INDIAN HEALTH SERVICE (IHS) COMMUNITY HEALTH REPRESENTATIVE (CHR)

Project Evaluation Report: Implementation of a Cognitive Screening Tool in a Community Health Setting

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CONTENTS

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A. BACKGROUND

According to a recent study by the Indian Health Service (IHS) and collaborators using administrative healthcare data from the Indian Health Service (IHS), "An estimated 38,000 American Indian/Alaska Native (AI/AN) people aged ≥ 65 years were living with Alzheimer's disease and related dementias (ADRD) in 2020, a number expected to double by 2030 and quadruple by 2050." Most compelling was a top-line research finding that 14% of AI/AN IHS patients with a dementia diagnosis had early-onset dementia (between the ages of 45-84) during the study period from 2016 through 2020. Many people with dementia or impaired cognition suffer silently in their communities. Dementia is under-recognized, underdiagnosed, misdiagnosed, and undertreated in all populations, including AI/AN people.

These findings have tremendous implications, highlighting the need for partnerships across IHS to identify risk reduction strategies and engage in early detection and accurate and timely diagnosis of ADRD. This work must include both the younger generation and the older aging population. Cognitive evaluations to diagnose ADRD are usually conducted in the primary care setting, with specialist support provided as needed by neurologists or psychologists. A full cognitive assessment is required to diagnose dementia. The challenges include provider confidence or knowledge, the cost of implementing cognitive diagnostic tests, and the time involved in administering them in a primary care or community setting. This is particularly problematic in the Indian health system, which is strained by time constraints, knowledge gaps, and lack of training specific to ADRD. Early detection and diagnosis of ADRD is a federal priority.

What is the Mini-Cog©?

The Mini-Cog© is an evidence-based quick screening tool for early dementia. The test takes just three minutes. The test can help identify the need for a detailed cognitive evaluation and is intended for use by trained professionals. A Cochrane review in 2021 showed that the Mini-Cog© had a sensitivity of 76% (meaning up to 24% in false negatives) and a specificity of 73% (meaning up to 27% in false positives). However, that same review noted the sparsity of research, with only four studies included. Another study published in 2018 showed that the Mini-Cog© had a sensitivity of 85.71%, specificity of 79.41%, positive predictive value of 0.8108, and negative predictive value of 0.6550, while a 2015 meta-analysis reported a sensitivity of 91% and specificity of 86% based on nine studies in the cohort.

The Mini-Cog© consists of a 3-item recall test for memory and a scored clock drawing test. It is only a screening test and is not a diagnostic tool. Providers, including CHRs, using the Mini-Cog© must be able to make appropriate referrals for patients based on its results. Learn more about the Mini-Cog© standardized instrument at www.mini-cog.com.

Who are CHRs?

The IHS Community Health Representative (CHR) Program is the largest Tribally contracted program, comprising over 1,200 CHRs across 300+ CHR Programs. CHR is used interchangeably with the umbrella term community health worker (CHW).

According to the American Public Health Association (APHA), a community health worker is a frontline public health worker who is a "trusted member of and/or [someone who] has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve service delivery's quality and cultural competence. A community health worker also builds individual and community capacity by increasing health knowledge and self-sufficiency through various activities such as outreach, community education, informal counseling, social support, and advocacy (APHA, 2009)."

As public health professionals, CHRs are primarily in community-based organizations (CBOs) that provide essential frontline health services, often delivered in the home setting to Tribal communities.

Purpose/Objectives

This pilot project aimed to explore the feasibility of CHRs using the Mini-Cog© brief cognitive screening in community settings, including a referral process to the clinical setting. Secondary aims were to raise awareness of dementia and Alzheimer's among I/T/U staff and tribal members, establish peer-to-peer learning networks, and examine data collection and EHR documentation approaches. The IHS Alzheimer's Program partnered with the IHS CHR Program to support the pilot. The IHS Division of Clinical and Community Services (DCCS) CHR Program recruited six programs to participate in the six-month demonstration project. The project implementation period was January – June 2024. The project team aimed to understand barriers and challenges for screening adoption, communication between CHR programs and providers, and referrals.

This report provides an overview of the first cohort of the pilot program activities and shares formative evaluation findings to inform future year pilot process improvements.

B. COLLABORATORS

The Division of Clinical and Community Services (DCCS), Alzheimer's and Dementia Program's National Elder Care Consultant, Dr. Jolie Crowder, initiated the project concept. Project collaborators include:

- Michelle Archuleta, National CHR Consultant, served as project lead.
- Grace Medlock, HPDP/Health Education Program Assistant, served as project support.
- Jamie Olsen, Alzheimer's Program Management Analyst, helped facilitate monthly webinars and assisted with data tracking and project management support.
- Subject Matter Experts (SMEs): Dr. Crowder; Dr. Tim Ricks, Division of Oral Health; Edie Yau, Alzheimer's Association; and Dr. Kerstin Reinschmidt, Oklahoma University Dementia Care Network.
- Michelle Begay, Acting Deputy Directory, Office of Direct Service and Contracting Tribes, provided guidance on funding approaches.

C. PILOT PARTICIPANTS

Participating programs were:

- Cheyenne River Sioux Tribe
- Citizen Potawatomi Nation
- Nimiipuu Health
- Northern Valley Indian Health
- San Carlos Apache
- Santo Domingo Pueblo CHR Program

D. ADDITIONAL RESOURCES

- Each of six pilot sites received $10,000, for total direct expenditures of $60,000.
- The pilot project team included SMEs in the CHR program and dementia, and two additional DCCS staff provided project support.
- The CHR program lead served as the peer learning webinar facilitator.
- Monthly agendas and programming content were adapted from the DOH Mini-Cog© pilot.

- The Oklahoma University Dementia Care Network (a HRSA Geriatric Workforce Enhancement Program (GWEP) grantee) provided pre-pilot dementia training via training modules and an in-person webinar, all at no cost to IHS.

E. EVALUATION QUESTIONS

1. Can CHRs implement cognitive screening using the Mini-Cog©?
2. What barriers and facilitators exist to screening at the local level?
3. How can we improve the IHS process for a rapid implementation multi-site pilot to best meet local needs?
4. What national training, educational, or other resources and support could IHS provide to support local screening pilot efforts?
5. Should the pilot continue beyond year one?

F. EVALUATION METHODS

A mixed methods approach to pilot program evaluation included:

- Pilot participant submission of monthly reports, including activity data and brief lessons learned
- Recurring opportunities for pilot site feedback during monthly webinars
- Final participant debrief webinar after the pilot
- Regular team debriefs over the course of the pilot
- Participant evaluation survey

A spreadsheet was used to track monthly participant reporting data. Monthly peer-to-peer participant webinars were convened from January to June 2024. During these meetings, participants were asked to identify challenges and successes and provided technical assistance and support to resolve questions or issues. Peer (team) debriefs were convened after each group webinar and routinely during project planning and implementation meetings. The team reflected on new and ongoing themes and identified process improvement opportunities on an ongoing basis. After the pilot was completed, an evaluation survey was developed and distributed electronically to all participants in July 2024. The survey included quantitative and qualitative questions soliciting feedback on program activities and satisfaction with the pilot.

G. COMPONENTS/TIMELINE

Pre-Pilot

Before the start of the pilot, participants participated in two dementia and project training activities.

- Part I: Online Module Agenda – Introduction and Basic Information (self-directed)
- Part II: Live Session Training - Zoom webinar with Dr. Kerstin Reinschmidt and Michelle Archuleta December 7, 2023

This project kicked off in December of 2023 with a presentation by Dr. Kerstin Reinschmidt and Michelle Archuleta. This presentation aimed to introduce the IHS National CHR Strategic Plan and related priorities supporting the CHR Dementia Screening Pilot, discuss the purpose of the CHR Dementia Mini-Cog© Screening Pilot and its relevance in Indian Health, and provide Dementia training for Community Health Workers/Community Health Representatives—select CHW roles in addressing dementia.

Beginning in January 2024, Zoom meetings were held on the 4th Wednesday of every month with the participating sites (as many CHR staff from those sites as possible) and SMEs.

1. **Meeting 1, January 24, 2024** – provided an overview of cognitive impairment by SMEs and reviewed the parameters for the six-month project.
2. **Meeting 2, February 28, 2024** – provided a more detailed overview of available resources, including webinars, the Mini-Cog© tool, and the AD8 to utilize as a possible second screening tool.
3. **Meeting 3, March 27, 2024** – provided a presentation on available resources through the Alzheimer's Association, as presented by Edie Yau, Director, Alzheimer's Association.
4. **Meeting 4, April 24, 2024** – discussed the monthly reports, lessons learned, and implementation challenges and approaches in each of the community health settings.
5. **Meeting 5, May 22, 2024** – shared the Mini-Cog© Dementia Screener Tutorial PowerPoint, discussed monthly reports/lessons learned, and shared and discussed the past month's work.
6. **Meeting 6, June 26, 2024** – discussed lessons learned and how to spread this initiative collectively across I/T/U programs.

The general timeline for the project was as follows:

Component	Dates
Part I: Online Module Agenda – Introduction and Basic Information ▪ Recorded training on the basics of dementia ▪ Training agenda with the links to pre-& post-test surveys ▪ PPT slides for notetaking ▪ Self-paced	Self-paced. Due before December 7, 2023
Part II: Live Session Training ▪ Zoom webinar with Dr. Kerstin Reinschmidt and Michelle Archuleta that discussed roles and competencies of CHRs related to dementia care and services	December 7, 2023, at 3 pm CT
Kick-off Meeting	January 24, 2024, at 3 pm CT
Monthly Meetings	4th Wednesday of every month at 3 pm CT
Monthly Reports	Due Friday before the monthly meetings

H. FINDINGS

Outcomes from Monthly Reports

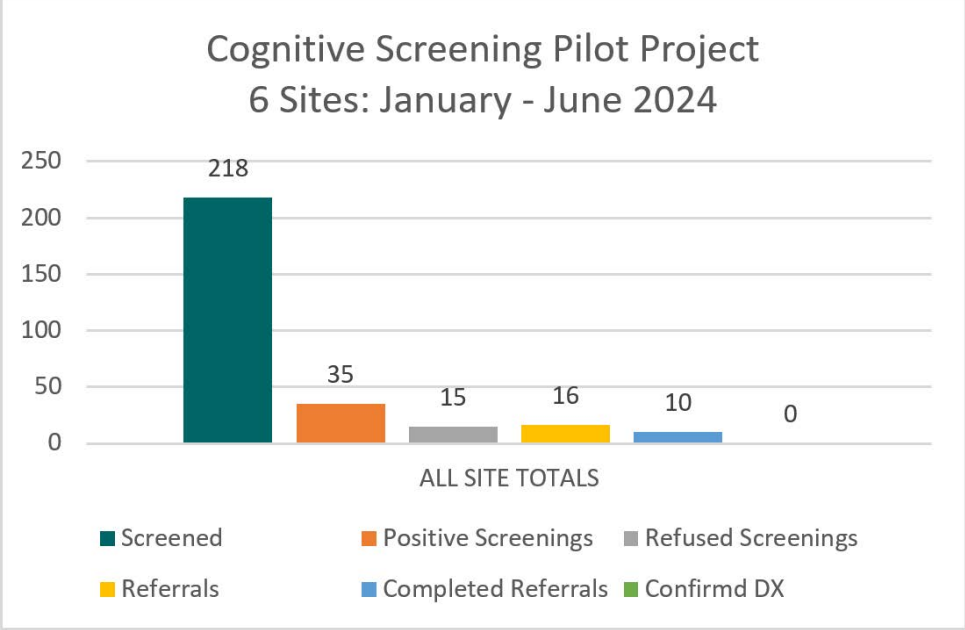
The six participating programs submitted monthly reports describing what prompted screenings, how many patients were referred to a behavioral health or primary care provider for follow-up evaluation, and how many completed those referrals. As shown in the table below, 218 patients were screened collectively over

the six months, with 16% screening positive. Fifteen out of the thirty-five participants who screened positive were referred to the clinical setting, with more than half of those referred completing the referral.

Individual program participation varied from site to site and month to month, depending on factors such as staffing and concurrent duties. Program sites are listed below randomly to preserve anonymity. Some notable findings from monthly reporting:

- The program that completed the most screenings (93 patients) reported conducting screenings at previously scheduled outreach events and senior centers.
- The program that completed the second-highest number of screenings also conducted some screenings at regularly scheduled events.
- The program most consistent in the number of screenings reported across the project period noted they modified their home health visit workflow to embed screenings into routine care. The large increase in the number of screenings in their last month resulted from providing staff incentives and a "contest" to incorporate screenings into practice.
- One program never reported completing any screenings.
- Several issues impacted participation and contributed to lower screenings: infrequent participation in calls, inconsistency in reporting, other issues with project-start-up, and report submissions were inconsistent.

Monthly meetings and report submissions were mandatory but not tied to the issuance of the incentive payment due to the pilot's formative nature. No program reported receiving a follow-up from a clinical referral to confirm or receive an update on the diagnosis status during the project period.



Pilot Site Survey Results

Five of six pilot sites responded to the final pilot project evaluation survey. Below is a summary of the survey findings.

1. **How useful were the following to the success of your work as part of the Mini-Cog© screening pilot:**
   General dementia training by Oklahoma University (one online and one live) taken prior to pilot start

- **Mini-Cog© training provided in January on the first call**
- **Monthly collaborative calls and discussions**
- **Subject matter expertise and clinical guidance from staff**

One hundred percent (100%) of respondents found the training and support activities very or extremely useful when asked to rate support activities on a 5-point scale from extremely useful to not at all useful.

2. **What activities from those training and monthly calls were most useful to you?**

Participants mentioned the following activities as most useful (listed in order of frequency mentioned): networking and engagement with peers, learning from other organizations' workflows, and practical demonstrations of the Mini-Cog© test via Zoom calls.

3. **What resources from the training and monthly calls were most useful to you?**

Respondents identified sharing and learning from other programs as the most useful resource. At least one person mentioned educational flyers, information for caregivers, or direct advice from SME consultants.

4. **What could we have done to make the pilot more effective for you and your program?**

Suggestions to enhance the pilot's effectiveness varied for each respondent and included:

- More hands-on practice with the Mini-Cog© to build confidence
- Provide strategies to engage elders, including reducing the stigma associated with screening
- Integrate more advanced dementia training throughout the pilot's duration
- Access to RPMS to input data for 648 programs
- In the latter part of the pilot, offer more enrichment and learning, including how to build a seamless connection between CHR screenings and clinical care

5. **Describe the top 3 barriers or challenges you experienced and how you overcame them while participating in the pilot.**

Multiple respondents mentioned the following three barriers with equal frequency:

- Engagement with clinical settings and providers on the pilot activities and referrals
- Responses from elders who were resistant to participating due to the topic
- CHR's confidence in implementing the screening after training

Other barriers mentioned by at least one respondent included:

- Staff turnover
- Time
- External distractions by local priorities
- The challenge of following through on referrals

6. **Describe your 2 best practices or benefits that came from participating in the pilot.**

The most significant benefit identified by multiple respondents was increasing staff knowledge about dementia, brain health, and the importance of screening. Multiple respondents also mentioned developing stronger relationships with elders and creating workflows for screening. Other benefits mentioned by at least one respondent included:

- Increased CHR confidence in administering Mini-Cog© screenings
- Educational resources they created for the project
- Ongoing process now in place for screening

One respondent commented:

> *"…getting see the benefit of utilizing CHR's for screenings in that CHR's notoriously reach areas and elders that otherwise are not being reached-- hopefully getting them connected to referrals, diagnosis, interventions, and treatment."*

7. **Comments about the pilot overall:**

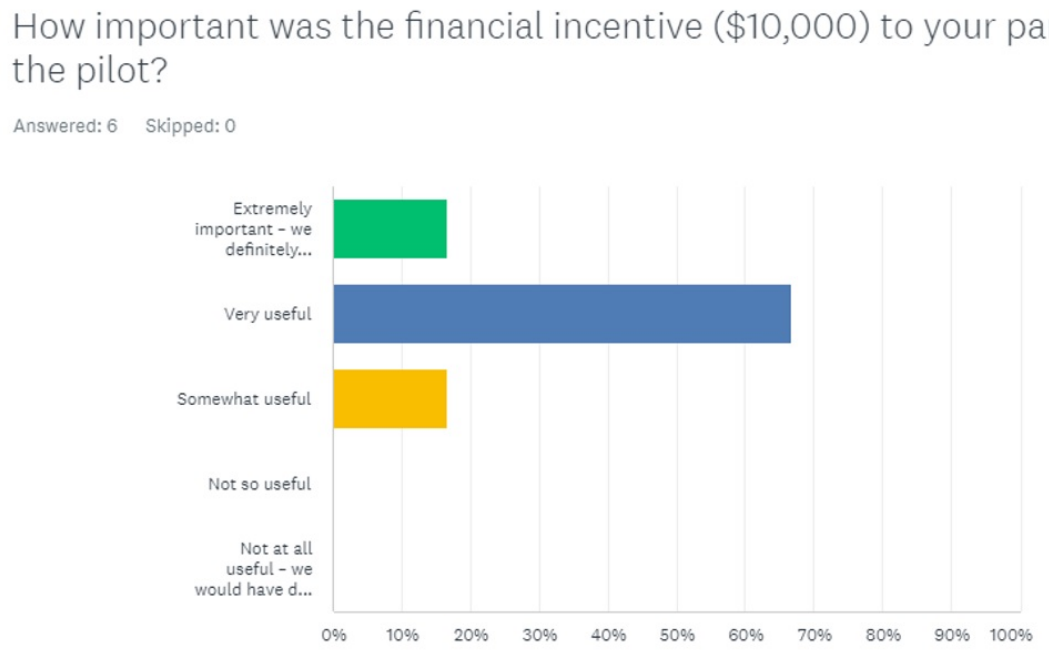
The majority of participants expressed appreciation for the opportunity to participate in the pilot. One respondent mentioned feeling rushed initially and suggested more support and time to build trust with elders. The pilot was a valuable opportunity for staff training and opening dialogue about dementia.

8. **Comments on pilot duration:**

Opinions on the pilot's duration were mixed, with half of the respondents feeling it was "Too short" and the other half considering it "Just right." No respondent indicated it was too long.

9. **How important was the financial incentive ($10,000) to your participation in the pilot?**

Most respondents (83%) considered the $10,000 incentive very or extremely useful, and no respondents felt that the funding was unnecessary.



10. **How did you or will you use the money?**

Responses varied for how funds were used and included:

- Supporting CHR salaries
- Purchase books about the dementia journey

- Purchase self-care journals for caregivers
- Education and outreach session expenses
- Future training and program supplies

11. Do you believe that it is appropriate for CHRs to do Mini-Cog© screenings?

One hundred percent of respondents (100%) agreed that it is appropriate for CHRs to conduct Mini-Cog© screenings.

12. Do you plan to continue implementing Mini-Cog© screenings in your CHR program?

One hundred percent of respondents (100%) plan to continue implementing screening in their programs.

Participant Debrief Results

The final monthly meeting included a focus group-style discussion of participants' experiences and recommendations for future pilots.

The most significant takeaway from the participant debrief was the group's consensus that additional training on dementia was a priority, including the need to incorporate active teach-back strategies for the Mini-Cog© and a strong preference for in-person training to allow for questions and answers. A second theme included participants' overwhelming support for the need and ability for CHRs to conduct these types of screenings. Finally, participants discussed the need to engage clinical settings and providers earlier and create a clear pathway for referrals and warm handoffs at the project's outset.

Lessons Learned from Team Debriefs

Members of the project team met following each monthly call and conducted a post-project debrief. This process resulted in many reflections and lessons learned.

IHS process facilitators and challenges

Planning and approach

- The narrow scope of the pilot goal and objectives in the first year was "just right."
- Consistent program support for administration and logistics is essential to the success of these types of initiatives. The pilot process of engaging local sites requires extensive ongoing, in-depth contact and follow-up to stay in touch with them to ensure they are on track and/or to follow up with sites not participating in meetings.
- Using resources (RFP, collaborative meeting agendas, report templates, project report, etc.) from the Division of Oral Health Mini-Cog© screening pilot accelerated the approach; however, both the resources and process had to be adapted to fit the unique needs of the CHR program.
- The CHR program lead and project support team were unfamiliar with dementia and/or screening. They had to learn alongside the pilot program participants.
- Having SME support for the topic and screening tool was critical for learning by the project team and local sites; presence on all calls for problem-solving and building confidence in doing the screening was important.

Implementation and recruitment

- The application was simple, and applicants reported no issues.
- Funding transfers were a challenge in one area. This ultimately required internal guidance for amendments/ modifications to Indian Self-Determination and Education Assistance Act (ISDEAA) agreements from headquarters to initiate payments. This was an extensive process.

- Recruitment used Area Office Coordinators (AOCs) to identify and select one site per region. AOCs had to endorse the site. This was helpful in making the AOC aware. However, it may have inhibited or prevented other sites from participating or from being aware that they may have wanted to participate.
- Recruitment lasted approximately four weeks and was adequate but did not result in at least one recommendation per IHS area.
- Providing only virtual training and video resources on the Mini-Cog© was easiest. However, based on participant feedback, it was not the most effective.
- A medical staff person would have been helpful as a resource to help sites that faced local challenges with the clinic and clinical staff. This includes support for those clinical sites resistant to CHRs taking on the training and/or supporting the local clinical sites and providing clinical support to training on conducting follow-up cognitive evaluations for positive screenings.
- More details/scripting of tasks and activities would be required to support this work on dementia and leading and help to learn in a peer-to-peer sharing environment if there is a desire to push this out to the area offices to manage.
- Some programs failed to participate regularly in the monthly meetings or submit all reports, both of which were required. Funding was not contingent upon outcomes or mandatory requirements.

Local implementation successes and challenges

Facilitators to early adopter success

- CHRs who were confident in their ability to implement other screenings.
- "Just doing it."
- Existing local knowledge of the screening tool.
- Using pre-scheduled local events, e.g., health fair and senior center, with large groups of attendees.
- Embedding the process into routine workflows increases the likelihood of ongoing sustainability.

Challenges at the local level

- At some sites, local leadership and the clinic were not aware that the CHR program had signed up to participate.
- Some clinics and clinicians questioned whether it was appropriate for the CHR to conduct dementia screening and, in some instances, any screening.
- Majority of sites started with limited to no experience working with patients with dementia.
- Staff confidence was the biggest barrier to getting started.
- One site reached saturation with their population (running out of people to screen), and said it would require different methods or approaches to reaching patients.
- Need to better understand and explore warm handoffs during future pilot cohorts. For some entities, it was as simple as information written on paper.
- Guidance on entering data into RPMS was provided, but we don't know if anyone used RPMS or if the tools were helpful.
- There was no close-out on the referral process or the information-sharing loop between the CHR and clinic. Results of provider follow-up cognitive evaluations were rarely provided back to the CHR program. As a result, CHRs didn't know how or if this should change their approach to supporting, educating, and engaging with patients.

I. DISCUSSION AND RECOMMENDATIONS

Findings suggest that the pilot's first year successfully answered the first evaluation question: CHRs can implement cognitive screenings. Numerous opportunities were identified by the project team and participants for continued learning, improvements, and ongoing exploration of methods to formalize local pathways to improve the overall effectiveness of community screenings. The original project team is actively planning year two pilot cohort activities. These efforts incorporated immediate changes based on lessons learned and evaluation results into pilot program processes and activities. Examples include:

- Updated the application to require signatures from local leadership
- Incorporated more extensive in-person training, on both dementia and Mini-Cog tool
- Modified the payment process to align and ensure compliance with calls and reporting

The formative evaluation data and screening outcomes of the first pilot year support continued investment for future year pilot activities.

J. APPENDIX A – MINI-COG© TOOL

Mini-Cog©

Instructions for Administration & Scoring

ID: _____ Date: _____

Step 1: Three Word Registration

Look directly at person and say, "Please listen carefully. I am going to say three words that I want you to repeat back to me now and try to remember. The words are [select a list of words from the versions below]. Please say them for me now." If the person is unable to repeat the words after three attempts, move on to Step 2 (clock drawing).

The following and other word lists have been used in one or more clinical studies.[1-2] For repeated administrations, use of an alternative word list is recommended.

Version 1	Version 2	Version 3	Version 4	Version 5	Version 6
Banana	Leader	Village	River	Captain	Daughter
Sunrise	Season	Kitchen	Nation	Garden	Heaven
Chair	Table	Baby	Finger	Picture	Mountain

Step 2: Clock Drawing

Say: "Next, I want you to draw a clock for me. First, put in all of the numbers where they go." When that is completed, say: "Now, set the hands to 10 past 11."

Use preprinted circle (see next page) for this exercise. Repeat instructions as needed as this is not a memory test. Move to Step 3 if the clock is not complete within three minutes.

Step 3: Three Word Recall

Ask the person to recall the three words you stated in Step 1. Say: "What were the three words I asked you to remember?" Record the word list version number and the person's answers below.

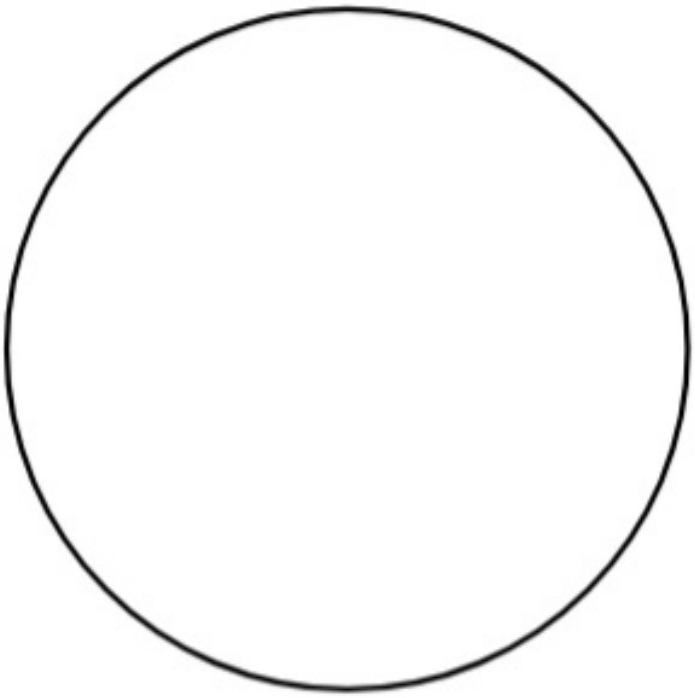
Word List Version: _____ Person's Answers: _____ _____ _____

Scoring

Word Recall: _____ (0-3 points)	1 point for each word spontaneously recalled without cueing.
Clock Draw: _____ (0 or 2 points)	Normal clock = 2 points. A normal clock has all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). Hand length is not scored. Inability or refusal to draw a clock (abnormal) = 0 points.
Total Score: _____ (0-5 points)	Total score = Word Recall score + Clock Draw score. A cut point of <3 on the Mini-Cog™ has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.

Clock Drawing

ID:_____ Date:_____



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