NATIONAL MINORITY QUALITY FORUM

Center for Sustainable Health Care Quality and Equity

Biogen

DRIVing Equity in Alzheimer's Clinical Research

Subtitle

DRIVE
Center for Sustainable Health Care Quality and Equity

Alzheimer’s Disease 101

Alzheimer's is the most common cause of dementia in the US. Each type of dementia affects different parts of the brain, causing different patterns of symptoms. Alzheimer’s symptoms start slowly, typically with problems learning and remembering new information. Symptoms progress gradually. Memory problems worsen, and individuals eventually have difficulty thinking and processing information, speaking, and ultimately responding to their environment. Many with Alzheimer's do not remember that they cannot remember, so lack awareness of their deficits.

There are many other causes of cognitive decline. Consider screening for:

- Hearing & vision loss
- Depression
- Sleep apnea
- Alcohol & other substance abuse
- Potentially inappropriate medications, including antihistamines and anticholinergics

Ask specifically about cognitive decline at the Annual Wellness Visit

Additional information:

National Institute on Aging | Mayo Clinic | Alzheimer’s Association | Alzheimer’s Association in Spanish | CDC

Early Signs and Symptoms of Alzheimer's

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgement
9. Withdrawal from work or social activities
10. Changes in mood and personality

Read more: Alzheimer's Association - Early Signs & Symptoms

Quick Facts about Alzheimer's

Over 7 million Americans live with Alzheimer's

Nearly 900,000 additional direct care workers will be needed by 2032 to provide dementia care

Between 2000 and 2022 deaths from Alzheimer's increased 142%

In 2025, Alzheimer's and other dementias will cost the nation $384 billion

Nearly 12 million Americans provide unpaid care for people with Alzheimer's or other dementias

Reference: Alzheimer's Association - 2025 Facts & Figures

The Importance of Early Detection

Early detection is key to providing quality healthcare through appropriate management of comorbid conditions, giving patients the opportunity to express their wishes and allowing patients to enroll in clinical trials and access appropriate treatments.

Primary care clinicians may face challenges with recognizing the signs of cognitive impairment due to lack of training on dementia, concerns about stigma and the usefulness of early diagnosis, lack of time and difficulty talking about dementia.

Early Detection Resources

Resources to Help with Assessment of Cognitive Decline

- Cognitive Assessment Toolkit
- General Practitioner Assessment of Cognition
- Mini-Cog
- AD8 Dementia Screening Interview
- Short Informant Questionnaire on Cognitive Decline in the Elderly

Clinical Research in Alzheimer's

- Two Alzheimer's treatments may delay progression of the disease — donanemab (Kisunla™) and lecanemab (Leqembi®) --- but there is no cure. Many clinical trials are underway to find new treatment options for Alzheimer's, and also to improve and facilitate diagnosis.
- Research participation not only helps advance Alzheimer's treatment, but it also often affords benefit to the patient by providing access to new therapies without cost; a better standard care; and even compensation

Engaging all patients with cognitive decline about clinical trials is paramount to provide them additional care options while they have the capacity to decide for themselves. It also gives you the opportunity to meet them where they are to understand and address any concerns they may have about clinical research.

Alzheimer's Disparities Quick Facts

65 and older, age adjusted	Non-Hispanic Black	Hispanic Americans	Non-Hispanic White
Rate of Alzheimer's in adults	19%	14%	10%

52%
Black Americans

41%
Hispanic Americans

Do not feel confident that there is access to providers who are culturally competent

42% of Black caregivers of people with Alzheimer's

Have faced discrimination when navigating health care settings for their care recipient compared to **only 17% of White caregivers**. Their top concern is that **providers don't listen to their concerns.**

Read more: Alzheimer's Association Special Report

Diversity in Clinical Research

- Diversity in clinical research is critical to **ensure that advances in treatment are safe and effective for all populations** impacted by a given health condition.
- Black and Hispanic people and older individuals remain underrepresented in clinical trials. Alzheimer's is more common among Black and Hispanic people, yet they are much less likely to be included in research studies
  - Patient barriers include a fear, a lack of trust, language and cultural differences, time conflicts, lack of knowledge, transportation challenges, and other factors
  - System barriers include the design of clinical trials, such as exclusion of common co-morbidities, a time-limited perspective, and implicit bias
- Community engagement throughout the clinical research process can help increase diversity by addressing patient and health system barriers; social determinants of health must be addressed.

Primary care physicians and their care teams are a lynchpin of clinical trial recruitment, particularly for people of color: they are trusted by their patients. But they also face barriers, including time constraints, lack of knowledge, and concerns about their patients'

Read more: USC Disparities in Clinical Trials Study

Clinical Trial Resources

- NIH Clinical Trial Finder
- Alzheimer's Association Trial Match
- ADNI Brain Aging Study
- Alzheimer's.gov Clinical Trials
- Alzheimer's Clinical Trial Consortium
- Alzheimer's Research Patient Stories

Alliance for Representative Clinical Trials (ARC)/ MyClinical

If you have any interest in becoming a principal investigator for clinical trials, NMQF has a program that can help.

ARC is a program of community clinicians that are organized to diversify and bring clinical trials to racial and ethnic minority communities, and others, that have been underrepresented in clinical trials. It is a collaborative effort among investigators from community clinics including Federally Qualified Health Centers (FQHCs) across the United States. Via the Principal Investigator Institute (PI Institute), ARC provides the required clinical research fundamental training needed to become principal investigators.

MyClinical is a full-service investigative research network designed to empower independent community clinicians and Federal Qualified Health Clinics to conduct and increase inclusivity in clinical trials. The network is envisioned to serve as a single entity that represents clinical trials sites, liaise with sponsors, as well as streamline and coordinate all clinical trial activities alleviating burden from the investigator and clinic site.

Support includes a network managed by a central administrative staff that oversees and streamlines:

- ✓ Site selection/Investigator selection
- ✓ Study initiation
- ✓ Site training
- ✓ Contracting and budgeting
- ✓ Regulatory readiness process
- ✓ Data Management
- ✓ Quality assurance and safety
- ✓ Participant recruitment
- ✓ Community outreach

Culturally Appropriate Care

Social Determinants of Health (SDoH)

Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. The challenges that patients face with SDoH can negatively impact health outcomes.

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community, Safety, & Social Context	Health Care System
Racism and Discrimination					
Employment Income Expenses Debt Medical bills Support	Housing Transportation Parks Playgrounds Walkability Zip code/ geography	Literacy Language Early Childhood Education Vocational Training Higher Education	Food Security Access to healthy options	Social integration Support systems Community Engagement Stress Exposure to violence/trauma Policing/justice policy	Health Coverage Provider & pharmacy availability Access to linguistically and culturally appropriate & respectful care Quality of care

Health and Well-Being: Morality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

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Social Determinants of Health (SDoH)

There are several ways that clinicians and care teams can help patients with challenges they may be facing with SDoH. If your office has a social worker, they may be able to help with the below recommendations. Otherwise, it is worth it to see what local resources are available that patients can be directed to, such as local Office for the Aging.

Recommendations:

- Assess food insecurity, housing insecurity/ homelessness, financial barriers, and social capital/social community support to inform treatment decisions, with referral to appropriate local community resources
- Provide patients with additional self-management support from lay health coaches, navigators, or community health workers when available
- Consider the involvement of community health workers to support the management of diabetes and cardiovascular risk factors, especially in underserved communities and health care systems

Below is a webinar with information about providing culturally appropriate care:

Facing implicit bias

Implicit Bias

A preference or aversion to a certain person or group, that can show up in our attitudes and actions. It occurs unintentionally but can still affect our judgment, decisions, and behaviors.

EVERYONE HAS BIAS!

Recognizing your biases so that you can mitigate them is important.

In medical care, bias has led to disparities in health outcomes such as:

- Non-white patients receive fewer cardiovascular interventions and fewer renal transplants
- Black women are more likely to die after being diagnosed with breast cancer
- Non-white patients are less likely to be prescribed pain medications (non-narcotic and narcotic)
- Black men are less likely to receive chemotherapy and radiation therapy for prostate cancer and more likely to have testicle(s) removed
- Patients of color are more likely to be blamed for being too passive about their health care and labeled as difficult or noncompliant

Implicit Association Test to Identify Bias

Tips for Good Patient/Provider Communication

- **Use Simple Language:** Avoid medical jargon. Use clear, plain language that is easy to understand.
- **Visual Aids:** Incorporate images, diagrams, and videos to explain complex concepts.
- **Teach-Back Method:** Ask patients to repeat information back to you in their own words to ensure understanding.
- **Limit Information:** Provide essential information in small, manageable chunks.
- **Written Materials:** Offer easy-to-read brochures and handouts, using large fonts and plenty of white space.
- **Encourage Questions:** Create an environment where patients feel comfortable asking questions.
- **Use an Interpreter:** Reach patients in the language that is most comfortable for them and do not rely on a child to translate for an adult.

Conversation Starters

For Patients:

- “As part of the annual wellness visit, we should do a check of you memory and mental health.”
- "I like to check in with all my patients about how they’re doing not just physically, but also with things like memory, focus, or managing daily tasks. Have you noticed any changes recently?"
- "Some of my patients have shared that they’re forgetting things more often or feeling more disorganized than usual. Is that something you’ve experienced?"
- "You mentioned having trouble remembering things lately. Would it be okay if we did a brief screening to see if there’s anything we should keep an eye on together?"

For Caregivers:

- "I know that family members often notice small changes before we do. Have you observed any differences in [patient’s name]’s memory or thinking that you’d like to share?"
- "Sometimes it's helpful to get another perspective. [To the patient:] Would it be okay if I asked your [spouse/daughter/etc.] if they’ve noticed any changes in your memory or daily routines?"

Reflection Questions

- Have you noticed differences in your interactions with patients of color compared to white patients?
  - In how you speak to them?
  - In what you put in your patients' charts?
- How often do you inform patients and their families about clinical trials?
  - Are you consistent across all types of patients, regardless of cultural identities?
- What resources, standards and guidelines can you put in place to address disparity challenges and ensure consistent care for all patients?

Putting DRIVE into Action

SHC's DRIVE program **helps primary care teams promote high quality, equitable care through the rapid cycle improvement model,** by promoting a champion-led, patient-centered, team-based approach. This module outlines six practical steps for increasing screening for Alzheimer's and referring them to clinical trials.

STEP 1

ID Your Team: The Champions

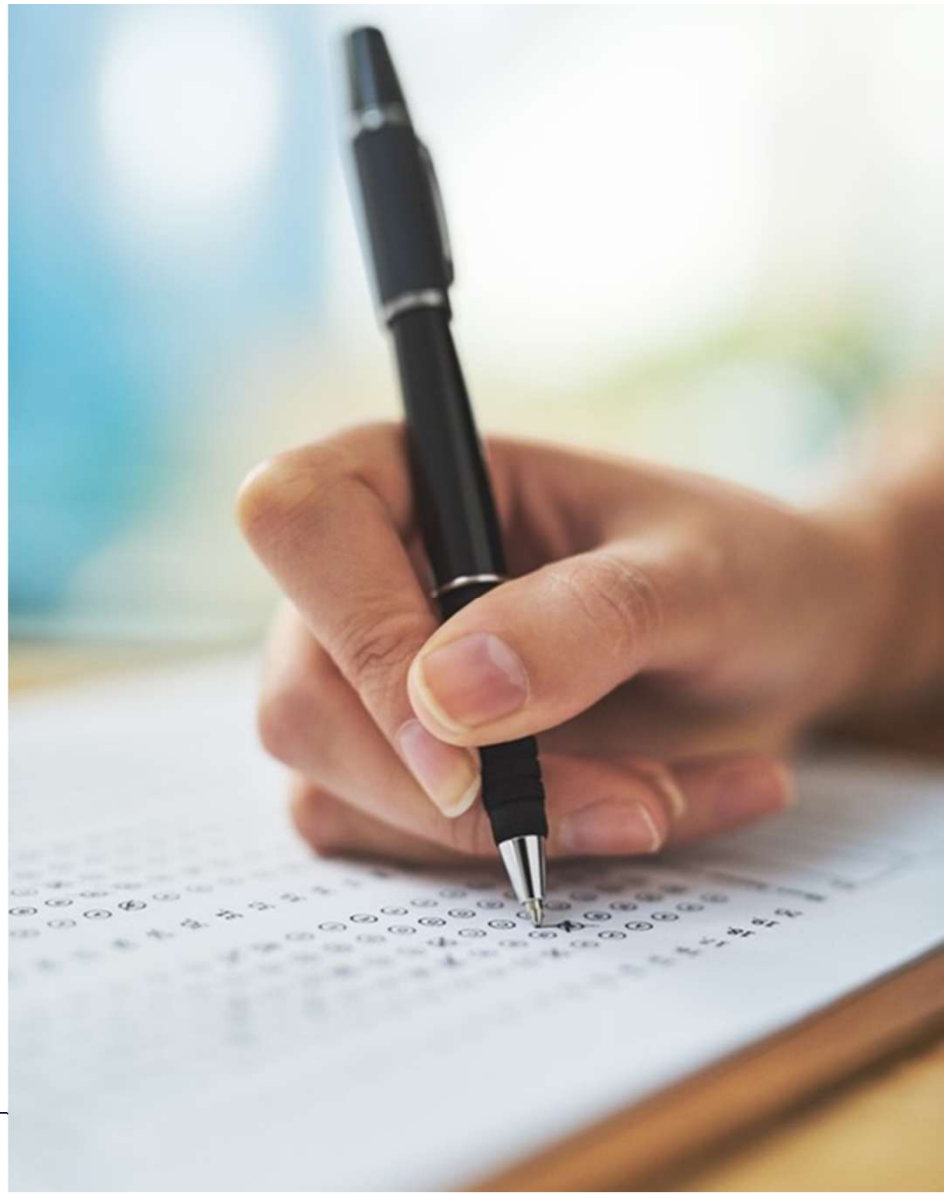
- A health system leader often champions a DRIVE program, identifying the practice sites to participate and connecting educational, IT, nursing, equity, specialty care, research, and communication resources
- At the practice level, whether a clinic, FQHC, or residency program, champions are recruited to lead program implementation
- Champions at the practice level typically include a physician or advanced practice clinician along with a nurse, practice manager, patient navigator, pharmacist, and/or resident
- Practice champions develop the QI strategy and lead its implementation

STEP 2

Complete Your Practice Assessment

- A brief online survey helps you assess:
  - Your practice and patients
  - Your current approaches to health equity, research, and alzheimer's
  - Barriers you and your patients face
  - What you would like to work on in the QI activity.
- One or more of the practice champions should complete one survey for a given clinic site
- This information will guide your project design.

Access your practice assessment survey here



STEP 3

Learn More About Your Community

- Community health assessments can help you tailor your DRIVE program to fit the needs of the community your clinic serves
- A community health assessment can provide information about: demographics; health status; social and economic factors impacting health; available health services and community resources
- Community data and reports often are available in your region:
    - Hospitals, FQHCs, local foundations, and other health and social service providers often have published community health assessments
    - Local, county, and state health and public health departments often have relevant data and reports
- National surveys and data sources are also available to probe your community needs
- Research opportunities can be identified from a national database, patient advocacy organizations, and clinical research leaders at local health care institutions

STEP 4

Design Your Activity

- Plan-Do-Study-Act (PDSA) is a structured, straightforward approach to implementing quality improvement projects in practices
- This approach works on many types of changes - from improving a patient care process to executing a new workflow - and in practices of all sizes
- This approach can be adapted to many clinical practices, supporting a sustainable culture of quality improvement
- Start small and be VERY specific – timelines, level of improvement, role of individuals
- Share your plan with the overall staff and system leadership for their input, suggestion of resources to assist with implementation, and buy-in
- Use this template below to develop your plan.

Access your Plan-Do-Study-Act Worksheet here

STEP 5

Put the Plan Into Action

Train staff participating in the activity: what is going to be done and why

Present in regular staff meetings or have a breakfast or lunch presentation

Track QI cycle efforts and results, using a run chart

Consider the impact of the QI cycle and next steps:

Expand – it worked great

Adjust – impact was uneven

Try a new approach – it just didn't work

STEP 6

Communicate, Celebrate, Continue

- Share the results of your work with the whole practice team
- Acknowledge and celebrate those who contributed
- Let the leadership know about your success
- Inform your patients and the whole community about your commitment to improving quality care for all your patients
- Continue cycles of healthcare quality and equity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Have a
Question?
Contact: shc@nmqf.org
We gratefully acknowledge support for this
DRIVE Toolkit from Biogen