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# **Tools for Screening, Identification, Referral, and Care Planning for People With Alzheimer's Disease and Their Caregivers**

## **Final Report**

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## CONTENTS

|  |    |
|--|----|
| Section 1 Introduction.....  | 1  |
| Section 2 Brief Cognitive Impairment Screening Instruments for Use by Nonclinicians.....   | 2  |
| 2.1 Criteria for Selection.....  | 2  |
| 2.2 Instrument Descriptions.....   | 3  |
| 2.2.1 Brief Screen for Cognitive Impairment.....   | 4  |
| 2.2.2 Clock-Drawing Test.....  | 5  |
| 2.2.3 Older Adult Behavior Checklist.....  | 6  |
| 2.2.4 Public Health Center Cognitive Dysfunction Screening Test.....   | 7  |
| 2.2.5 Symptoms of Dementia Screener.....   | 8  |
| 2.2.6 Telephone Interview of Cognitive Status-modified.....  | 9  |
| 2.3 Comparison of Instruments.....   | 10 |
| Section 3 Needs Assessment Tools.....  | 13 |
| 3.1 Criteria for Selection.....  | 13 |
| 3.2 Tool Descriptions.....   | 13 |
| 3.2.1 Caregiver Alternatives to Running on Empty (Project C.A.R.E.) and the<br>Duke University Information and Assessment Toolkit..... | 14 |
| 3.2.2 Alzheimer’s Navigator.....   | 14 |
| 3.2.3 Benjamin Rose Institute Care Consultation Intervention.....  | 14 |
| 3.2.4 Tailored Caregiver Assessment and Referral Navigator.....  | 15 |
| 3.3 Summary of Needs Assessment Tools.....   | 16 |
| Section 4 State Tools for Needs Assessment and Referral.....   | 18 |
| 4.1 Georgia.....   | 18 |
| 4.1.1 Determination of Need–Revised.....   | 18 |
| 4.1.2 Gateway to Aging and Disability Services.....  | 18 |
| 4.2 Minnesota.....   | 20 |
| 4.2.1 Identification and Care Coordination.....  | 20 |
| 4.2.2 Family Questionnaire.....  | 21 |
| 4.2.3 Mini-Cog.....  | 22 |
| 4.2.4 Montreal Cognitive Assessment.....   | 22 |
| 4.2.5 Saint Louis University Mental Status Examination.....  | 23 |
| 4.3 New York.....  | 23 |
| 4.3.1 AD8.....   | 23 |
| 4.4 Ohio.....  | 24 |

|  |  |    |
|--|--|----|
| 4.4.1  | Memory Impairment Screen .....                     | 25 |
| 4.4.2  | General Practitioner Assessment of Cognition ..... | 25 |
| Section 5 Conclusions.....                                   |  | 26 |
| References.....  |  | 28 |
| Appendix A. Methods.....                                     |  | 30 |
| Appendix B. Additional Screening Instruments .....           |  | 32 |
| Appendix C. Cognitive Screening Tools Permissions Pages..... |  | 34 |

### **LIST OF EXHIBITS**

|    |  |    |
|----|--|----|
| 1. | Summary of Reviewed Dementia Screening Instruments .....   | 11 |
| 2. | Strengths and Weaknesses of Reviewed Dementia Screening Instruments .....  | 12 |
| 3. | Duke University Information and Assistance Toolkit: Helping Families Choose<br>Appropriate Help .....  | 15 |
| 4. | Overall Needs Assessment Tools .....   | 17 |
| 5. | Phone Call Flowchart, Georgia Gateway .....  | 19 |
| 6. | Minnesota’s ACT on Alzheimer’s Identification and Care Coordination Flow Chart.....  | 21 |
| 7. | Example of Calculating Sensitivity, Specificity, Positive Predictive Value, and<br>Negative Predictive Value for a Screening Instrument for Alzheimer’s Disease..... | 31 |

## **SECTION 1**

### **INTRODUCTION**

Many people with Alzheimer’s disease (AD) and related dementias living in the community are undiagnosed (Alzheimer’s Association, 2013). Undiagnosed disease prevents individuals and their caregivers from obtaining needed services and planning for the future. Lack of identification of dementia may lead to poorer outcomes.

Establishing a definitive diagnosis of AD and related dementias is difficult, even when done by a physician. Commonly used instruments for identifying people with dementia, such as the Mini-Mental State Examination (MMSE), are often long, difficult to score, designed to be administered by trained clinicians, and may have difficulty detecting early-stage dementia (Mitchell, 2009).

Despite these difficulties, it is critical for long-term services and supports systems, especially for Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs), to find ways to identify people with possible dementia and to refer them for diagnosis and services. Providing the services that people with dementia and their caregivers require is unlikely unless agencies can identify them as having possible dementia, especially because few people seeking information self-identify as having dementia (Tilly et al., 2011).

Closely related to the problem of identifying people with possible dementia is the issue of referrals to organizations and services that specialize in serving this population by taking their special needs into account in care planning. People with cognitive impairment use more services per person than people without cognitive impairment (Johnson & Wiener, 2006). In addition, people with dementia typically use different services than do people without cognitive impairment. People with dementia often need constant supervision, using substantial amounts of adult day health services and residential care services, such as assisted living facilities.

The purpose of this report is to describe:

- Screening instruments for possible AD and other dementias that can be administered by people without clinical training
- Needs assessment and referral tools that are available for potential use
- Tools used for care planning, screening, and referral by current System Integration grantees of the Alzheimer Disease Supportive Services Program (ADSSP): Georgia, Minnesota, New York, and Ohio

## SECTION 2

### BRIEF COGNITIVE IMPAIRMENT SCREENING INSTRUMENTS FOR USE BY NONCLINICIANS

This section assesses cognitive impairment screening instruments available for use by nonclinicians. Reliability and validity are key factors for evaluating and choosing screening instruments. Because of the potential consequences of misclassifying people, how screening instruments score on these calculations is critically important. Reliability assesses whether the instrument yields the same results when tested on the same person on multiple occasions (test-retest reliability) or whether the test yields the same results when two different people administer the test (inter-rater reliability). In contrast, validity is commonly measured by how well the items on an instrument “hang together” (internal consistency) and by how well an instrument’s results correlate with other measures of the same characteristic, especially other measures that are strongly believed to be valid (criterion validity) (Aday, 1996). *Appendix A* provides additional details on how measures are typically assessed for their reliability and validity.

#### 2.1 Criteria for Selection

We selected screening instruments for AD for review based on the following criteria:

- The instrument is intended to *screen for* (but not diagnose) dementia, cognitive impairment, or AD
  - Instruments intended to screen for delirium were excluded
- The screener is *clearly and explicitly* intended to be administered by a lay interviewer in person or by phone, either to the client or to a knowledgeable informant (e.g., caregiver or spouse)
  - The instrument is not intended to be solely self-administered
  - The instrument is not intended to be administered solely by physicians, nurses, social workers or other clinicians
- The supporting journal article about the screening instrument was published in English with an abstract available, preferably published in the past 10 years (key older articles were identified via searches of bibliographies)

Screening instruments were mostly identified through electronic searches of journal databases. *Appendix A* provides more detailed information about the search terms used.

## 2.2 Instrument Descriptions

In this section, we briefly summarize the six screening instruments for AD and dementia that met our criteria. *Appendix B* provides information about two additional screening instruments, the Mini-Mental State Exam and the Short Portable Mental Status Questionnaire, which did not meet our inclusion criteria but are still of interest because they are widely used.

The instruments described are:

- Brief Screen Cognitive Impairment
- Clock-Drawing Test
- Older Adult Behavior Checklist
- Public Health Center Cognitive Dysfunction Screening Test
- Symptoms of Dementia Screener
- Telephone Interview of Cognitive Status-modified

### 2.2.1 Brief Screen for Cognitive Impairment

| Category                                  | Description  |
|---|--|
| <b>Citation</b>                           | Hill, J., McVay, J. M., Walter-Ginzburg, A., et al. Validation of a brief screen for cognitive impairment (BSCI) administered by telephone for use in the Medicare population. <i>Dis Manag.</i> 2005; 8:223-234.  |
| <b>Brief Overview of Scale/Instrument</b> | <p>The Brief Screen for Cognitive Impairment is a three-item screen designed to be incorporated into larger telephonic health-risk assessments typically conducted by Medicare managed care plans. Items include:</p> <ol style="list-style-type: none"> <li>1. Delayed recall of 3 words (dog, apple, house) (0 = no words recalled to 3 = all words recalled)</li> <li>2. Frequency of help with planning trips for errands (0 = never needs help, to 4 = frequently needs help)</li> <li>3. Frequency of help remembering to take medications (same scoring as item 2)</li> </ol> <p>A two-question version for the 10%–15% of Medicare enrollees who do not take any medications has been tested to perform similarly to the 3-question version.</p> |
| <b>Developed By</b>                       | Team of researchers from Institute for the Study of Aging, Fallon Clinic, and AstraZeneca  |
| <b>Target Population</b>                  | Medicare enrollees. Validation sample n = 70.  |
| <b>Intended Users</b>                     | Can be administered by lay interviewers via telephone.   |
| <b>Scoring</b>                            | Scores are weighted and summed to arrive at final score. Delayed recall and medication help each get a weight of 2.0, and errand help gets a weight of 1.0. If client does not take any medications, the weighted scores of the other two items perform similarly to the three-item version.   |
| <b>Materials Available</b>                | Original pilot and validation study articles contain the three items and scoring algorithms.   |
| <b>Strengths</b>                          | Brief (80 seconds). Simple scoring. Acceptable to interviewees. The developers claim good test-retest reliability on all items, although no data were provided. Good internal consistency (Cronbach's alpha = 0.79), and good external validity as demonstrated by correlation with the MMSE (correlation of 0.64). With a cutoff of 6, sensitivity = 0.77 and specificity = 0.97.   |
| <b>Weaknesses</b>                         | Validity has only been tested in a small sample, for telephonic administration only. Not a standalone instrument—designed to be integrated into a larger health risk assessment.   |

### 2.2.2 Clock-Drawing Test

| Category                                  | Description   |
|---|---|
| <b>Citation</b>                           | Nishiwaki, Y., Breeze, E., Smeeth, L., Bulpitt, C. J., Peters, R., Fletcher, A. E. Validity of the Clock-Drawing Test as a screening tool for cognitive impairment in the elderly. <i>Am J Epidemiol</i> 2004; 160: 797-807   |
| <b>Brief Overview of Scale/Instrument</b> | Participants were given a blank sheet of paper, a pencil, and the following instruction: “Draw a large clock face and put all the numbers in.” After this had been done, participants were asked to draw in the clock hands to indicate a time of 10 past 11. For postal administration, participants were provided with a blank sheet of paper in the questionnaire and the instructions given above.  |
| <b>Developed By</b>                       | Sunderland et al., 1989   |
| <b>Target Population</b>                  | Over 75, living in the community; the study sample consisted of participants in a cluster randomized trial in the UK (n=13,557).  |
| <b>Intended Users</b>                     | The test was administered via a mailed survey (44%) or in person by either nurses (25%) or laypersons (31%).  |
| <b>Scoring</b>                            | A nurse scored all tests. The nurse evaluated three items: “correctly drawn clock shape,” “all numbers in the correct position,” and “hands of the clock set to the correct time.” A score of 1 was assigned for each of these items if the nurse judged that the drawing, the assignment of numbers, and the time were correct. The nurses did not have prior psychological knowledge but were trained to judge abnormalities not captured by the above criteria. For instance, if the drawing was a very disorganized, bizarre, or otherwise abnormal representation of a clock, the nurse recorded a score of 0, or a 1 if the clock was normal. Final possible scores ranged between 0 (worst) and 4 (best). The study used a cutpoint of 2 in primary analyses.  |
| <b>Materials Available</b>                | N/A   |
| <b>Strengths</b>                          | Brief, simple, and acceptable to clients. Test–retest reliability of CDT ranges from 0.87 to 0.94 and interrater reliability ranges from 0.82 to 0.97, depending on the scoring method. In this study, lay interviews were more sensitive but less specific than mail surveys (neither method was as sensitive/specific as nurse interviews). For nurse-administered interviews, sensitivity = 76.5% and specificity = 87.1% for moderate/severe cognitive impairment (MMSE < 17). Negative predictive value overall was 86.9% using a cutoff of ≤23 on the MMSE, and 98.7% with a cutoff of ≤17. Negative predictive value was over 85% in all except those over age 90 years, and was similarly high for all three modes; in fact, the negative predictive value was higher when the instrument was administered by laypersons than when it was administered by nurses. |
| <b>Weaknesses</b>                         | Overall, using an MMSE score of ≤17, sensitivity = 61.4%, specificity = 87.9%, and positive predictive value = 13.2%. Positive predictive value was 43.9% for an MMSE score of <23, but the sensitivity was lower (34.5%). Positive predictive value was quite poor (<30%) for all age groups, methods of administration, and severity cutpoints.   |



### 2.2.3 Older Adult Behavior Checklist

| Category                                  | Description   |
|---|---|
| <b>Citation</b>                           | Brigidi, B. D., Achenbach, T. M., Dumenci, L., Newhouse, P. A. Broad spectrum assessment of psychopathology and adaptive functioning with the Older Adult Behavior Checklist: a validation and diagnostic discrimination study. <i>Int J Geriatr Psychiatry</i> 2010; 25: 1177-1185   |
| <b>Brief Overview of Scale/Instrument</b> | <p>The Older Adult Behavior Checklist (OABCL) was developed for adults aged 60+ using a “bottom up” or empirically based approach to psychopathology. The informant responds to 113 items describing problems interspersed with 20 items describing personal strengths, based on the client’s functioning over the preceding 2 months.</p> <ul style="list-style-type: none"> <li>• Adaptive Functioning Scales: Friends; Spouse/ Partner; Personal Strengths</li> <li>• Syndrome Scales: Anxious/Depressed; Worries; Somatic Complaints; Functional Impairment; Memory/Cognition Problems; Thought Problems; and Irritable/Disinhibited</li> <li>• DSM-oriented Scales: Depressive Problems; Anxiety Problems; Somatic Problems; Dementia Problems; Psychotic Problems; and Antisocial Personality Problems</li> </ul> |
| <b>Developed By</b>                       | Achenbach et al. (2004)—supported by the nonprofit Research Center for Children, Youth, and Families, which publishes the OABCL.  |
| <b>Target Population</b>                  | Older community-dwelling adults. Study sample consisted of persons aged 60-97 from outpatient memory and geriatric psychiatry clinics at the University of Vermont-Fletcher-Allen medical center serving urban, suburban, and rural Vermont and upstate New York and from 26 nonclinical settings in urban, suburban, and rural New Jersey, Pennsylvania, and Vermont (n=727).  |
| <b>Intended Users</b>                     | Can be self-administered on paper or on the Web or administered by lay interviewers in about 15 minutes—completed by a knowledgeable informant.   |
| <b>Scoring</b>                            | OABCL scores are compared to age- and sex-specific norms based on a U.S. national sample spanning ages 60–98.   |
| <b>Materials Available</b>                | For a fee, through Achenbach System of Empirically Based Assessment (ASEBA) ( <a href="http://www.aseba.org/catalog.pdf">http://www.aseba.org/catalog.pdf</a> ).  |
| <b>Strengths</b>                          | Mean test-retest correlation was 0.94. The instrument correctly classified 84% of participants diagnosed with either mood disorder or dementia, Alzheimer type (sensitivity = 0.82, specificity = 0.86). The OABCL has national norms and is rapidly scored.  |
| <b>Weaknesses</b>                         | Clinicians who performed the diagnostic examination/comparison of the OABCL to the MMSE were not blinded to the participants’ MMSE scores. Not an Alzheimer-specific instrument. Somewhat long.   |

### 2.2.4 Public Health Center Cognitive Dysfunction Screening Test

| Category                                  | Description   |
|---|---|
| <b>Citation</b>                           | Park, M. H., Lee, D. H., Lee, H. J., Song, M. S. The PHC-cog: a brief cognitive function screening test for the elderly. <i>Neurol India</i> . 2005 Mar;53(1):60-4.   |
| <b>Brief Overview of Scale/Instrument</b> | The Public Health Center Cognitive Dysfunction Screening Test (PHC-Cog) was designed to be administered by laypersons and used for population-based screening for dementia. Items were derived from the MMSE, the Barthel Index, the IADL, and the Korean Dementia Screening Questionnaire. There were originally 10 items on the client section, which were reduced to 5 after testing, along with 15 items on the informant section. Administration takes approximately 1 minute. The instrument relies heavily on time disorientation items. |
| <b>Developed By</b>                       | A team of Korean geriatric neurologists and nurses.   |
| <b>Target Population</b>                  | Older persons in community/primary care settings, particularly in developing countries.   |
| <b>Intended Users</b>                     | Designed to be administered by laypersons or clinic staff.  |
| <b>Scoring</b>                            | Scoring is based on the total number of incorrect responses (lower scores indicate better functioning). Using a cutoff of 6 on the client section, sensitivity = 0.75, specificity = 0.92. Using the same cutoff on the informant section, sensitivity = 0.79, specificity = 0.83.  |
| <b>Materials Available</b>                | An English translation is available in the appendix, although the wording is awkward.   |
| <b>Strengths</b>                          | Brief, simple scoring, good psychometrics (better than MMSE in this sample). Requires little if any professional time.  |
| <b>Weaknesses</b>                         | As written, can only be used if the client is visiting the clinic for a flu vaccination. Some clients with less education may have trouble with the interlocking pentagons. Would require significant adaptation.   |

### 2.2.5 Symptoms of Dementia Screener

| Category                                  | Description   |
|---|---|
| <b>Citation</b>                           | Mundt, J. C., Freed, D. M., Greist, J. H. Lay person-based screening for early detection of Alzheimer’s disease: development and validation of an instrument. <i>J Gerontol B Psychol Sci Soc Sci.</i> 2000 May; 55(3):P163-70.   |
| <b>Brief Overview of Scale/Instrument</b> | <p>The Symptoms of Dementia Screener (SDS) is a series of 11 yes/no questions administered to a knowledgeable informant that was designed to be a dementia screening instrument applicable to the general public that did not require clinical expertise or training to administer.</p> <ol style="list-style-type: none"> <li>1. Does he/she often repeat himself/herself or ask the same question over and over?</li> <li>2. Is he/she more forgetful, that is, have trouble with short-term memory?</li> <li>3. Does he/she need reminders to do things like chores, shopping, or taking medicine?</li> <li>4. Does he/she forget appointments, family occasions, or holidays?</li> <li>5. Does he/she seem sad, down in the dumps, or cry more often than in the past?</li> <li>6. Has he/she started having trouble doing calculations, managing finances, or balancing the checkbook?</li> <li>7. Has he/she lost interest in his (her) usual activities such as hobbies, reading, church, or other social activities?</li> <li>8. Has he/she started needing help eating, dressing, bathing, or using the bathroom?</li> <li>9. Has he/she become irritable, agitated, or suspicious or started seeing, hearing, or believing things that are not real?</li> <li>10. Are there concerns about his (her) driving, for example, getting lost or driving unsafely?</li> <li>11. Does he/she have trouble finding the words he/she wants to say, finishing his (her) sentences, or naming people or things?</li> </ol> |
| <b>Developed By</b>                       | Pfizer  |
| <b>Target Population</b>                  | Older adults. The validation sample included 103 participants—25 unimpaired, 17 MCI, 61 possible/probable AD—who had previously received a complete neuropsychological evaluation. The SDS examiners were blinded to the results of the evaluation.   |
| <b>Intended Users</b>                     | Laypersons  |
| <b>Scoring</b>                            | The a priori hypothesis was that three or more affirmative answers to the set of questions would indicate a positive dementia screen, but five or more was the ROC optimum (sensitivity: 90.2, specificity: 84.6, positive predictive value: 85.9, negative predictive value: 84.6) and was recommended in the discussion section.  |
| <b>Materials Available</b>                | Article includes complete questionnaire, with a copyright statement/all rights reserved.  |
| <b>Strengths</b>                          | Simple, straightforward questionnaire that is readily understood by informants, requires little cognitive processing for rendering responses, and can easily be administered by mail, telephone, or in person by lay examiners with no clinical expertise.  |
| <b>Weaknesses</b>                         | Validation sample was small, regionally constrained, not diverse. Instrument has not been tested in a diverse population. Copyrighted. Subjective/proxy respondent. Some questions seem poorly worded. Does not appear to have been used much (cited by few other studies in 11 years since publication).   |
| <b>Abstractor Comments</b>                | The lead author (Mundt) also published a version that is designed to be administered via computer-automated touch-tone telephone.   |

### 2.2.6 Telephone Interview of Cognitive Status-modified

| Category                                  | Description  |
|---|--|
| <b>Citation</b>                           | Buckwalter, J. G., Crooks, V. C., Petitti, D. B. A preliminary psychometric analysis of a computer-assisted administration of the Telephone Interview of Cognitive Status-modified. <i>J Clin Exp Neuropsychol</i> 2002; 24: 168-175   |
| <b>Brief Overview of Scale/Instrument</b> | <p>The Telephone Interview of Cognitive Status-modified (TICS<sub>m</sub>) is a computer-assisted telephone interview instrument designed to be administered by lay interviewers by phone. It assesses a variety of cognitive domains including orientation, comprehension, attention, naming, working memory, verbal abstraction, and immediate verbal memory. The instrument was modeled after the MMSE and then modified to remove items difficult to verify over the phone; the TICS<sub>m</sub> also added a delayed verbal recall measure to increase sensitivity to early dementia.</p> <ul style="list-style-type: none"> <li>• Full name (2 pts)</li> <li>• Date (5 items) (5 pts)</li> <li>• Name and phone number (2 pts)</li> <li>• Count backward from 20 to 1 (2 pts)</li> <li>• 10 word immediate recall (10 pts)</li> <li>• Serial 7 subtractions (5 pts)</li> <li>• Naming (4 items) (4 pts)</li> <li>• Repetition (2 items) (2 pts)</li> <li>• President and Vice President (4 pts)</li> <li>• Tap the phone 5 times (2 pts)</li> <li>• Identify opposites (2 items) (2 pts)</li> <li>• 10 word delayed recall (10 pts)</li> </ul> |
| <b>Developed By</b>                       | Brandt et al., 1988; Welsh, Breitner, & Magruder-Habib, 1993. The scoring system is published in Welsh et al., 1993.   |
| <b>Target Population</b>                  | Older adults in primary care settings and epidemiological studies. Study sample consisted of participants in The Women's Memory Study conducted by the Southern California Permanente Medical Group and the University of Southern California (n=3,681), all 75 years of age, who had been members of Kaiser Permanente for 7+ years, randomly selected based on use of HRT in the past 7 years.   |
| <b>Intended Users</b>                     | Primary care practices, managed care plans, researchers—administrators are intended to be trained laypersons.  |
| <b>Scoring</b>                            | The scale has 23 questions, scored as 12 items, for a total of 50 points. A computer program was developed which displays each question, and allowable prompts, on the screen. When the interviewer enters an acceptable response, the next question is displayed. The program requires all responses, correct or incorrect, be entered. Immediate scoring is completed using a standard algorithm.  |
| <b>Materials Available</b>                | Unknown  |
| <b>Strengths</b>                          | Interrater reliability reported elsewhere as 97%, administration time 5–10 minutes (Breitner et al., 1991).  |
| <b>Weaknesses</b>                         | Test-retest, predictive validity, and construct validity not provided.   |

### 2.3 Comparison of Instruments

Screening instruments were compared on the following criteria: materials available, time to administer, administrator qualifications, and psychometric properties: sensitivity, specificity, positive predictive value, negative predictive value, test-retest reliability, inter-rater reliability, and correlation coefficients, both internal and compared with the MMSE (as the “gold standard,” since it is the most commonly used instrument). *Exhibit 1* presents a summary of each of the instruments. *Exhibit 2* presents a summary of each instrument’s strengths and weaknesses.

The aspects of validity that measure whether a test is able to accurately rule out a diagnosis are:

- *Specificity*: how likely is the test to detect the *lack* of a characteristic in someone who does not have the characteristic?
- *Negative Predictive Value*: the proportion of persons with a negative result who *do not* have the characteristic.

The accuracy of a test in establishing a diagnosis is measured with:

- *Sensitivity*: how likely is the test to detect a characteristic in someone who has the characteristic?
- *Positive Predictive Value*: the proportion of persons with a positive result who *do* have the characteristic.

Specificity and sensitivity are typically inversely related: as one goes up, the other goes down, and vice versa. Please see *Appendix A* for more details on these properties.

The ideal dementia screener for widespread community use would be brief, easily scored, with excellent accuracy, and able to be administered by laypersons. Several promising instruments meet these criteria, including the Brief Screen for Cognitive Impairment, clock-drawing test, and Symptoms of Dementia Screener. On the other hand, if a screener is needed for telephone administration, the Brief Screen for Cognitive Impairment seems to be a promising candidate, with high accuracy and an 80-second administration time. Finally, although the MMSE was not designed for administration by laypersons, it also has high accuracy and is certainly the most widely used instrument in clinical and research settings.

**Exhibit 1. Summary of Reviewed Dementia Screening Instruments**

| Instrument   | Availability         | Number of Items | Time to Administer (minutes) | Mode   | Administrator Qualifications | Given To             | Sensitivity              | Specificity              | Positive Predictive Value     | Negative Predictive Value | Test-Retest  | Inter-Rater Reliability | Chronbach's Alpha | Correlation with MMSE |
|--|----------------------|-----------------|------------------------------|--|------------------------------|----------------------|--------------------------|--------------------------|-------------------------------|---------------------------|--------------|-------------------------|-------------------|-----------------------|
| Brief Screen for Cognitive Impairment (BSCI) (Hill et al., 2005)                                 | Published article    | 3               | 1.5                          | Phone  | Layperson                    | Client               | 0.77                     | 0.97                     | N/A                           | N/A                       | N/A          | N/A                     | 0.79              | 0.64                  |
| Clock-drawing test (Nishiwaki et al., 2004)  | N/A                  | 1               | Varies                       | Paper (in person)  | Layperson or nurse/clinician | Client               | Nurse: 0.77<br>Lay: 0.61 | Nurse: 0.87<br>Lay: 0.88 | <0.30 for all versions tested | > 85%                     | 0.87 to 0.94 | 0.82 to 0.97            | N/A               | N/A                   |
| Older Adult Behavior Checklist (Brigidi et al., 2010)  | \$ ©, online         | 113             | 15                           | Paper, computer-aided self-admin, or in-person interview | Self or layperson            | Informant            | 0.82                     | 0.86                     | N/A                           | N/A                       | 0.94         | N/A                     | N/A               | N/A                   |
| Public Health Center Cognitive Dysfunction Screening Test (Park et al., 2005)                    | Published article    | 20              | 1                            | In-person interview                                      | Layperson                    | Client and informant | P: 0.75<br>I: 0.79       | N/A                      | N/A                           | N/A                       | N/A          | N/A                     | N/A               | N/A                   |
| Symptoms of Dementia Screener (Mundt et al., 2000)   | Published article, © | 11              | Varies                       | Paper (mail), phone                                      | Self or layperson            | Informant            | 0.90                     | 0.85                     | 0.86                          | 0.85                      | N/A          | N/A                     | N/A               | N/A                   |
| Telephone Interview of Cognitive Status-modified (Buckwalter et al., 2002; Knopman et al., 2010) | \$ ©, online         | 23              | 5-10                         | Phone  | Layperson                    | Client               | 0.52                     | 0.44                     | 0.80                          | 0.18                      | N/A          | 0.97                    | N/A               | N/A                   |

NOTE: \$ = fee required; © = copyrighted. N/A = not available. Chronbach's alpha is a measure of internal consistency. Measures above 0.7 generally are considered acceptable.

## Exhibit 2. Strengths and Weaknesses of Reviewed Dementia Screening Instruments

| Instrument & Reference   | Strengths   | Weaknesses  |
|--|---|---|
| Brief Screen for Cognitive Impairment (BSCI) (Hill, et al., 2005)                                  | Short administration time (80 seconds), simple scoring, acceptable to clients, good psychometric properties in terms of sensitivity/specificity, test-retest reliability, internal consistency, and criterion validity (correlation with the MMSE). Designed specifically for lay administration. | Not a standalone instrument, has only been tested in a small sample (n=70) and only by telephone; unknown positive and negative predictive value.   |
| Clock-drawing test (Nishiwaki, et al., 2004)   | Brief, acceptable to clients, and simple.   | Lay interviews more sensitive but less specific than mail surveys; neither is as sensitive/specific as nurse interviews. Positive predictive value was < 0.30 for all modes and versions tested; negative predictive value was > 85% in all except those over age 90 years and was higher when administered by laypersons than when administered by nurses. |
| Older Adult Behavior Checklist (Brigidi, et al., 2010)   | Correctly classified 84% of clients diagnosed with either mood disorder or dementia; national norms are available; rapid scoring.   | Not a dementia-specific instrument, somewhat lengthy (15 minutes), requires knowledgeable informant, unknown negative predictive value and positive predictive value.   |
| Public Health Center Cognitive Dysfunction Screening Test (Park, et al., 2005)                     | Brief, simple scoring, good psychometrics, requires little if any professional time.  | As written, can only be used if clients are visiting a clinic for a flu vaccination and have a knowledgeable informant with them. Would need to be adapted to be used in the United States.   |
| Symptoms of Dementia Screener (Mundt, et al., 2000)  | Simple, straightforward questionnaire that can be administered by mail, telephone, or in person by lay examiners with no clinical expertise.  | Validation sample was small, regionally limited, and not diverse. Instrument has not been tested in a diverse population. Requires proxy respondent. Some questions seem poorly worded.   |
| Telephone Interview of Cognitive Status-modified (Buckwalter, et al., 2002; Knopman, et al., 2010) | Brief, designed for telephone administration by laypersons.   | Validation sample was small; psychometric properties poor for a screening instrument.   |

## SECTION 3 NEEDS ASSESSMENT TOOLS

### 3.1 Criteria for Selection

Several tools are available that are designed to identify the service needs of people with chronic illness, including dementia/cognitive impairment, and their family caregivers. Few, however, are evidence based. This section provides a brief summary of some of the needs assessment and referral tools that meet the following criteria:

- Assess a variety of needs of people with dementia/cognitive impairment or their family caregivers
- Can be completed by counselors, care coordinators, or family caregivers
- Involve follow-up for identified areas of need by a trained counselor or caregiver specialist over the phone, in person, or on the Internet, or a resource link to such a person
- Can be accessed on the Internet

Three of the four instruments reviewed in this section begin with a few items that function as triggers for additional, more detailed assessments. All have some mechanism for linking with local and online resources, whether or not a counselor is involved. The Duke University Information & Assistance Toolkit and the Alzheimer's Navigator are available to the public and do not require training, but they are not supported by peer-reviewed studies. In contrast, the proprietary tools, the *Benjamin Rose Institute Care Consultation (BRI CC)* and the *Tailored Caregiver Assessment and Referral (TCARE<sup>®</sup>)* require training, support software and manuals, and are evidence-based. The sole tool identified for caregivers to use directly, the Alzheimer's Navigator, requires access to a computer and the skills to use it.

### 3.2 Tool Descriptions

This section describes four tools:

- Caregiver Alternatives to Running on Empty (Project C.A.R.E.) and the Duke University Information and Assessment Toolkit
- Alzheimer's Navigator
- Benjamin Rose Institute Care Consultation Intervention
- Tailored Caregiver Assessment and Referral Navigator



### ***3.2.1 Caregiver Alternatives to Running on Empty (Project C.A.R.E.) and the Duke University Information and Assessment Toolkit***

The North Carolina Division of Aging and Adult Services Project C.A.R.E. (Caregiver Alternatives to Running on Empty) provides a number of assessment and referral tools on its website, <http://www.ncdhhs.gov/aging/ncprojectcare.htm>. For example, the 88-page Duke University Information & Assistance Toolkit (Gwyther & Ballard, 2002) was developed to help Information and Assistance specialists and care managers/family caregiver specialists provide resource information and enhance communication skills with family caregivers of people with dementia. Included is a one-page problems and solutions sheet that addresses possible approaches to helping family caregivers with their needs (*Exhibit 3*). All information is available at no charge. This material was developed as part of an Alzheimer's Disease Supportive Services Program grant to North Carolina.

### ***3.2.2 Alzheimer's Navigator***

The Alzheimer's Navigator™ is a free interactive web-based assessment and referral system that generates customized information and resources for family caregivers and people with dementia. The user first completes a 5-minute welcome survey with trigger questions that lead to more focused survey items in the domains of knowledge of AD, working with healthcare professionals, care options, future planning, caregiver support, activities of daily living, symptoms and behavior, home safety, and driving. An action plan built on these survey results is then provided to the user, including links to local resources, information about AD, and action steps for each topic. Developed by the Alzheimer's Association, the tool also refers the user to the Association's 24-hour toll-free Helpline to speak with a master's-level care consultant if needed.

### ***3.2.3 Benjamin Rose Institute Care Consultation Intervention***

The BRI CC is licensed telephone- and web-based information and support service for older adults with at least one health condition or disability and their friend or family caregiver. Based on an initial brief telephone assessment with trigger questions for both the caregiver and the care receiver, the service provides care consultation with professional counselors for health- and care-related information, use of community resources, coaching and support, and ways to involve family and friends. BRI CC intervention materials, supporting software, and training/ongoing support for telephone counselors are available for a fee from the Benjamin Rose Institute on Aging. The BRI CC program was based on the Cleveland Alzheimer's Managed Care demonstration (Bass et al., 2003).

**Exhibit 3. Duke University Information and Assistance Toolkit: Helping Families Choose Appropriate Help**

| My Problem Is...   | You May Need...  |
|--|--|
| <i>"I need help bathing him."</i>  | Personal care, home health aide  |
| <i>"I just want time to run errands."</i>  | Respite care or adult day center   |
| <i>"I was looking for something that would give my father a reason to get up in the morning. He's a people person. If I keep him home with just me, it's boring for him. He needs stimulation and I need a break."</i> | Adult day center program, student or volunteer companion/escort to senior center program or other community activities |
| <i>"I Need help getting him to the day center"</i>   | Transportation, escort   |
| <i>"I need someone to teach me caregiving skills."</i>   | Home health nurse or class for family caregivers   |
| <i>"He calms down when he's riding in the car. I want someone to take him for rides to his old neighborhood."</i>  | Private companion, senior companion, student   |
| <i>"I was looking for someone with patience and understanding to work with my husband."</i>  | Private companion or sitter from church, neighborhood or newspaper ad  |
| <i>"What I needed was someone to help with the washing when I was sick."</i>   | Chore worker, homemaker service or private maid service  |
| <i>"I have live-in help, but we both needed respite. My husband is such a high-demand man that there is no respite. Even when he goes to the hospital, he still requires both of us to be there."</i>                  | Home care agency private duty companion, aide or Licensed Practical Nurse  |
| <i>"I was looking for help so I can keep him home. Our home is a better environment than a nursing home."</i>  | Private or agency home aide or home health service   |
| <i>"I was looking for the expertise of others."</i>  | Social workers, Area Agency on Aging, Alzheimer's Association support group or family physician                        |
| <i>"I was looking for somebody I could trust and somebody that I knew would take care of my husband while I run errands. I would like to go out to lunch with friends without worry."</i>                              | Senior companion program, church volunteer or any of the above   |
| <i>"I feel burnt-out and depressed."</i>   | Caregiver support group, physician or counselor  |

Source: Gwyther & Ballard (2002).

**3.2.4 Tailored Caregiver Assessment and Referral Navigator**

TCARE is a licensed six-step assessment and referral process that enables care providers to develop tailored plans of care based on family caregivers' identified needs (Montgomery & Kwak, 2008). Specially trained and certified TCARE caregiver specialists (care managers and practitioners) use the 32-item standardized assessment to (1) help caregivers develop personalized goals and strategies to reduce stress, and (2) locate available and appropriate resources for each family using an automated program. Based on caregiver identity theory,

TCARE assists informal caregivers to shift from their roles as family members to their roles as caregivers (Montgomery & Kosloski, 2009). TCARE is being used by community-based organizations (such as AAAs, ADRCs, and home health agencies) in Georgia, Michigan, Minnesota, Washington, and Wisconsin.

### **3.3 Summary of Needs Assessment Tools**

*Exhibit 4* summarizes the four needs assessment tools reviewed.

**Exhibit 4. Overall Needs Assessment Tools**

| <b>Tool</b>                                      | <b>Website</b>  | <b>Source</b>  | <b>Mode</b>                 | <b>Length</b>                          | <b>Target Population</b> | <b>Cost</b> | <b>Administered By</b>                       | <b>Training Required</b> | <b>Efficacy</b>  |
|--|---|--|-----------------------------|--|--------------------------|-------------|--|--------------------------|--|
| Duke University Information & Assistance Toolkit | <a href="http://www.ncdhhs.gov/aging/ad/Duke_IA_Toolkit.pdf">http://www.ncdhhs.gov/aging/ad/Duke_IA_Toolkit.pdf</a>               | Duke University Medical Center For the North Carolina Department of Health & Human Resources Division of Aging | Online                      | Not specified                          | Client and caregiver     | Free        | Care coordinators, care managers, caregivers | No                       | Not available  |
| Alzheimer’s Navigator                            | <a href="https://www.alzheimersnavigator.org/">https://www.alzheimersnavigator.org/</a>   | Alzheimer’s Association  | Online                      | Initial assessment—5 minutes           | Client and caregiver     | Free        | Caregiver, person with dementia              | No                       | Not available  |
| Benjamin Rose Institute Care Consultation        | <a href="http://www.benrose.org/research/EBP_Care_Consultation.cfm">http://www.benrose.org/research/EBP_Care_Consultation.cfm</a> | Benjamin Rose Institute  | Phone, online. No in-person | Initial assessment—15 minutes          | Client and caregiver     | Cost        | Care Coordinator                             | Yes                      | Evidence-based improved care, less stress, fewer visits to the emergency department and hospital, and delayed nursing home placement (Bass et al., 2003) |
| TCARE  | <a href="http://www.tcarenavigator.com/">http://www.tcarenavigator.com/</a>   | University of Wisconsin–Milwaukee  | Online - software required  | Initial assessment (Step 1)—40 minutes | Caregivers               | Cost        | Care Manager                                 | Yes                      | Evidence-based reduction in caregiver identity discrepancy, stress burden, and depressive symptoms over time (Montgomery & Kwak, 2008).                  |

## SECTION 4

### STATE TOOLS FOR NEEDS ASSESSMENT AND REFERRAL

States are currently operating large-scale long-term services and supports systems through Medicaid, Older Americans Act programs, and state-funded programs. To manage these programs, they must assess the needs of consumers and arrange for referrals where appropriate. This section reviews tools for needs assessment and referral used by the four states currently receiving Systems Integration grants from the Administration on Aging through the ADSSP—Georgia, Minnesota, New York, and Ohio.

The four Systems Integration states use a range of tools to assess the needs of consumers and arrange for referrals where appropriate. The states vary in how well-developed their referral systems are and which instruments they are using. There is little overlap between states, although two states suggest using the Mini-Cog. The screening instruments recommended or currently used by the states do not appear to have been validated for administration by laypersons.

#### **4.1 Georgia**

##### ***4.1.1 Determination of Need–Revised***

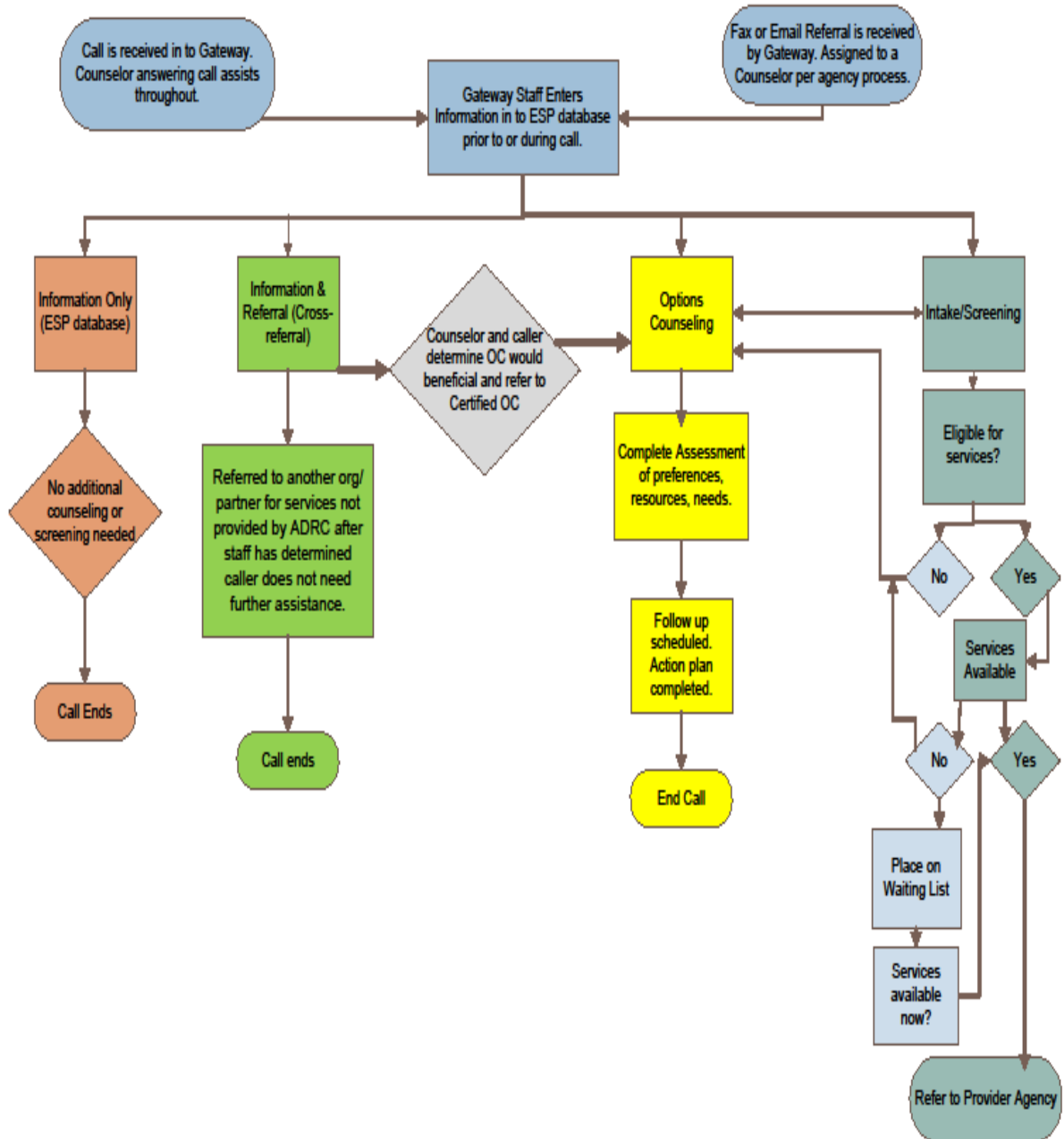
The *Determination of Need–Revised (DON-R)* was initially developed as a tool for determining eligibility for home and community-based services in Illinois. It was created by researchers at the Gerontology Center of the University of Illinois at Chicago and is in the public domain. It is currently used by Georgia to determine appropriateness for home and community-based services. The DON-R assesses functional impairments and unmet needs for care in the following domains: eating, bathing, grooming, dressing, transferring, continence, managing money, telephoning, preparing meals, laundry, housework, outside home, routine health, special health, and being alone. For each domain, level of impairment and unmet need are scored on a 0–3 scale, with places for comments from the assessor. The DON-R is usually administered by telephone.

##### ***4.1.2 Gateway to Aging and Disability Services***

The *Gateway to Aging and Disability Services* is the single entry point for aging services and the no wrong door for all other populations. Georgia’s Gateway is statewide and operates in each of the 12 ADRCs. The goals of ADRC are to provide older adults and people with disabilities (and professionals serving those populations) with information about and access to needed services; to assess individuals’ needs and eligibility for services; to target those most in need; and to establish the ADRC as the primary source of information and assistance for older

and disabled persons, their caregivers, and care providers. Their goal is to provide callers with a seamless “no wrong door” experience, with a single point of contact for each caller. *Exhibit 5* presents phone call flowchart for the entry to the ADRC through the Gateway system.

**Exhibit 5. Phone Call Flowchart, Georgia Gateway**



Note: “Options counseling” refers to counseling about long term services and supports (e.g., long-term care). “Intake/Screening” includes the DON-R and the TCARE assessment. Source: Georgia Division of Aging Services, 2011.

The referral process consists of using a person-centered approach to (Georgia Division of Aging Services, 2011):

- Assessing the needs of the inquirer;
- Identifying appropriate resources;
- Assessing appropriate methods of response;
- Providing enough information about each resource to help inquirers make an informed choice;
- Helping inquirers for whom services are not available identify alternative resources; and
- Actively participating in linking the inquirer to needed services when necessary.

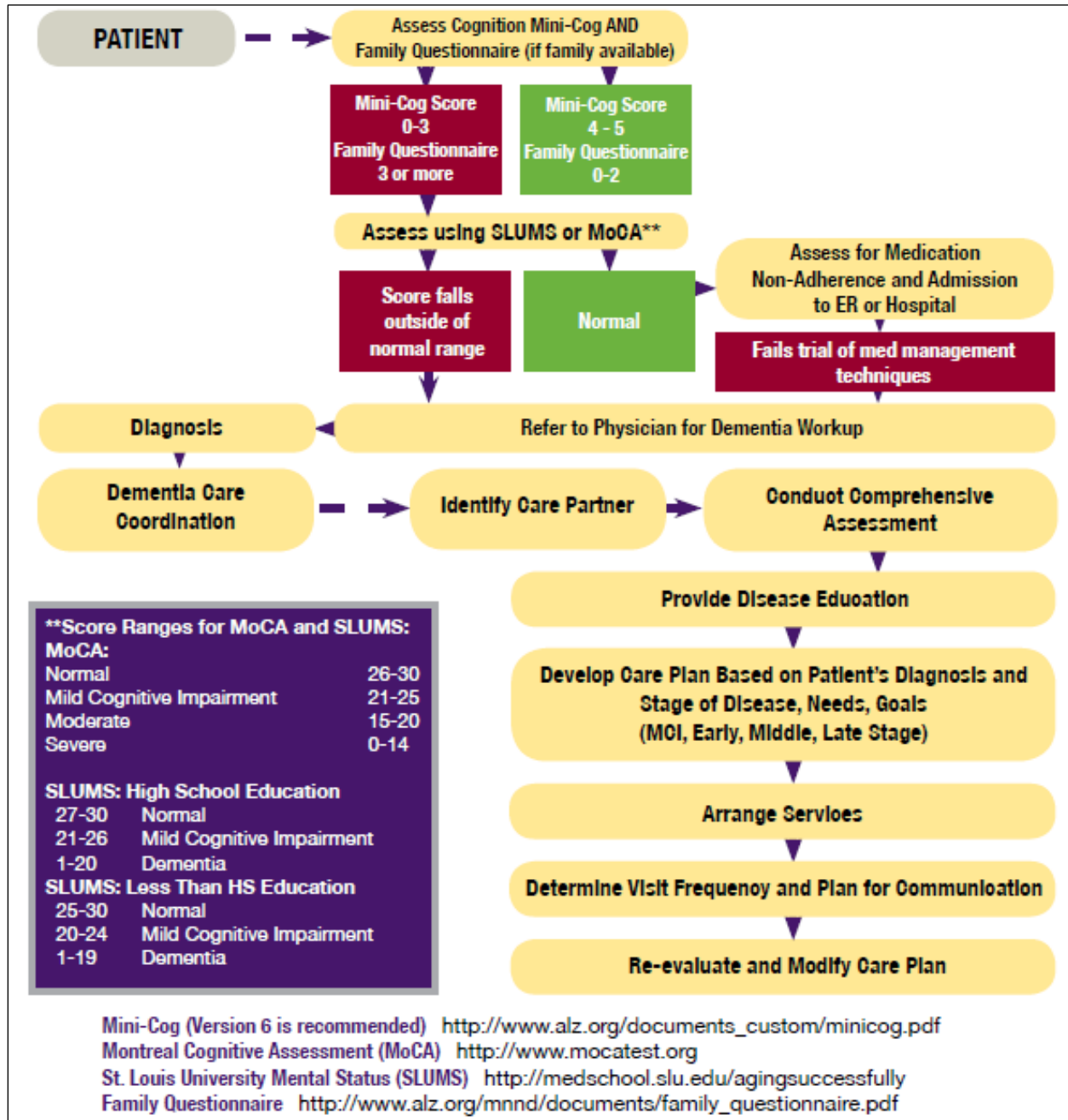
## **4.2 Minnesota**

### ***4.2.1 Identification and Care Coordination***

The Senior LinkAge Line<sup>®</sup> is the Minnesota Board on Aging's free statewide information and assistance service. The Senior LinkAge Line<sup>®</sup> service is provided by six AAAs that cover all 87 counties of Minnesota and helps connect individuals to local services. The Senior LinkAge Line<sup>®</sup> is Minnesota's One Stop for information and assistance. With a single call an older person or caregiver will get assistance to determine services that might be helpful. Senior LinkAge Line<sup>®</sup> helps connect to services in the community and also provides the actual assistance to help the caller get the information and personalized help they need to make good decisions. This may include providing face-to-face help in the individual's home and community.

Minnesota's ACT on Alzheimer's is a statewide collaborative group including more than 150 stakeholders (individuals, nonprofits, government agencies, and private sector organizations). Their goals are to (1) identify and invest in approaches to care for AD that reduce costs and improve care; (2) increase early detection; (3) support caregivers with information, resources, and support; (4) develop community resources for supporting residents affected by AD; and (5) raise awareness and reduce stigma. They have published several tools for providers, including the care coordination flow chart shown in ***Exhibit 6*** below (ACT on Alzheimer's of Minnesota, 2013). The state through its Integrated Systems grant has developed a Memorandum of Understanding (MOU), which encourages the adoption of the ACT on Alzheimer's tools by health care providers, which can be used as a collaborative agreement between providers and AAAs to provide optimum referrals to services to at-risk adults and their caregivers. The state promotes cognitive screening using the Family Questionnaire, the Mini-Cog, SLUMS, and MoCA, each of which is described in further detail below.

**Exhibit 6. Minnesota’s ACT on Alzheimer’s Identification and Care Coordination Flow Chart**



Source: ACT on Alzheimer’s of Minnesota, 2013.

#### 4.2.2 Family Questionnaire

The Family Questionnaire is a five-question tool developed by the Alzheimer’s Association and the National Chronic Care Consortium. It is designed to help identify persons over age 65 with memory problems who do not have a diagnosis of dementia and have come to a



clinic with a family member or friend. Scoring is simple: each of the five questions is answered on a 0–2 scale corresponding to “not at all,” “sometimes,” or “frequently.” Scores are summed, and a total of 3 or more is intended to prompt further evaluation. The five questions are as follows:

In your opinion, does \_\_\_\_\_ have problems with any of the following?

1. Repeating or asking the same thing over and over?
2. Remembering appointments, family occasions, holidays?
3. Writing checks, paying bills, balancing the checkbook?
4. Deciding what groceries or clothes to buy?
5. Taking medications according to instructions?

#### **4.2.3 Mini-Cog**

As mentioned in Section 1.2.2, the Mini-Cog incorporates both a clock-drawing test and a three-word recall test. Minnesota’s ACT for Alzheimer’s provides a number of different versions of the recall test that have been used in at least one clinical study; version 1 consists of the words *banana*, *sunrise*, and *chair*, whereas version 6 consists of *leader*, *season*, and *table* (ACT on Alzheimer's of Minnesota, 2013). The administrator is instructed to ask the client to repeat the three words immediately after hearing them, then the clock-drawing test is administered, and finally the administrator asks the client to recall the three words from step 1 again. Scoring is simply 1 point for each word spontaneously recalled without cueing; 2 points for a normal clock and 0 for an abnormal clock. Total scores of 4 or 5 rule out cognitive impairment, while scores below 4 indicate possible impairment.

#### **4.2.4 Montreal Cognitive Assessment**

The Montreal Cognitive Assessment (MoCA) is a screening instrument for mild cognitive impairment that assesses attention and concentration, executive function, memory, language, drawing skills, conceptual thinking, ability to make calculations, and orientation to time and place. The instrument takes approximately 10 minutes to administer and must be conducted face-to-face. The total possible score is 30 points, with 26 or above scored as normal. The 11 tasks include (1) drawing a line from numbers to letters printed on a page in a particular pattern; (2) copying a drawing of a cube; (3) a clock-drawing test; (4) naming animals shown in illustrations; (5) recalling five words; (6) four attention tests (repeating numbers in order, listening for/responding to hearing a particular letter in a sequence, counting backward from 100

by sevens); (7) repeating sentences; (8) saying words that begin with the letter B, then the letter F; (9) explaining what pairs of words have in common; (10) recalling the words in task 5; and (11) being orientated to time and place.

#### **4.2.5 Saint Louis University Mental Status Examination**

The Saint Louis University Mental Status (SLUMS) Examination was developed by Saint Louis University and Department of Veterans Affairs researchers as an alternative to the MMSE for detecting mild cognitive impairment. The SLUMS includes 11 items covering orientation, short-term memory, calculations, animal naming, clock drawing, and recognizing geometric figures. Scores range from 0 to 30, with scores of 27 and higher considered normal for persons with a high school diploma or better.

### **4.3 New York**

The NY Connects/ADRC screening process in New York is still under development. As part of the Systems Integration grant work, a Dementia Screening Work Group is being convened to recommend what basic dementia screening elements should be incorporated into the local NY Connects/ADRC intake process. The Dementia Screening Work Group will review available tools and instruments to develop the best approach for New York. As a starting point for the review, the Work Group will examine the potential of the *AD8 (Eight-item Interview to Differentiate Aging and Dementia)* (Galvin et al., 2005). This tool was shared by participating New York State Alzheimer's Association Chapters.

#### **4.3.1 AD8**

The AD8 is administered to either an informant (preferred by the developers) or a client. It can be given to the respondent on a clipboard for self-administration or can be read aloud to the respondent, either in person or over the telephone. The respondent is instructed to indicate whether a change has occurred in the person's ability for each of the items, specifically related to cognition. No time period is specified for the change when read aloud, although the printed materials specify "in the last several years." The items include the following:

- Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)
- Less interest in hobbies/activities
- Repeats the same things over and over (questions, stories, or statements)
- Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)

- Forgets correct month or year
- Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)
- Trouble remembering appointments
- Daily problems with thinking or memory

Scoring is simple: 1 point is given for each answer indicating a change. A score of 2 or more indicates cognitive impairment is likely. Administered to either the informant (preferable) or the client, the AD8 has a sensitivity >84%, specificity >80%, positive predictive value >85%, and negative predictive value >70%.

#### 4.4 Ohio

The Ohio Department of Aging, through the Dementia Capable Ohio initiative, requested and received from its Alzheimer's Association partners recommendations for assessment and screening to inform the eventual development of a universal assessment system for the state (Ohio Department of Aging, 2012). The report suggests that the following indicators should prompt further screening:

Any of the "Ten Signs" ([http://www.alz.org/national/documents/checklist\\_10signs.pdf](http://www.alz.org/national/documents/checklist_10signs.pdf)) from the Alzheimer's Association (Alzheimer's Association, 2003)

- Concerns expressed by the individual or his or her family
- Repetition or confabulation during a conversation
- Confusion and disorientation
- Difficulty focusing during a conversation
- Changes in personality, behavior, lucidity, or memory
- Environmental observations indicating cognitive changes

Cognitive impairment screening tools recommended by the report include the *Mini-Cog*, *Memory Impairment Screen (MIS)*, *General Practitioner Assessment of Cognition (GPAC)*, *St. Louis University Mental Status Exam*, *Montreal Cognitive Assessment*, and the *Mini-Mental State Exam*. All except the MIS and GPAC (summarized below) are described elsewhere in this report. The Alzheimer's Association report also recommended that individuals undergoing assessment be evaluated in terms of their functional ability, using an instrument such as Functional Assessment Staging of Alzheimer's Disease (FAST) or an informal discussion with the individual regarding their ability to dress, bathe, do chores, etc.

#### **4.4.1 *Memory Impairment Screen***

The *Memory Impairment Screen* was developed by researchers at the Albert Einstein College of Medicine, which owns the copyright, but makes the test available as a service to the research community (commercial use requires a license) (Kuslansky et al., 2002). The administrator of the instrument asks clients to complete the following tasks: (1) classifying each of the following four words into the correct categories: checkers (game), saucer (dish), telegram (message), and Red Cross (organization); (2) a distractor activity, such as counting to 20 forward and backward; (3) remembering the four words without prompts; and (4) remembering the four words after being given the category prompts. The instrument takes about 4 minutes to administer.

#### **4.4.2 *General Practitioner Assessment of Cognition***

The *General Practitioner Assessment of Cognition* was designed to screen for cognitive impairment in a primary care setting (Brodaty & Dementia Collaborative Research Centre, 2009). The instrument includes a 4-minute assessment of the client and a 2-minute interview with a caregiver (such as a spouse). The client assessment items include (1) remembering a name and address; (2) accurately stating today's date; (3) drawing a clock face and correctly showing the time as 10 minutes past 11 o'clock; and (4) telling the administrator something that has been in the news within the last week. The informant interview asks the caregiver to rate the client's functional abilities compared to 5 or 10 years ago on the following items: Does the client have more trouble remembering things that have happened recently than he or she used to? Does he or she have more trouble recalling conversations a few days later? When speaking, does the client have more difficulty in finding the right word or tend to use the wrong words more often? Is the client less able to manage money and financial affairs (e.g., paying bills, budgeting)? Is the client less able to manage his or her medication independently? Does the client need more assistance with transport (either private or public)?

The instrument is available at no charge in either paper-and-pencil or online versions (with computer-based scoring). For the client assessment, each correct answer scores one point, with a total score between 0 and 9. A score of 9 indicates no significant cognitive impairment; scores between 5 and 8 require the informant assessment; and a score of 0 to 4 indicates cognitive impairment. For the informant assessment, each "yes" answer scores one point, and scores between 0 and 3 indicate cognitive impairment.

## SECTION 5 CONCLUSIONS

General screening of the elderly population for AD is controversial because of the substantial possibility of false negatives and false positives (Boustani, , 2003). Although the Affordable Care Act requires that physicians include “detection of any cognitive impairment” as part of the Medicare Annual Wellness Visit, the Centers for Medicare & Medicaid Services (CMS) does not recommend any specific screening and diagnosis instruments (42 CFR 410.15).

State long-term services and supports systems do not have the luxury to wait for the “perfect” screening and assessment instrument. For example, more than 3 million people with disabilities receive Medicaid home and community-based services annually and many more received Administration for Community-Living services and seek information and referral for long-term services and supports (Ng et al., 2012). States must be able to provide relevant information to people who inquire, refer them to the appropriate programs and providers, assess them for functional eligibility for public programs, and develop budgets and care plans for people who qualify.

This paper attempts to aid states in these tasks by identifying instruments to screen, refer and develop care plans for AD for people contacting AAAs and ADRCs. These tasks are typically performed by front-line workers who are not trained medical personnel, such as physicians, nurses, or master’s in social work. Thus, in deciding which instruments to use, states need to consider the following issues:

*Is there evidence that the instrument can be successfully used by nonmedical personnel?* Many commonly used instruments were actually developed and tested for use by trained medical personnel. There is good evidence that many instruments have different levels of accuracy depending on the qualifications of the administrator. The ideal instrument for use by ADRCs needs to be accurate even if administered by a nonclinician.

- *Is the instrument copyrighted or licensed in some way that requires payment for its use?* Not all instruments are in the public domain. Some instruments require payment of a fee for their use. In some cases, the fee is not large, but it is an additional expense.
- *How long does it take to administer the instrument?* Many contacts to AAAs and ADRCs are by telephone or online. Instruments that are too long are both time consuming to administer and may cause the caller or web-user to lose interest. On the

other hand, longer instruments may be more accurate because they gather more information. The screening instruments reviewed varied from 3 to 155 items.

- *Can the instrument be administered either by telephone or in person?* The ideal instrument for use by ADRCs can be administered either over the telephone or face to face.
- *Is there evidence that the instrument has acceptable validity, reliability, and other psychometric properties?* There is a substantial research literature on the psychometric properties of instruments to screen for AD and cognitive impairment, more generally. Instruments typically involve a tradeoff between false positives and false negatives.
- Once an individual with possible AD has been identified, are there standard protocols for referral, care planning, and follow up? Identifying individuals with possible AD is only the beginning of the care process. Information about the possible cognitive impairment needs to be transmitted to staff conducting eligibility determinations and care planning. Dementia-capable providers need to be identified and relationships established. While fewer in number than screening protocols, instruments are available to help with referral and service planning of people with cognitive impairments.

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## APPENDIX A. METHODS

We used a wide range of search terms in combinations using the National Library of Medicine's Medical Subject Heading (MeSH) terms and free text. For cognitive impairment, we used "Alzheimer," "cognitive impairment," or "dementia" in conjunction with the subheading term "diagnosis" or the free-text term "screen\*" (the asterisk is a wild-card character that searches for any words that start with screen, such screens, screening, screener, etc.). To identify studies mentioning laypersons, we used "layperson" or "lay person" or "lay-person" or "layman" or "lay interviewer" or "nonclinic\*" or "nonphysician" or "non-physician." Additional searches were performed for "mini mental state exam" or MMSE and for "Short Portable Mental Status" or SPMSQ in conjunction with the terms for laypersons. Articles that met all criteria were then abstracted using a form developed for this review.

The aspects of validity that measure whether a test is able to accurately rule out a diagnosis are *specificity* (how likely is the test to detect the *lack* of a characteristic in someone who does not have the characteristic?) and *negative predictive value* (the proportion of persons with a negative result who *do not* have the characteristic). The accuracy of a test in establishing a diagnosis is measured with *sensitivity* (how likely is the test to detect a characteristic in someone who has the characteristic?) and *positive predictive value* (the proportion of persons with a positive result who do have the characteristic). Specificity and sensitivity are typically inversely related: as one goes up, the other goes down, and vice versa.

**Exhibit 7** contains an example of how sensitivity, specificity, positive predictive value, and negative predictive value are calculated. Assume that 167 persons are tested. As shown in the top part of the table, 70 persons who had the condition tested positive (true positives), and 65 tested negative according to the test (false negatives), while 18 persons without the condition tested positive (false positives) and 14 tested negative (true negatives). Given these results, the bottom rows show how to calculate sensitivity, specificity, positive predictive value, and negative predictive value.

**Exhibit 7. Example of Calculating Sensitivity, Specificity, Positive Predictive Value, and Negative Predictive Value for a Screening Instrument for Alzheimer’s disease**

**Actual Status**

|                                 | <b>Positive (+)</b>     | <b>(Negative) -</b>     | <b>Total</b> |
|---------------------------------|-------------------------|-------------------------|--------------|
| <b>Test Result Positive (+)</b> | True positive (TP): 70  | False positive (FP): 18 | 88           |
| <b>Test Result Negative (-)</b> | False negative (FN): 65 | True negative (TN): 14  | 79           |
| <b>Total</b>                    | 135                     | 32                      | 167          |

Sensitivity: TP divided by (TP+FN) = 70/135 = 0.52  
 Specificity: TN divided by (FP+TN) = 14/32 = 0.44  
 Positive predictive value (PPV): TP divided by (TP+FP) = 70/88 = 0.80  
 Negative predictive value (NPV): TN divided by (TN+FN) = 14/79 = 0.18

**APPENDIX B.**  
**ADDITIONAL SCREENING INSTRUMENTS**

The two instruments described in this appendix are commonly used by clinicians, and although there is no published literature evaluating their psychometric properties when administered by laypersons, the instruments may be of interest.

**Mini-Mental State Examination**

| Category                                  | Description   |
|---|---|
| <b>Citation</b>                           | Mitchell AJ. A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. <i>J Psychiatr Res</i> 2009; 43: 411-431  |
| <b>Brief Overview of Scale/Instrument</b> | The Mini-Mental State Examination (MMSE) is the most widely used instrument for screening for cognitive impairment. The instrument includes 19 questions testing 11 domains, including orientation, registration, attention/calculation, recall, naming, repetition, comprehension (verbal and written), writing, and construction  |
| <b>Developed By</b>                       | Originally developed by Folstein et al., 1975. A new version was developed by Psychological Assessment Resources, or PAR (MMSE-2). A telephone version was developed by Roccaforte et al., 1992 (ALFI-MMSE).  |
| <b>Target Population</b>                  | Adults  |
| <b>Intended Users</b>                     | No studies were identified validating the use of lay interviewers to administer the MMSE, although it is often done in practice. According to the current copyright holder, the test requires a minimum of a 4-year degree in psychology, counseling, or a closely related field PLUS satisfactory completion of coursework in test interpretation, psychometrics and measurement theory, educational statistics, or a closely related area; OR license or certification from an agency that requires appropriate training and experience in the ethical and competent use of psychological tests.  |
| <b>Scoring</b>                            | Originally, a cutoff of 23 vs. 24 was recommended for persons with at least 8 years of education, but numerous other cutoffs have been calculated based on different samples.   |
| <b>Materials Available</b>                | Originally free, now copyrighted and permission/fee required for use (minimental.com).  |
| <b>Strengths</b>                          | A meta-analysis of the MMSE's psychometric properties found that the negative predictive value (the proportion of persons with a negative result who do not have cognitive impairment) as measured by the MMSE ranged from 74.8% to 97.7% depending on whether the instrument was administered by a neurologist or other specialist vs. a clinician without special training (Mitchell, 2009). Some studies of the MMSE find that its scores are not correlated with specific functional limitations or the service needs of people with dementia. In particular, people with extensive deficits in executive function can have normal MMSE scores.<br><br>Identifying dementia: In a meta-analysis of 13 studies in a specialist setting, sensitivity = 76.1%, specificity = 88.6%, positive predictive value = 89.3%, negative predictive value = 74.8%. In a meta-analysis of 21 studies in nonspecialist settings, sensitivity = 82.1%, specificity = 86.1%, positive predictive value = 40.5%, negative predictive value = 97.7%.<br><br>Identifying mild cognitive impairment: In a meta-analysis of 5 studies, sensitivity = 62.7%, specificity = 63.3%, positive predictive value = 37.0%, negative predictive value = 83.2%. |
| <b>Weaknesses</b>                         | Requires extended professional time to administer. Variable clinical utility (rule-in/rule-out value) in different settings. Not designed for lay administration.   |

## Short Portable Mental Status Questionnaire

| Category                                  | Description  |
|---|--|
| <b>Citation</b>                           | Lewis BE, Mills CS, Mohs RC, Hill J, Fillit H. Improving Early Recognition of Alzheimer's Disease: A Review of Telephonic Screening Tools. <i>J Clin Outcomes Manage</i> 8(8), 41-45. 2001.  |
| <b>Brief Overview of Scale/Instrument</b> | <p>The SPMSQ is designed to measure the existence and level of cognitive impairment. There are 10 items measuring several different cognitive domains, including orientation (three questions), recall (four questions), semantic knowledge (two questions), and computation (one question). The original questions are as follows (different wordings are available):</p> <ol style="list-style-type: none"> <li>1. What are the date, month, and year?</li> <li>2. What is the day of the week?</li> <li>3. What is the name of this place?</li> <li>4. What is your phone number?</li> <li>5. How old are you?</li> <li>6. When were you born?</li> <li>7. Who is the current president?</li> <li>8. Who was the president before him?</li> <li>9. What was your mother's maiden name?</li> <li>10. Can you count backward from 20 by 3's?</li> </ol> |
| <b>Developed By</b>                       | Pfeiffer et al., 1975 (original face-to-face interview)<br>Roccaforte et al., 1994 (telephone version)   |
| <b>Target Population</b>                  | Older adults   |
| <b>Intended Users</b>                     | Nurses/clinicians  |
| <b>Scoring</b>                            | <p>0-2 errors: normal mental functioning<br/>           3-4 errors: mild cognitive impairment<br/>           5-7 errors: moderate cognitive impairment<br/>           8 or more errors: severe cognitive impairment</p> <p>One more error is allowed in the scoring if a client has had a grade school education or less.<br/>           One less error is allowed if the client has had education beyond the high school level.</p>   |
| <b>Materials Available</b>                | Widely available.  |
| <b>Strengths</b>                          | Sensitivity = 0.74, specificity = 0.79. Relatively simple scoring with adjustments for education.  |
| <b>Weaknesses</b>                         | Different versions available with different phrasings (such as "What is today's date, including month, day, and year" for item 1) with little information on whether these have been validated in different populations. To our knowledge, no studies have assessed whether the instrument is valid when administered by nonclinicians.  |

## APPENDIX C.

### COGNITIVE SCREENING TOOLS PERMISSIONS PAGES

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