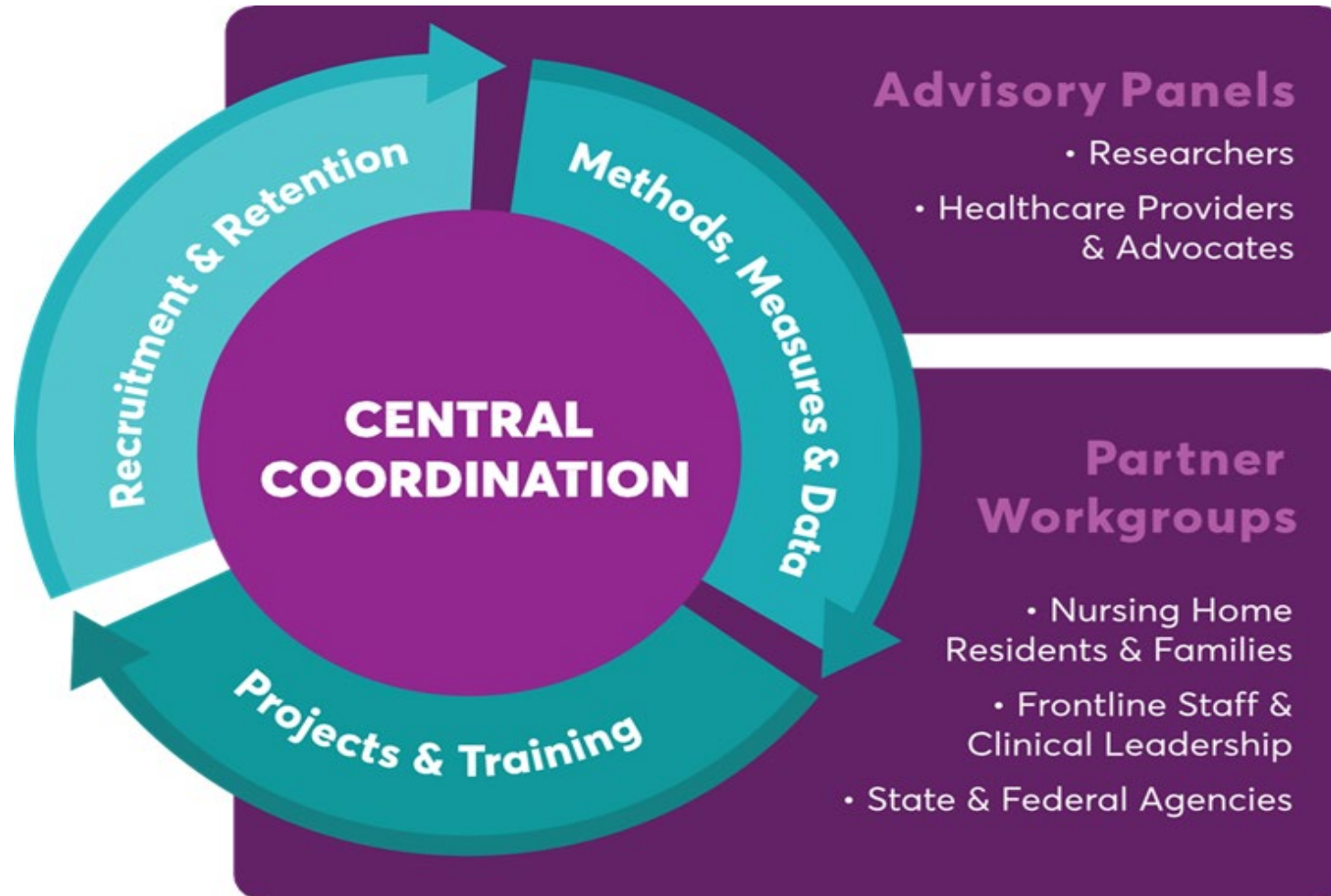
Aim 2: Develop a sustainable, collaborative community of engaged NH researchers and partners.

Aim 3: Build research capacity for high-quality, high-impact clinical trials in NHs.

**Nursing Home
EXplanatory clinical
Trials**

**Supporting
Transformation by
Enhancing
Partnerships**

Organizational Structure



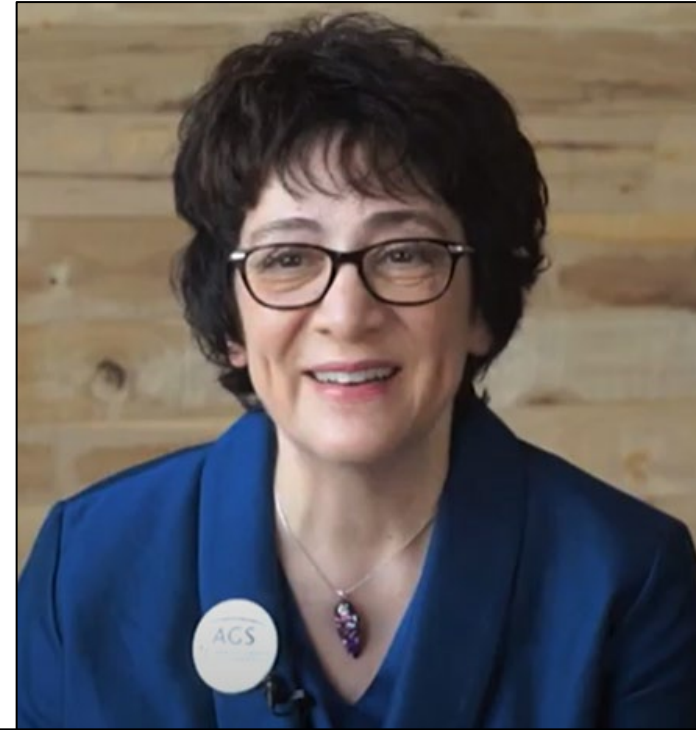
Central Coordination Team



Core Lead:

Kathleen Unroe, MD, MHA, MS

*Professor of Medicine, Indiana University School of Medicine
Research Scientist, Indiana University Center for Aging
Research, Regenstrief Institute*



Core co-lead:

Debra Saliba, MD, MPH

*UCLA Anna & Harry Borun Endowed Chair in Geriatrics
VA GLAHS GRECC Physician Scientist
VA GLAHS HSR Center of Innovation Director for Education
Director, UCLA/JH Borun Center for Gerontological Research
Senior Natural Scientist, RAND Health*

Recruitment and Retention Core

Investigators	Institutions
Core Lead: Sheryl Zimmerman, PhD, MSW	University of North Carolina, Chapel Hill; Cecil G. Sheps Center for Health Services Research and Schools of Social Work and Public Health
Associate Lead: Jasmine Travers, PhD, MHS, RN, FAAN	New York University Rory Meyers College of Nursing
Jennifer Carnahan, MD, MPH, MA	Indiana University School of Medicine, Regenstrief Institute
Gail Towsley, PhD, MS, NHA	University of Utah College of Nursing
Alice Bonner, PhD, RN, FAAN	Institute for Healthcare Improvement, Moving Forward Nursing Home Quality Coalition, Johns Hopkins University School of Nursing



Sheryl Zimmerman



Jasmine Travers Altizer



Jennifer Carnahan



Gail Towsley



Alice Bonner

Recruitment and retention - resources

NEXT STEPs Resources: <https://nextstepsnetwork.org/resources/>

RESOURCES FOR INVESTIGATORS

RESOURCES FOR NURSING HOME LEADERS

INFOGRAPHICS

OPPORTUNITIES

REFERENCES

TRAINING

NEXT STEPs WORDS MATTER

Words matter, including when conducting research in nursing homes. Researchers new to the field may unintentionally use words that indicate a lack of familiarity with nursing homes, and that in some instances convey disrespect. The "Not That/Use This" table provides examples of common words to avoid and suggested alternatives, and the reasons why. Of course, cultural and other considerations may affect the terms preferred by individuals or groups, so in all circumstances the best practice is to inquire what terms are preferred.

NOT THAT	USE THIS	WHY?
WORDS REFERRING TO PEOPLE		
Subject	Participant	Recognize dignity as a human being.
Patient	If medical or short-term: patient, resident. If not medical, or if long-term: person, resident	Recognize that people are more than their medical condition.
Elderly, senior, aged, old person	Older person/people/adult, or specify age range	
Handicapped	People living with disabilities, or with a specific impairment	Avoid ageist/ableist perceptions.
Able bodied/normal	People without disability/impairment	
Vulnerable	People who are at increased risk of harm; may also specify what is meant by "vulnerable"	
Blind	Refer to specific level of vision impairment (blind, legally blind, limited vision, partially sighted)	Recognize differences in opacity.
Deaf	People who are deaf or hard of hearing	
Wheelchair-bound, bed-bound	People who use a wheelchair People who are bed-bound	
Adjective-first descriptions (e.g., dementia/diabetic patient)	Person-first reference (e.g., person with dementia/diabetes)	Recognize that people are more than their medical condition and functional status.
Terms referring to people as care tasks (e.g., feeder, total assist)	People who require a specific type of care	
Terms of endearment (e.g., honey, baby, sweetheart)	Person's preferred name (e.g., Mary, Mrs. Jones)	Recognize dignity as a human being.
Loved one	Family member, friend, or specify particular relationship.	Recognize that family and friends may not be in a loving relationship, and their role is not informal; in addition, some residents may have a specific designated decisionmaker.
Caretaker, informal caregiver/partner	Family/friend caregiver, care partner, support person, or specify particular personal or legal relationship (e.g., legally authorized representative [LAR], healthcare power of attorney)	
Stakeholder	Interest groups, community members, people affected, collaborators	Avoid suggesting a power differential.

Words Matter

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NEXT STEPs Norms of Engagement Nursing Home Leadership

NORMS OF ENGAGEMENT FOR NURSING HOME RESEARCH

It is important to conduct nursing home research to understand resident care needs and how to optimize care. Partnering in research need not create burden as long as everyone understands and has a voice in the process. The list below includes topics to discuss and questions to ask when talking with researchers as you consider whether to engage in research; it also provides space for you to take notes.

Goals:	
<ul style="list-style-type: none"> What are the goals of the study? (Consider if they align with your priorities.) Is the study an intervention? (An intervention changes care practices.) <ul style="list-style-type: none"> What is the new practice? How does it affect our standard care? 	
<p>Overall Activities:</p> <ul style="list-style-type: none"> Who will participate in the study? (Participants may include direct care or other staff, residents, families, administrators, and others.) <ul style="list-style-type: none"> Will type of participant participate during work hours? How long will it take? Will participation affect regularly planned activities? What are the study activities? (Activities include how consent is obtained and participants are identified, the source of the information that will be collected and how and how often it will be collected, and others.) Will you need access to our medical records or other data systems? What space is needed for the research? Can we choose to participate in some, but not all, activities? <p>Timeline:</p> <ul style="list-style-type: none"> How long does the study last? (The timeline includes when consent is obtained, data are collected, and the study is completed.) How long can we have to decide whether we'll participate? If we don't participate now, can we participate in the future? If we agree to participate, can we end our participation at any time? <p>Benefits of and Risks to Participation:</p> <ul style="list-style-type: none"> What are the benefits to our nursing home/staff/residents/families? What are the risks to our nursing home/staff/residents/families? <ul style="list-style-type: none"> What protections are in place to limit these risks? How will personal/sensitive information about residents be protected? Has the study been reviewed by an oversight committee? (Examples include a university Institutional Review Board [IRB], and others.) Will there be potential liability based on the findings? Will we receive recognition for participating? (Examples include certificate of participation, acknowledgement in dissemination materials, and others.) <p>Paperwork:</p> <ul style="list-style-type: none"> Are we required to sign anything to participate? (Examples include a Memorandum of Agreement, Data Use Agreement, and others.) If asked by our organization, will you sign or modify related paperwork? (Examples include consent forms, confidentiality agreements, and others.) 	

Norms of Engagement (Nursing Home Leadership)



Partner Workgroups

Partner Workgroups meet every quarter by Zoom and ad hoc as indicated to provide input on NEXT STEPs resources and efforts (e.g., providing input on what matters in terms of research priorities)

- Residents (N=8)
- Family members (N=8)
- NH clinical and administrative leaders (e.g., administrator, DON; N=7)
- Frontline NH staff (e.g., nurses, nurse aides, social services; N=8)

Later:

- State and federal regulatory agencies

Partner Workgroup Perspectives

Residents, regarding what researchers should understand about NH life:

Residents lack control over daily life (e.g., people entering room; lighting, roommates); NHs serve people of all ages; be cautious of “staged” environments during visits

Families, regarding research participation:

Concerns about consent, time demands, emotional toll; fear of retaliation when NHs control research access, and differential treatment based on cooperation (i.e., some felt pressured/exploited in past experiences)

Administrators, regarded experiential learning program:

Program can benefit researchers and NH staff; suggested using a shadowing approach; warned against overwhelming NH staff with questions; emphasized importance of understanding lived experience

Methods, Measures, and Data Core

Investigators	Institutions
Core Lead: Susan Hickman, PhD, FAAHPM, FGSA	Indiana University Schools of Medicine and Nursing, Regenstrief Institute
Associate Lead: Andrew Zullo, PharmD, ScM, PhD	Brown University School of Public Health, Providence VA Medical Center
Wanzhu Tu, PhD, FAHA	Indiana University School of Medicine, Regenstrief Institute, Indiana University Fairbanks School of Public Health
Julie Lima, PhD, MPH	Brown University School of Public Health
Jennifer Stevens-Lapsley, PT, PhD, FAPTA	University of Colorado School of Medicine, VA Eastern Colorado Health Care System
Cathleen Colon-Emeric, MD, PACP, MHS	Duke University School of Medicine
Stefan Gravenstein, MD, MPH	Brown University Schools of Medicine and Public Health, Providence VA Medical Center



Susan Hickman



Andrew Zullo



Wanzhu Tu



Julie Lima



Jennifer Stevens-Lapsley



Cathleen Colon-Emeric



Stefan Gravenstein

Methods - Resources



NEXT STEPS Best Practices: Conducting Research in Nursing Homes
(Information for Investigators)

Before a Study Begins: A Roadmap to
Regulatory Requirements for Developing
Research in Nursing Homes

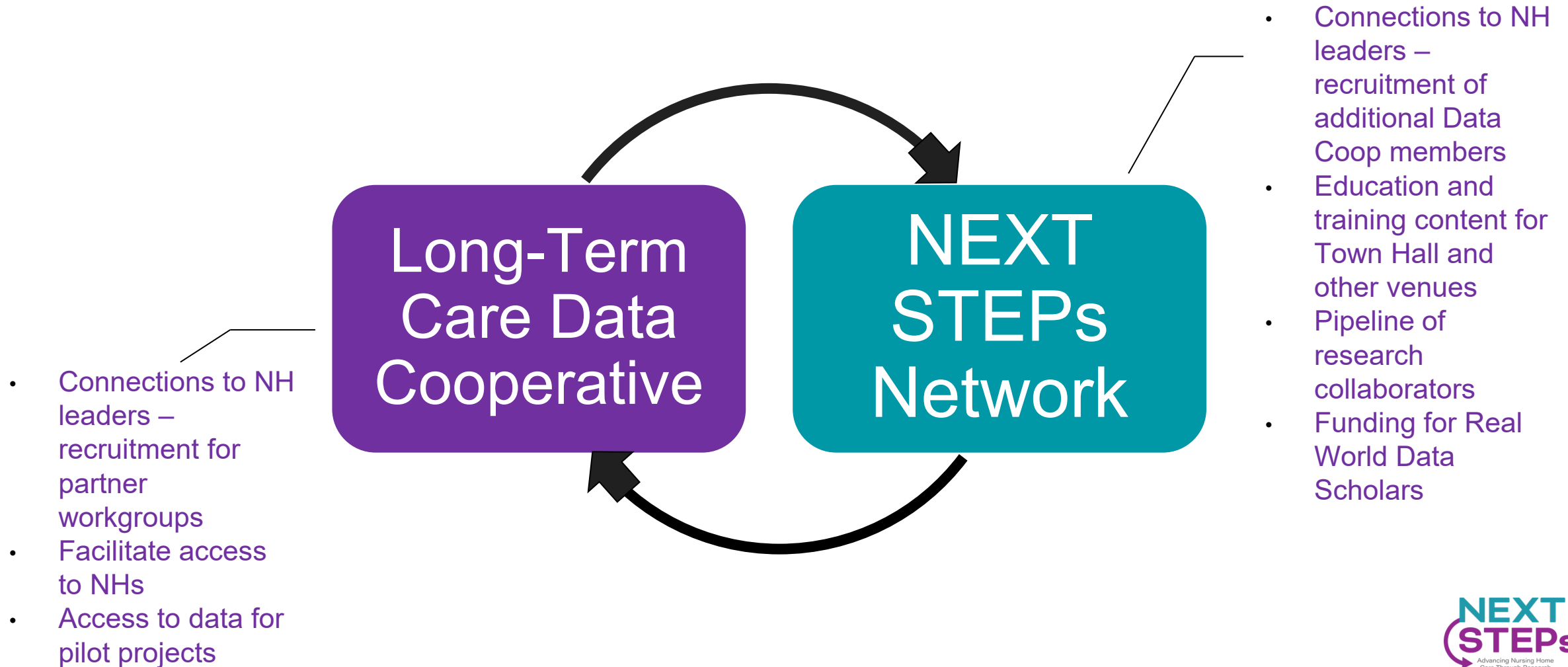


- HIPAA
- Agreements
 - Business Associate Agreements
 - Data Use Agreements
- Federal Wide Assurances
- IRB Approval

NEXT STEPs: Nursing Home Data Sources Compendium

Data Source	Description	Key Variables	Access (Public/Restricted) & Process	HIPAA-protected (yes/no)	Smallest Unit of Analysis (e.g., resident, facility)	Other Possible Units of Analysis	Linkable & At What Unit(s)	Benefits	Limitations	Use Case Examples	Cost (0=free, \$=low, \$\$=moderate, \$\$\$=high)	URL to Access Data
Agency for Healthcare Research and Quality (AHRQ) Nursing Home Survey on Patient Safety Culture	A standardized, validated survey developed by AHRQ to assess the culture of patient safety within NHs, focusing on staff perspectives about communication, teamwork, management support, and resident safety practices.	Staff responses to items across multiple safety domains (e.g., communication openness, non-punitive response to mistakes, staffing, training, teamwork, handoffs, and transitions); facility characteristics.	Public; survey instrument and aggregate results are freely available on the AHRQ website. NHs can administer the survey internally or submit data voluntarily to AHRQ's Comparative Database. Access to raw individual-level response data from the Comparative Database requires a data use agreement.	No (data are de-identified and do not contain resident-level health information)	Staff respondent	Facility, Unit within facility	Not linkable to other external datasets; facility-level data may be linked internally with staffing or quality data by the facility itself	Provides a standardized tool for assessing organizational safety culture; facilitates benchmarking against national norms; identifies areas for improvement in safety-related communication and practice.	Data submission is voluntary; limited external comparability if facilities do not participate in AHRQ's Comparative Database; no direct link to resident outcomes or clinical quality measures.	Assessing staff perceptions of safety culture, evaluating the impact of training or policy changes on perceived safety climate, guiding quality improvement initiatives in NHs.	0	https://www.ahrq.gov/topics/surveys/nursing-home/index.html
Health and Retirement Study (HRS) - Linked	HRS survey data linked to Medicare claims (Parts A, B, C, D), Medicaid data, and Minimum Data Set (MDS) assessments, enabling detailed longitudinal analyses of healthcare utilization and outcomes in the context of rich sociodemographic, cognitive, and end-of-life preference data.	All unlinked HRS variables plus: Medicare claims (hospital, SNF, hospice, outpatient, Part D), Medicaid claims, MDS clinical assessments, dates of NH stays, diagnosis and procedure codes, and mortality indicators.	Restricted; requires HRS and CMS data use agreements, IRB approval, and submission of a restricted data request through the HRS website.	Yes	Individual respondent	Resident, Episode of Care, Facility (limited), Household, Survey Wave	Yes, resident-level, technically facility-level via MDS but not well-suited for facility-level inference	Combines rich psychosocial, cognitive, and preference data with healthcare utilization and NH clinical assessments; supports end-of-life, dementia, and long-term services research in nationally representative older adults.	Restricted to HRS participants who consented to linkage; not representative of NHs; not designed for facility-level analysis; linkage periods vary by data source.	Evaluating life-sustaining treatment use and treatment concordance among residents with dementia in their last 90 days of life; identifying associations between advance care planning and intensity of NH or hospital care; stratifying care patterns by NH use.	\$	https://hrs.isr.umich.edu/data-products/restricted-data
Health and Retirement Study (HRS) - Unlinked	A longitudinal panel survey of U.S. adults over age 50, designed to examine aging, retirement, health, and economic well-being. The unlinked HRS includes interview data, physical and psychosocial measures, and self-reported health and healthcare use.	Demographics, income and wealth, functional and cognitive status, self-reported chronic conditions, insurance coverage, caregiving, residential transitions, end-of-life planning.	Public; most data are freely available upon registration via the HRS website. Sensitive files (e.g., geographic detail) require a restricted data application.	No (unlinked survey data are not considered HIPAA-protected)	Individual respondent	Household, Cohort, Survey Wave	Yes, resident-level, facility-level	Rich, nationally representative longitudinal survey with psychosocial and economic depth; captures preferences, caregiving dynamics, and transitions relevant to NH and long-term care planning.	Does not contain clinical or claims data; relies on self-report; NH residents underrepresented; not suitable for analyzing care delivery or outcomes.	Examining predictors of NH entry, financial stress and caregiving burden, or advance care planning among older adults at risk for institutional care.	0	https://hrs.isr.umich.edu/data-products
National Dementia Workforce Survey (NDWS)	A nationally representative survey of the dementia care workforce in long-term care settings, including NHs and assisted living. Conducted to understand training, attitudes, work environment, and care practices of direct care workers and licensed staff.	Staff role and training, dementia-specific care experience, attitudes toward dementia, staffing and workload, burnout, care strategies.	Restricted; access may be available via request to the survey team or affiliated research institutions. No public use files currently posted.	No (staff self-report survey; does not include resident health data)	Individual staff member	Facility, Occupation, Region	Possibly linkable at facility level, but linkage is limited and requires permission	Unique insights into the experiences, perspectives, and practices of the NH dementia care workforce; enables study of workforce preparedness and training needs.	Not yet longitudinal; self-reported data may be subject to bias; access to data is limited and not publicly posted.	Evaluating staff preparedness to care for residents with dementia; assessing burnout, attitudes, or care strategies in NH dementia care workforce.	0	https://www.ndws.org/surveys-and-data/how-to-access-data
National Long Term Care Survey (NLTCs) - Linked	A longitudinal survey of Medicare beneficiaries aged 65+ linked to Medicare claims data (Parts A, B, D), Medicaid claims, and/or MDS assessments. Enables detailed analyses of long-term care utilization and outcomes in relation to functional and cognitive status.	All NLTCs survey variables (e.g., ADLs, IADLs, cognitive status, caregiver burden) plus: Medicare claims (diagnoses, procedures, payments), Medicaid claims, MDS assessments (functional/cognitive status, services received), mortality data.	Restricted; requires application and data use agreements via Duke University or CMS (ResDAC), depending on the linked file. Some may be available through the NIA LINKAGE Program.	Yes	Claim	Resident, Episode of Care, Facility (limited), Survey Wave, Region	Yes, resident-level, technically facility-level via MDS but not well-suited for facility-level inference	Combines detailed survey data with claims-based outcomes; supports research on transitions of care, disability, and service use over time.	Linkage limited to survey respondents who consented; data are dated (last survey in 2004); not fully representative of current NH population; limited facility-level detail.	Studying transitions into and out of NHs, evaluating disability-related care use and spending, analyzing trajectories of functional decline and service utilization.	\$	https://www.icper.umich.edu/web/NACDA/studies/9681

Partnering with the Long-Term Care Data Cooperative (LTCDC)



RWD Scholars



- Partnership between IMPACT, NEXT STEPs & Long-term Care Data Coop
- IMPACT ~ 2 awards | NEXT STEPs Network ~ 2 awards
- 60K for one year; travel to be budgeted by candidate
- LTCDC only or other RWD data platforms
- Integration of IMPACT (Dae, Lexy); NEXT (Susan, Andrew); LTCDC (Betsy)
 - Training admin – RFAs, Grant Review, Selection, impact notifications
 - Programmatic interaction (mentoring, RIP)
 - Handoff to NEXT STEPs for funding, award notices
 - Monitoring (e.g., final reports, publications review procedures)

Projects and Training Core

Investigators	Institutions
Core Lead: Cari Levy, MD, PhD, CMD	University of Colorado School of Medicine, U.S. Department of Veterans Affairs
Associate Lead: Barbara Resnick, PhD, RN, CRNP	University of Maryland School of Nursing
Sarah Berry, MD, MPH	Harvard Medical School and Beth Israel Deaconess Medical Center
Joan Carpenter, PhD, CRNP, ACHPN	University of Maryland School of Nursing
Nicole Fowler, PhD, MHSA	Indiana University School of Medicine



Cari Levy



Barbara Resnick



Sarah Berry



Joan Carpenter



Nicole Fowler

NEXT STEPs Pilot Grant Program

Award Details:

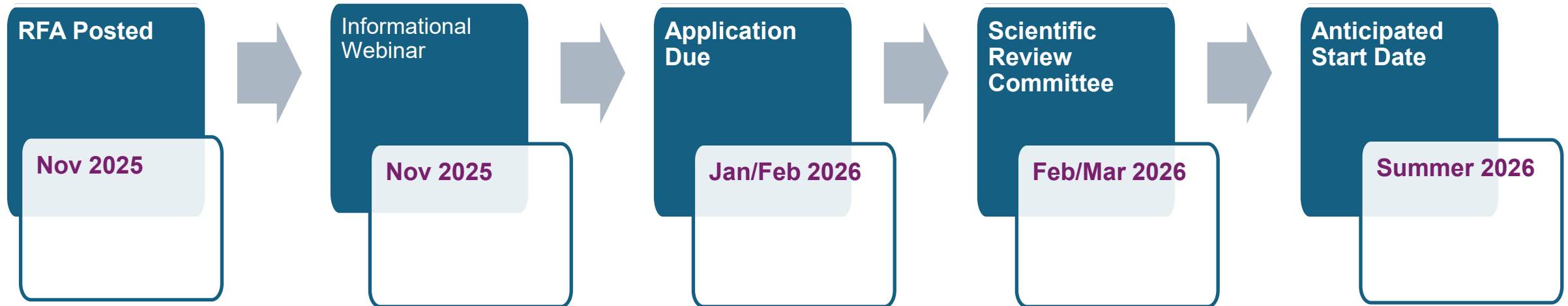
- 1 year
- \$75 per year, total direct costs
- Not renewable
- 8 Pilots will be awarded
- Must complete project in 1 year

Review Criteria:

- Importance of Research to Nursing Home Community
- Rigor and Feasibility
- Expertise and Resources
- Project Merit
- Overall Impact

NEXT STEPs Pilot Grant Program

Cycle 2 Planned Dates



Research Studios

Objective

Improve the quality of clinical trials with structured, interactive discussions

Methods

- 60-minute consultation
 - 2 investigators focus on specific questions at a specific stage in the research process
 - Brief project summary (5 minutes)
 - Moderated discussion centered on pre-defined and emerging questions, focused discussion on problem-solving (20 minutes)
 - Moderator and panelists summarize comments (5 min)
- Investigator receives a summary report and digital recording from the discussion

Products

Research Studios

- Research Studios launched in July 2025
- PTC Hosts Research Studio monthly
- Interested investigators sign-up via Smartsheet form
- We request investigator provide specific aims and 2-3 focused questions to be provided to mentors in advance of studio
- Research Studios are scheduled for November 5th and January 14th and there is 1 spot available each day!
- Future Studios will be 90-minute sessions

Contact Carrie Brill if interested CARRIE.BRILL@CUANSCHUTZ.EDU

Experiential Learning Program Overview



- Match interested researchers with a nursing home for an immersive learning experience
- Researcher will complete pre-work to help inform them on NH infrastructure prior to their visit
- NEXT STEPs team works with NH staff on date and schedule for researcher
- Researcher meets with PTC Core Lead and Staff to review expectations and schedule
- Researcher completes the in person visit
- Researcher meets with NEXT STEPs team to debrief on their site visit

Interested? Contact nhtrials@iu.edu

Inaugural Annual Meeting



Key takeaways

- NEXT STEPs is the opportunity to create infrastructure and strategy to increase clinical trials centered in nursing homes
- There are multiple ways to be involved in NEXT STEPs network!
 - Sign up and join the network
 - Research Studios
 - Resources to use to support your work
 - Experiential Learning Program
 - Apply for Pilot funding
 - Apply for Real World Data Scholars Program

Check us out at GSA!

GSA Symposium titled ***Take the NEXT STEP:
Practical Tools and Strategies for Clinical Trials
Work in Nursing Homes***

Date & Time:

Wednesday, November 12, 2025 from 2-3:30pm

Location: Hynes-Room 203

Providers & Advocates Advisory Panel

David Gifford, MD, MPH (Chair)	Chief Medical Officer, American Health Care Association and National Center for Assisted Living (AHCA/NCAL)
Debra Bakerjian, PhD, APRN, FAANP, FGSA, FAAN	PALTmed representative Associate Dean for Practice & Professor Clinical Nursing, UC Davis
Elizabeth Halifax, PhD, RN	Incoming President Consumer Voice Assistant Clinical Professor, UCSF School of Nursing
Chris Herman, MSW, LICSW	Senior Practice Associate–Aging National Association of Social Workers (NASW)
Nancy Lundebjerg, MPA	Chief Executive Officer, American Geriatrics Society
Arif Nazir, MD, CMD	Chief Medical Officer, Abode Care Partners Co-Founder and Chief Medical Officer, CareAscend
Kezia Scales, PhD	Vice President of Research & Evaluation, PHI
Robyn Stone, DrPH	SVP for Research, LeadingAge & Co-Director, LTSS Center @UMass Boston
Lauren Stratton, PhD	Senior Associate Director, Psychological Research and Program Evaluation, Alzheimer's Association
Gina Upchurch, RPh, MPH	Founder & Executive Director, Senior PharmAssist

Research Advisory Panel

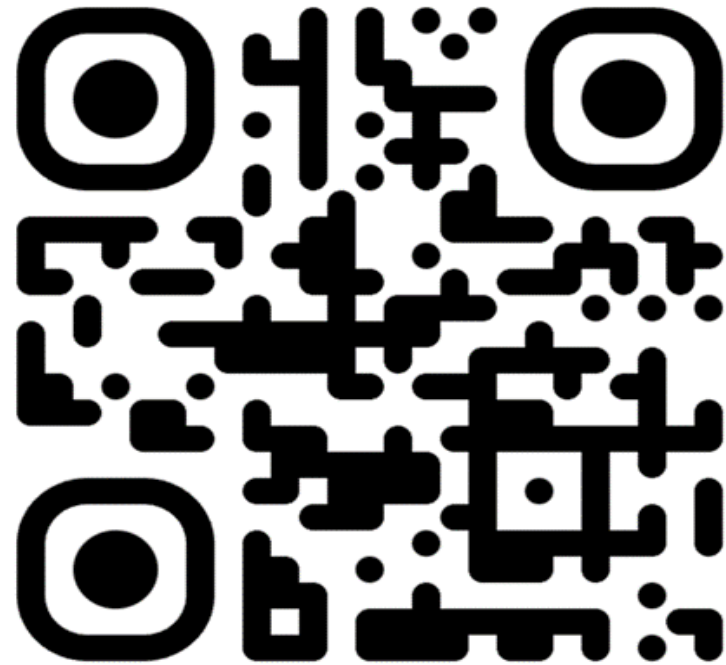
Joseph Ouslander, MD (Chair)	Professor of Geriatric Medicine, Charles E. Schmidt College of Medicine of Florida Atlantic University
Barbara Bates-Jensen PhD, RN, FAAN	Associate Dean of Academic Affairs and Professor of Nursing and Medicine School of Nursing and David Geffen School of Medicine, UCLA
Christine Eisenhower, PharmD, BCPS	Associate Professor, University of Rhode Island
Shaun Grannis, MD, MS	Vice President, Data & Analytics, Regenstrief Institute; Regenstrief Chair in Medical Informatics; Professor Family Medicine, Indiana University School of Medicine
Jerry Gurwitz, MD	Chief, Division of Geriatric Medicine, UMass Chan Medical School and UMass Memorial Health
Natalie E. Leland, PhD, OTR/L, BCG, FAOTA, FGSA	Professor, Department of Occupational Therapy, School of Health & Rehabilitation Sciences, University of Pittsburgh
Donovan T. Maust, MD, MS	Willard C. Blackney Jr. & Geraldine LaTendresse Blackney Research Professor in Geriatric Psychiatry and Associate Director, Geriatric Psychiatry, Univ of Michigan; Research Scientist, Ann Arbor VA Center for Clinical Management Research
Susan Mitchell, MD, MPH	Senior Scientist, Hebrew SeniorLife's Hinda and Arthur Marcus Institute for Aging Research; Professor of Medicine, Harvard University; Faculty, Division of Geriatrics, Beth Israel Deaconess Medical Center
Vince Mor, PhD	Professor of Health Services, Policy & Practice and the Florence Pirce Grant Professor, Brown University School of Public Health; Research Health Scientist, Providence VA

Questions

Contact Us!


Email: nhtrials@iu.edu

Website:
nextstepsnetwork.org





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