BOLD
PUBLIC HEALTH CENTER OF EXCELLENCE
EARLY DETECTION OF DEMENTIA

Early Detection of Dementia Toolkit - Health Systems

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TOOLKIT OVERVIEW

BOLD Early Detection Toolkits are intended to guide you in customizing dementia detection efforts to your needs and setting. Toolkits contain measures, strategies, and useful links to resources to help you work toward becoming more 'dementia-capable.' This toolkit supports a comprehensive approach to dementia detection and includes resources that encompass a broad view of the capacities needed to make your efforts most effective. Every section in this toolkit can stand alone as a separate resource.

WHAT IS DEMENTIA?

'Dementia' refers to a group of medical disorders caused by impairment of brain function for which the defining symptoms are cognitive – problems with memory, thinking, planning, judgment, language, awareness of one's own functioning, and other mental activities. Sometimes the first noticeable signs are changes in social or behavioral functioning. Dementia results from damage to the brain, most often by disease processes like Alzheimer's disease and related disorders, exposure to certain toxins, or, as recently highlighted by studies of athletes playing contact sports and survivors of war, by major or repeated brain injury. Clinically important cognitive decline can remain invisible to all but one's closest family and friends even as it undermines everyday functioning. It's the most potent cause of disability in later life, yet is often a silent partner in health care and community settings until it's been progressing for several years.

People living with dementia are usually aware of some changes in their memory or other mental abilities, but they may underestimate their extent and how much they affect their ability to get things done. They may never mention the problem to their primary care provider, and signs of dementia may not be obvious in regular medical appointments. "Subjective cognitive decline" (SCD) is not the same as dementia. SCD refers to a person's own experience of changes in memory or thinking. It can be caused by many different conditions and is much more common than dementia itself. However, when a person senses a change in their mental function – more forgetfulness, trouble paying attention, distractibility, or other symptoms – it's important to tell a professional about this and follow through with recommended evaluations. Some people with SCD will do well on cognitive tests, but some may go on to develop dementia in future years.

PREVALENCE

It's estimated that about 6 million Americans today have some form of dementia. Over 90% of people living with dementia are older adults (and prevalence increases dramatically with age), but younger people can also be affected. Because age is such a powerful risk factor, as our population ages over the next decades there will be many more affected individuals. Their unmet needs are already showing us how we need to change the way we care for people.

OVER 90%
of people living with dementia are older adults

OTHER RESOURCES

- Subjective Cognitive Decline – A Public Health Issue
- ADRD Full Report 2020 and Infographic – Alzheimer's Association
    1. Spanish version

EARLY DETECTION OVERVIEW

What is early detection?

Caring for people living with dementia starts with detecting the problem. Early detection of dementia means identifying affected individuals before a crisis occurs, whether or not they are aware or tell us they are having problems. Because many people living with dementia never spontaneously report symptoms – e.g. changes in their memory, thinking, or ability to get things done – successful early detection strategies use several different and complementary approaches. These approaches usually start with a conversation with the person (asking about memory and other symptoms), and with someone who knows the person well (a family member or friend), and some form of measurement. Measures can be screening tools that use mental tasks to identify cognitive impairment (performance-based screens) or changes in everyday functioning that are observed by close contacts (proxy or informant screens). Both have value and reinforce each other; they are often used in combination. Other tests may be recommended to look for possible causes once a problem is detected.

Other resources

- Advancing Early Detection - CDC
    1. Advancing Early Detection: A Health Brain Initiative Issue Map
    2. HBI Road map
- Earlier Diagnosis - Alzheimer's Association
    1. Biomarkers for earlier detection
    2. Brain imaging/neuroimaging
    3. Cerebrospinal fluid (CSF) proteins
    4. Blood and urine tests
    5. Genetic risk profiling
    6. Mild Cognitive Impairment (MCI)

Why is detection important?

Dementia ultimately effects many aspects of a person's life and the lives of loved ones. By the time it is diagnosed, affected people already need the help of someone else to manage at least some essentials of everyday living. Many professionals believe that it's important to detect cognitive impairment at milder stages, before a person must rely on others to be one's 'prosthetic memory,' in order to start preparing for future changes while one's ability to think ahead and express one's personal values and goals are still strong.

Other resources

• Benefits of early diagnosis - Alzheimer's Association
  1. Spanish version
• Why get checked? - Alzheimer's Association
  1. Medical benefits
  2. Emotional and social benefits
  3. More time to plan for the future
  4. Cost savings

Should routine dementia screening be conducted?

There is controversy about whether to screen people for dementia who are not complaining of problems. There are various reasons for the controversy: screening everyone over a certain age could turn up too many 'false positives' - people who don't do well on a particular screening test but are actually cognitively healthy. Another reason is that researchers have not studied whether people with dementia detected by screening do better in the long run than people whose dementia is detected 'spontaneously', usually after a delay of two (sometimes many more) years.

Many health care clinicians and systems have chosen a 'middle way' - to recommend use of a screening tool with people who bring up a concern about memory with their clinicians. Some others recommend that clinicians routinely ask about memory without waiting for individuals to mention it on their own. What's important is that health care providers think about the issue, become familiar with the evidence, and develop a clear and workable practice to use with their patients.

More about the controversy: Screening is at one end of a continuum, with "case finding" at the other. Case finding seeks to identify people who are having symptoms or signs that may be related to cognitive impairment. These include cognitive symptoms as described above, but they also include other conditions for which cognitive impairment increases risk. Here's an example: a 78-year-old man comes into clinic for an evaluation because of three falls in the past six months, never having fallen before. After a conversation about the how he fell and how falling has affected him, the clinician thinks about possible causes for falls in older people. Knowing that recurrent falls may be related to underlying dementia, the clinician conducts a cognitive screening test in addition to examining the patient for injury and mobility limitations.

Detecting dementia in this patient is important because ways to prevent falls in people with dementia often differ from approaches that work for people who are cognitively intact. This knowledge helps the clinician tailor a plan to improve this patient's safety.

There is fine line between case finding and screening. We might decide to screen all patients who are 75 years and older because their risk of having cognitive impairment or dementia is much higher than that of younger people. Similarly, we might decide to "screen" all patients who report a history of falls, or who have other condition associated with higher risk of cognitive impairment, such as diabetes or heart failure.

Think about it: Clinicians actually "screen" patients for many different conditions at every face-to-face encounter. They do this when they ask questions about a patient's or family member's concerns, about symptoms, and what people do day to day. Screening is also happening when a medical assistant takes a blood pressure measurement or asks questions about pain, or when a clinician orders a blood sugar test. Screening for cognitive impairment can also be an impersonal activity––completing a cognitive test at a health fair or doing an online test.

We believe that the best strategy for detecting cognitive impairment includes a conversation between a patient, healthcare provider, and family member when possible. This approach creates an opportunity to talk about brain health, any concerns that might be neglected in a routine visit for some other problem, and offer helpful support. It allows for normalizing discussion of brain health as an important part of overall health.

Red flags/indicators for screening (e.g., missed appointments)
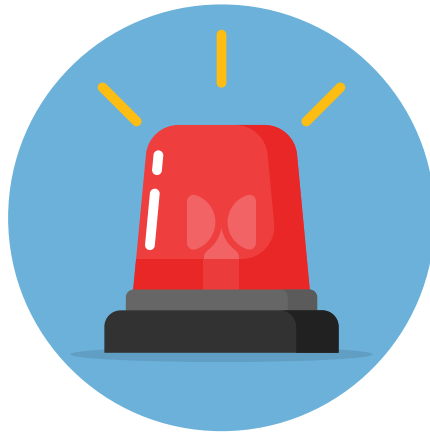
Many observable features may foreshadow the need to look for cognitive impairment. People living with dementia often forget what they're supposed to do in the future (prospective memory loss) – this can lead to missed medical or other appointments unless someone else acts as a 'supplemental memory'. It also undermines a person's ability to follow a plan of care at home, such as starting or stopping a medication, recording symptoms, keeping up with fluid intake or a proper diet, or monitoring weight, blood pressure, or blood sugar. If you've known the person for a long time, you'll likely notice a change in pattern – but if you don't know him/her well, you might overlook these lapses or miss their significance. At the health system level, administrative data extracted from electronic medical records can reveal patterns like this among people with dementia – as well as among individuals without a diagnosis who screen positive for cognitive impairment.

Ecological Model of Dementia Detection Stakeholders
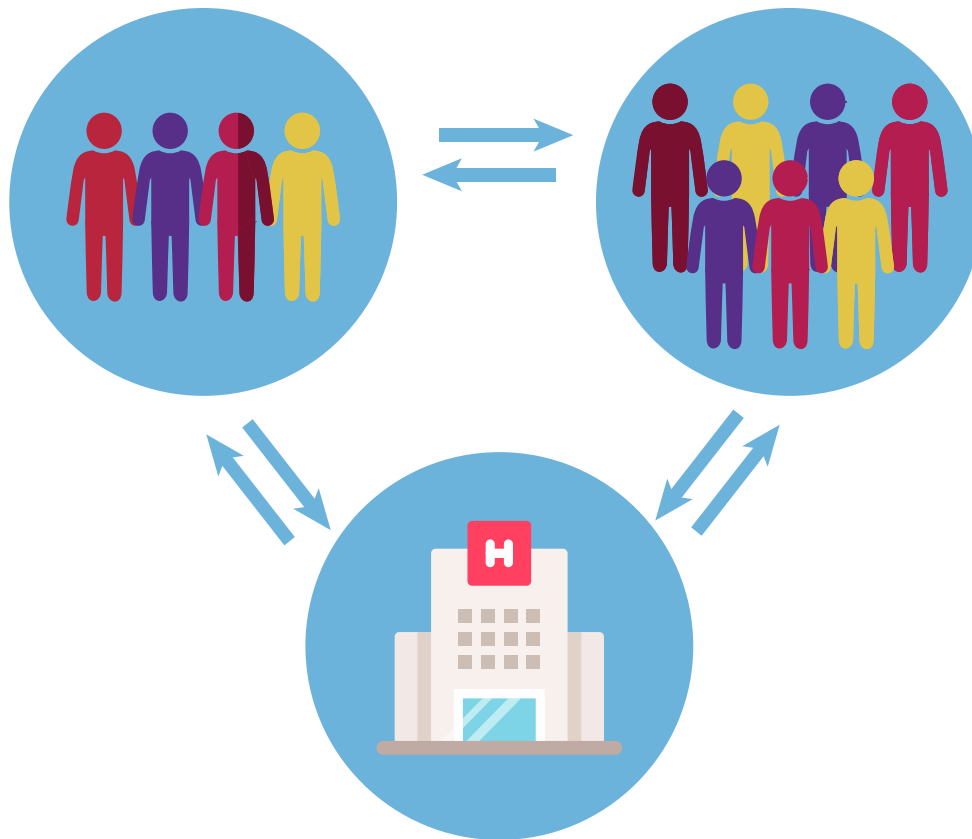
Where is dementia detected?

Dementia can be detected wherever affected people are – at home in the kitchen, in the supermarket, at the bank, on the bus, at the park, at the food bank, in the senior center, during a blood draw for lab tests – but a clinician is needed to make a medical diagnosis of dementia and identify what conditions and factors, reversible or permanent, are causing it.

This section covers the roles that health systems, communities, individuals, family, and friends can play in dementia detection.

STAKEHOLDER GROUP	ROLE
Individuals, families, and friends	We do want individuals experiencing cognitive changes (symptoms) and their family or friends who observe the effects of cognitive changes (signs) to pay attention, and bring those concerns and observations to a professional equipped to evaluate the situation. Don't ignore them.
Health systems	Health care professionals – usually a physician, nurse practitioner, or physician assistant – are charged with diagnosing dementia in their own patients, but this process is improved when an individual or family member brings it up. Doctors tend to act on detecting dementia when that happens! Some providers have adopted routine screening approaches, using, for example, the Medicare Annual Wellness Visit as a vehicle. The AWV requires detection of cognitive impairment as an essential component, but putting that into practice requires a clinician or health care system to determine exactly how to do it. The simplest method is first to ask about symptoms (see "Prescreening Conversation" document, and link to KAER toolkit), and then to use a screening tool (performance and/or proxy based). There is not yet consensus about whether to use screening tools with people who do not volunteer that they are having a problem, although it is known that doing so can increase recognition of dementia.
Communities	Today, we do not expect strangers who observe possible signs of dementia to report them to anyone, and it would usually be considered an invasion of privacy to do so unless there's obvious danger. But there are exceptions. Workers in community-based aging and service organizations are often in an excellent position to observe signs of dementia, and some organizations, including many Area Agencies on Aging (they exist in most communities) have developed training programs for staff on how to recognize when dementia could be present. What's missing in most settings is a standardized way to make that information actionable – for example, to help organize a focused visit to a health care provider.

Other resources

- What is dementia? – CDC
    1. Spanish version
- What is Alzheimer's disease? – CDC
    1. Spanish version
- The Truth about Aging and Dementia
    1. Spanish version
- 10 Warning Signs of Alzheimer's
    1. Spanish version
- Minorities and Women Are at Greater Risk for Alzheimer's disease
    1. Spanish version
- What is dementia? – Alzheimer's Association
- What is Alzheimer's disease? – Alzheimer's Association
- Alzheimer's and Dementia – Alzheimer's Association
    1. Know the 10 Signs
    2. Brain Tour
    3. Understanding Alzheimer's and Dementia
- Approaching Memory Loss Concerns – Alzheimer's Association
    1. Guide for those who have noticed changes in themselves in English and Spanish
    2. Guide for those who have noticed changes in others in English and Spanish
- 10 Early Signs and Symptoms of Alzheimer's – Alzheimer's Association
- How is Alzheimer's Disease Diagnosed? – Alzheimer's Association
    1. Medical tests
    2. How to discuss memory concerns with healthcare providers
    3. Post-diagnosis support

- Spanish version of Alzheimer's Association website (includes all of the resources listed above)
- Alzheimer's Disease Fact sheet - NIA
    1. How Alzheimer's Changes the brain video
    2. Spanish version
- What is Alzheimer's disease? - NIA
    1. Spanish version
- What is dementia? Symptoms, types, and diagnosis – NIA
- Frequently asked questions about Alzheimer's disease – NIA
- Preventing Alzheimer's Disease: What do we know? – NIA
    1. Preventing Cognitive Decline video
- What do we know about diet and prevention of Alzheimer's disease? – NIA
- Causes of Alzheimer's disease – NIA
    1. What happens to the brain in Alzheimer's disease? – NIA
    2. What causes Alzheimer's disease? – NIA
        a. Spanish version
    3. Assessing risk of Alzheimer's disease - NIA
        a. Assessing risk of Alzheimer's disease Infographic
        b. Spanish version
    4. Alzheimer's disease genetics fact sheet - NIA
    5. Alzheimer's disease in people with Down syndrome – NIA
        a. Alzheimer's Disease in people with Down syndrome Fact sheet
        b. Aging and Down syndrome: a health and well-being guidebook
            i. Spanish version

       c. Alzheimer's disease and Down syndrome: a practice guide for caregivers

          i. Spanish version

       d. Alzheimer's disease and Down syndrome overview

       e. Down syndrome and Alzheimer's disease

- What are the signs of Alzheimer's disease? – NIA

    1. Memory problems infographic

    2. Spanish version

- Do memory problems always mean Alzheimer's disease? – NIA

    1. Spanish version

- What is mild cognitive impairment? - NIA
- Noticing memory problems? What to do next? - NIA
- Frontotemporal disorders - NIA

    1. What are the symptoms of frontotemporal disorders?

- How are frontotemporal disorders diagnosed? - NIA
- What causes frontotemporal disorders? - NIA
- What are the different types of frontotemporal disorders? - NIA
- What are frontotemporal disorders? - NIA
- What is Lewy body dementia?
- Diagnosing Lewy body dementia
- Other dementias

Normalizing discussions about screening : Key considerations

- Brain health is important to everyone
    1. People want to talk about their thinking and memory
- Screening informs us about the possibility that a dementia condition could be present
    1. Positive screening tests do not always mean dementia, and they do not identify a cause or disease
- Know and say why you're screening––your reasons for screening
    1. Opportunities for health promotion, safety, and future planning as we age
- Keep it simple – plan what to say
    1. Conversation aids help: simple statements build confidence and make talking about it easier
        a. First ask about the person's own perception of their memory and thinking
        b. What to say if screen is "positive" (suggests impairment) vs "negative" (suggests no impairment)
    2. Have a plan for next steps – for positive and negative screen results; explain how you will follow up in each case
- Focus on the person
    1. Avoid "catastrophe thinking"
    2. Identify and acknowledge individual strengths
    3. Help build a foundation for living well
- Center on relationships that will last the journey
    1. The person and their loved ones
    2. Your role

You are traveling this journey together— relationships were never more important.

Think about the 'why'

Choose a goal screening – this is a partial list.
Think about others!

- Offer an annual screening test for all older patients to motvate health promotion
- Include three questions about thinking and memory for all older patients at annual visits
- Offer cognitive screening when there has been an accident (e.g. a fall or motor vehicle accident) or a new decline in function
- Offer cognitive screening if you see unexplained weight loss or poor control of chronic conditions
- Offer cognitive screening whenever you're concerned about someone's memory
- Offer cognitive screening whenever someone else mentions any concern about memory

Screen people meeting selected criteria

- those who complain of symptoms or whose family reports a problem
- everyone over a specific age

Establish a starting point for future tracking

- people who want 'a baseline' assessment of their cognition even if they are not noticing any problems now
- people with a history of Alzheimer's disease in the family
- people interested in how to maintain optimal health as they age

Think about the 'how'

Talk about brain health

Many older people are relieved to learn that their doctor wants to talk with them about their thinking and memory and its importance in their lives. Very few older adults refuse – most welcome a conversation and would want their doctors to know if they were having a problem. (In clinical studies, less than 5% refuse a simple cognitive measure such as a MiniCog!).

PRE-SCREENING

Navigating pre-screening conversations

Preparing for cognitive screening is as important as screening itself: the process starts with creating time and space, having a positive frame of mind, and knowing what to say. Having short, simple statements to use when you need them eases everybody's worry.

Conversations about thinking and memory can be deeply personal. Being aware of their possible sensitivity is important to a successful experience and new understanding. Otherwise, the conversation may be received as abrupt or intrusive. One person may be in search of answers or looking for help, but another may be unaware or want to avoid the issue. To ease difficulties related to conversations about cognition, try using the following steps:

Build trust: Rapport is the foundation. Knowing the person enhances relationship and conveys concern for them and creates a feeling of safety. This makes bringing up potentially difficult issues much easier.

Use positive framing: The second step is to normalize cognitive assessment as part of routine health care. Reframe conversations around cognition to characterize the results of an assessment in the most positive way. "I want you to stay as healthy as you can – and I'll work with you to do that."

Be ready with short, simple statements: The third step is to prepare short, simple statements to explain the importance of the screening, the screening process, how long it will take, and what the results mean.

Building trust

Building trust is easier when you have prior interactions and know the person. But that is not always possible. There will be times when the relationship is brand new––the first medical visit, the first lunch at the community center or encounter with a particular staff member. Trust must be built in the moment to have a successful conversation and for a successful assessment of cognitive function. Though formal cognitive assessment and screening are not usually part of community service programs, these settings offer many chances to notice interactions with others and changes in conversation and behavior that could suggest cognitive difficulties. In clinical care, there is no question that making regular cognitive assessment 'normal' along with other assessments – e.g., vision, hearing, blood pressure, gait and balance, sleep, nutrition, routine labs – would smooth the process. Then there's less need to focus on establishing the rationale, but the elements of a successful conversation remain the same. Trust comes from rapport with and concern for the person as an individual. Trust strengthens relationship and a sense of safety. A personal approach – valuing the person as a partner who is 'seen' as an individual – strengthens the foundation for a relationship of care over time. Simple things help, like sitting down at eye level, making good eye contact, "checking in" with questions like "is this room/seat comfortable for you?" "Am I speaking clearly enough?" "What questions do you have about this?"

Feelings matter: Use positive framing and pay attention to your body language.

What one says leading up to an assessment makes it much easier to explain the results in the most positive way. Although by no means equivalent, blood pressure screening––something we are quite familiar with––provides a useful analogy.
In one instance, the examiner might say, "Let's check your blood pressure because if you have hypertension, we will want to make sure you get it treated. Elevated blood pressure can lead to strokes." While this statement is true, it creates unnecessary fear. Rather, by saying, "Can we check your blood pressure? This will tell us where you are right now and help us see if blood pressure is something we should work on as part of staying healthy," the issue is reframed and normalized. Also note: "we," not "you," conveys partnership ––"We are doing this together."
Asking whether a person has worries or concerns about memory of thinking, or about changes in their ability to do everyday tasks. It is a great place to start a conversation about cognition. It makes the topic relevant – even if the person has no concerns, the topic is then relevant to everyday life. This gives our discussion some context and an opportunity for a shared agenda. Linking brain health/ brain assessment to the daily things that people do makes the conversation about what matters to them, not about personal worth or disability.

Words matter: Prepare short, simple statements.

With any performance-based cognitive screening or assessment tool, additional conversational set up helps this go more smoothly and leads to a better experience for the recipient. The person being screened may feel vulnerable: screening might be interpreted as a "test" of intelligence or ability, or personal agency. It may incite fears about potential loss of freedom and "who's in charge." Recipients who are less trusting may make statements like, "You are not trying to take away my driver's license, are you?" Moreover, cognitive screening can feel insulting because of the relative simplicity or obviousness of some questions (even if those same questions will be difficult for some).

One needs to cover some basic elements with the person being screened:
1) rationale – why you think this is important to do;
2) what you will do – ask questions, do some thinking tasks;
3) how much time it will take;
4) what the results mean – responding to "how did I do?"

Examples of pre-screening statements:

- Doing all that we can to keep our brains healthy is important for all of us.
- Sometimes we are concerned about our own ability to remember things. Sometimes other people seem more concerned than we are about ourselves.
- Sometimes people are concerned about their memory. Do you have any concerns about this?
- Just like it is important that you know what your blood pressure is, knowing about your memory and thinking ability is important as well.
- I want to be sure that I do all that I can to help you stay healthy.
- Have there ever been times when you thought your memory or thinking was not working as well as usual? If yes, can you tell me more about that?
- Do you know anyone who has trouble with their memory or thinking? Can you say more about that?
- Many of us are concerned about our memory or thinking in general. It's good to have a sense of how we are doing.

When preparing a general opening statement, be sure to include the following elements:

1. Getting permission
2. Explaining the rationale
3. Normalizing (counteracting stigma)
4. More rationale and some anticipation
5. Conveying respect, engendering trust and sense of caring
6. Attending to possible sensory changes (hearing or vision loss)
7. Anticipating what will follow - what will be done, how long it will take
8. More anticipatory - setting expectations to avoid embarrassment if the respondent is unable to answer correctly

Below is an example of a general statement. Feel free to adapt it, making sure to include all eight elements listed above.

"I would like to talk with you about your thinking and memory. Would that be OK with you?[1] I want to start with a few questions to help me get a sense of how you are doing.[2] This is something that I like to do with all my patients.[3] It gives us a place to start, to know whether we should talk beyond just this conversation.[4] Is where we are sitting comfortable enough for you?[5] Am I speaking clearly enough for you to hear me without having to make an effort?[6] OK! This should take us less than 5-10 minutes.[7] Some of the things I will ask you may be very easy or obvious to you and some things may be more difficult.[8] Shall we start?"

Note: "Am I speaking clearly enough for you to hear me without having to make an effort?" and how that is very different from saying, "are you able to hear me OK?" The former places the responsibility (and potential criticism) on the examiner and the latter places it the recipient. We also need to be sure that clarity in communication does not require increased effort because having to work hard to hear makes it difficult to demonstrate one's true ability.

COGNITIVE SCREENING OVERVIEW:

We hear the terms "detection", "screening", and "diagnosis". Are they interchangeable?

Detection can happen anywhere, particularly in community settings like the bank, coffee shop, or pharmacy. For instance, a pharmacist may notice behavioral changes in a person while they are picking up medication. Screening is the logical next step after detection. If the pharmacist has strong rapport with a person who is experiencing cognitive or behavioral changes, they can mention what they see to that person or someone with them (friend or family member), to encourage them to follow up with cognitive assessment. Diagnosis requires a health care professional's evaluation. A positive dementia screening result should lead to diagnostic consultation. Some people may be referred to a specialist, but primary care providers can do the diagnostic workup.

What are screeners?

Screeners or screening tools are used to predict the likelihood of cognitive impairment. Screening tools can detect early changes in cognitive functioning, and can also be used to monitor changes in cognitive functioning over time. There are two types of screening tools:

Performance-based screening tools are administered to patients. Examples of performance-based screening tools include:
- Mini-Cog
- Saint Louis University Mental Status Examination(SLUMS)
- Function-based screening tools are administered to informants (e.g., care partner, family member, close friend)
- 8-Item Informant Interview (AD8)
- Quick Dementia Rating System (QDRS)
- Functional Activities Questionnaire (FAQ)
- Both have value and are often used in combination. Other tests may be recommended to look for possible contributing factors once a problem is detected.

Who can do screening?

Administration of screening tools is not limited to health care professionals. Many screeners can be administered by any individual who has completed training specific to a screening tool. The training requirements and resources vary from screener to screener. Some are very short and simple.

Why does screening matter?

Undetected dementia can lead to adverse health outcomes. Detecting dementia earlier can lessen the occurrence of:

• Missed medical problems
• Avoidable accidents and injuries
• Medication errors
• Caregiver stress
• Family conflict
• Poor chronic disease control
• Wrong treatment
• Post-surgical complications
• Poor continuity of care
• Delirium
• Preventable emergency visits, hospitalizations, complications,
  and readmissions

What is the "best" screening tool to use?

The "best" screening tool is the one that works best in your setting, with your capacity and programmatic goals. The screening tools listed in our toolkit have been tested and validated in a variety of settings and among different communities. You may start by adopting one tool and later add or change to another as needs evolve. They are also promoted by AGS, KAER, and USPTF. To learn more about these screening tools, we refer you to our Cognitive Screening Tools Table on the following page.

MINI-COG

PROMOTED BY: ☑AGS ☑KAER ☑USPTF

PURPOSE OF TOOL

Dementia screener

TRAINING REQUIREMENTS

10 minutes, individual or group, or
Mini-Cog video (www.actonalz.org)

WHERE TO FIND IT

Mini-Cog.com

STRENGTHS

Includes memory and clock drawing (by itself a
sensitive screening tool). Brief, relatively free of bias due
to language and education, easy to use in non-specialist
settings. Explicit rules for administration and scoring
embedded in test form; Free

WHO CAN ADMINSTER THIS TOOL?

Can be administered by
non-clinicians with minimal training

LIMITATIONS

Individuals without regular exposure to analog clocks, or
limited experience with drawing or
writing, or those with low levels of educational
attainment may find this challenging
even if they don't have dementia; Memory threshold
score set to compensate for this limitation

TIME NEEDED TO ADMINISTER TOOL

Up to 3 minutes

OTHER CONSIDERATIONS

Version under development for those
unfamiliar with clocks

WHO IS THIS TOOL INTENDED FOR ?

Patient

LANGUAGE OR CULTURAL ADAPTATIONS ?

Available in multiple languages (e.g., French,
French Canadian, German, Norwegian, Portuguese,
Croatian, Czech, Spanish, Dutch, Thai, Korean,
Vietnamese, Chinese, Japanese, Tagalog, Hebrew,
Arabic, Urdu)

SAINT LOUIS UNIVERSITY MENTAL STATUS EXAMINATIONS(SLUMS)

PROMOTED BY: ☑AGS ☑KAER ☑USPTF

PURPOSE OF TOOL

Dementia screener; maybe used to track progression

TRAINING REQUIREMENTS

SLUMS Training video

WHERE TO FIND IT

https://www.slu.edu/medicine/internal-medicine/geriatricmedicine/agingsuccss-fully/assessment-tools/mental-statusex-am.php

STRENGTHS

Similar to Mini-Mental State Exam; Adds executive component

WHO CAN ADMINSTER THIS TOOL?

Individuals (e.g., social services, program coordinators, licensed nurses, nurse practitioners, occupational therapists, residence supervisors, other healthcare professionals) who have been trained by viewing training video

LIMITATIONS

Relatively little published data on use

TIME NEEDED TO ADMINISTER TOOL

10 + minutes

OTHER CONSIDERATIONS

Culture-bound story recall; Cultural adaptation needed for story recall portion, possibly other elements

WHO IS THIS TOOL INTENDED FOR ?

Patient

LANGUAGE OR CULTURAL ADAPTATIONS ?

Available in multiple languages, (e.g. Afrikaans, Arabic, Chinese-Hong Kong, Chinese-Taiwan, Danish, Dutch-Netherlands, English-Hong Kong, Finnish-Finland, French, German, Hebrew, Hindi, Portuguese, Romanian, Spanish-Colombia, Spanish-PR

CLOCK DRAWING TEST (CDT)

PURPOSE OF TOOL

Dementia screener

TRAINING REQUIREMENTS

Dependent on purpose of use and scoring system selected

WHERE TO FIND IT

No single site due to multiple versions and scoring systems

STRENGTHS

Requires many different cognitive abilities

WHO CAN ADMINSTER THIS TOOL?

Use by non- clinicians not reported

LIMITATIONS

Many scoring systems from simple to highly complex; Mini-Cog CDT is best validated of those using simple scoring

TIME NEEDED TO ADMINISTER TOOL

< 1 minute
(up to several minutes if individual has severe impairment)

OTHER CONSIDERATIONS

Severe vision loss or dominant hand motor impairment may interfere

WHO IS THIS TOOL INTENDED FOR ?

Patient

LANGUAGE OR CULTURAL ADAPTATIONS ?

Individuals without regular exposure to analog clocks, limited experience with drawing or writing, and non-literate individuals may not be able to do this even if they don't have dementia; There is no substitute

8-ITEM INFORMANT INTERVIEW (AD8)

PROMOTED BY: ☑AGS ☐ KAER ☑ USPTF

PURPOSE OF TOOL

Effective for detecting early cognitive changesassociated with Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia

TRAINING REQUIREMENTS

Unknown

WHERE TO FIND IT

https://otm.wustl.edu/washu-innovations/tools/ad8-licensing/

STRENGTHS

Brief; requires minimal training to administer

WHO CAN ADMINSTER THIS TOOL?

Self (informant) or interviewer

LIMITATIONS

Lack of knowledgeable informant may limit use for ongoing monitoring as individual's awareness of deficits diminishes

TIME NEEDED TO ADMINISTER TOOL

3+ minutes; requires variable thinking time before responding

OTHER CONSIDERATIONS

Derived from the Clinical Dementia Rating (CDR), a standard research tool for staging levels of impairment in US

WHO IS THIS TOOL INTENDED FOR ?

Informant (e.g., care partner, family, friend, etc.)

LANGUAGE OR CULTURAL ADAPTATIONS ?

Unknown but being used in many languages

QUICK DEMENTIA RATING SYSTEM (QDRS)

PROMOTED BY: ☐ AGS ☐ KAER ☐ USPTF

PURPOSE OF TOOL

Effective for detecting early cognitive changes associated with Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia

TRAINING REQUIREMENTS

Requires minimal training; can be self-administered

WHERE TO FIND IT

http://med.fau.edu/research/The%20 Quick%20Dementia%20Rating%20 System%20Instructions%20and%20 Form.pdf

STRENGTHS

Brief and simple format; less subject to age, gender, racial, ethnic, cultural, educational, orsocioeconomic biases

WHO CAN ADMINSTER THIS TOOL?

Self (informant) or interviewer

LIMITATIONS

Can be constrained by the availability of an observant informant

TIME NEEDED TO ADMINISTER TOOL

3-5+ minutes; requires respondent thinking time

OTHER CONSIDERATIONS

Can be completed before a visit or by phone or video

WHO IS THIS TOOL INTENDED FOR ?

Informant (e.g., care partner, family, friend, etc.)

LANGUAGE OR CULTURAL ADAPTATIONS ?

Not studied

FUNCTIONAL ACTIVITIES QUESTIONNAIRE (FAQ)

PROMOTED BY: ☑AGS ☐ KAER ☑USPTF

PURPOSE OF TOOL

Identify cognitive impairment based on independent activities of daily living

TRAINING REQUIREMENTS

None

WHERE TO FIND IT

https://www.alz.org/careplanning/downloads/functional-activities-questionnaire.pdf

STRENGTHS

High sensitivity and reliability; can discriminate among different stages of cognitive decline

WHO CAN ADMINSTER THIS TOOL?

Self (informant); clinicians, community organisation and care staff, researchers

LIMITATIONS

Some included IADLs don't apply to all individuals (social, cultural variation)

TIME NEEDED TO ADMINISTER TOOL

1-3 minutes

OTHER CONSIDERATIONS

Ease of use across multiple settings; tracking change over time

WHO IS THIS TOOL INTENDED FOR ?

Informant (e.g., care partner, family, friend, etc.)

LANGUAGE OR CULTURAL ADAPTATIONS ?

Little published experience; needs more study

INFORMANT QUESTIONNAIRE ON COGNITIVE DECLINE IN THE ELDERLY (IQCODE)

PROMOTED BY: ☑AGS ☐ KAER ☑USPTF

PURPOSE OF TOOL

Identification and staging of cognitive impairment based on change from 10 years earlier

TRAINING REQUIREMENTS

Not reported

WHERE TO FIND IT

https://www.alz.org/media/documents/short-form-informant-questionnaire-decline.pdf

STRENGTHS

Relatively unaffected by education or proficiency in one's usual language

WHO CAN ADMINSTER THIS TOOL?

Clinicians, clinical and research staff

LIMITATIONS

Requires informant who has known the person for years

TIME NEEDED TO ADMINISTER TOOL

5+ minutes, requires thinking time

OTHER CONSIDERATIONS

Measures a single general factor of cognitive decline

WHO IS THIS TOOL INTENDED FOR ?

Informant (e.g., care partner, family, friend, etc.)

LANGUAGE OR CULTURAL ADAPTATIONS ?

English, Arabic, Bahasa Indonesia, Chinese, Czech, Danish, Dutch, Finnish, French, German, Greek, Japanese, Lithuanian, Persian, Serbian, Spanish, Swedish, Thai, Turkish

NAVIGATING POST-SCREENING CONVERSATIONS

Cognitive function and dysfunction come with a broad array of experiences, abilities, and disabilities, ranging from normal and common experiences to those that are not. Cognitive capability exists on a continuum – each person has particular strengths and relative weaknesses, even when overall cognitive function is impaired, and prior functioning must always be taken into account – dementia represents a decline from a previous level of functioning. Intervening influences that affect performance on screening tests may range from preoccupation with worry unrelated to actual cognitive functioning (e.g. a seriously ill family member in the ICU), uncompensated sensory impairment, or clinical conditions that interfere with performance such as serious mood disorders. Refer to the "Navigating Post-Screening Conversations" infographic to learn more about discussion strategies in the result of a negative or positive screening.

Navigating post-screening conversations

Screening for cognitive impairment is a crucial first step to ensuring patients' overall health.

Detailed conversations with patients about their lives and their day to day activities provide context for cognitive screening and establishes an important partnership in ensuring best opportunities to maintain health. Supporting brain health is vital to overall health, regardless of the results of any screening activity. In the event of a positive screening test, continuity of care is essential and often helps to "complete the story". This work is never completed on one visit as there will always be more. This is a journey for both primary care providers and these patients and their families. Primary care is exactly the vehicle for such a journey because this is always about relationships between patients, their families and providers. When impairment is detected, having readily available information to refer to other resources (e.g., community-based organizations, state or local resources) is a critical element of ongoing care.

Assess for cognitive impairment: Administer a validated cognitive screening test to gauge your patient's cognitive functioning.

Discuss the importance of maintaining brain health: Regardless of the screening results, patients should be made aware of the healthy lifestyle behaviors that support healthy cognitive functioning.

Conduct a patient needs assessment: By conducting a needs assessment, you can get a better sense of the types of care and support your patient will need.

Refer patients to the appropriate resources: To ensure that parents are getting adequate care, refer them to the appropriate services for needed support.

After the Assessment

Below are some examples of key points to discuss with patients after administering a cognitive screening tool or after receiving screening results when completed by someone else:

- Always ask patients for their impressions first - "How do you think you did?" or "Do you have any concerns about your memory or being able to think clearly?"

- Emphasize that this is a measure of what they did on this test on that day

- Gather more context about their cognitive abilities by asking about everyday activities – this is an important step to establishing the history of their cognitive health

- Explain terminology – "Let's talk about this word that people often use called dementia"

- Ensure a continued partnership on their journey – "We will work on this together"

- Emphasize the positive "There are things we can do to help your brain stay healthier"

- Talk about good care for co-morbid conditions

- Talk about proper diet and better sleep

- Make a plan for physical activity and maintain or increase social engagement

Strategies for post-screening conversations

As you cover the key points highlighted above with your patients, it is also important to employ the following strategies listed below during post-screening conversations:

- Exercise emotional intelligence
- Explore the unstated
- Be reflective and use "us" and "we"
- Establish trust and the sense of continuity
- Identify strengths of the patient and dyad
- Find the "half-full cup"

Needs assessments and referrals

In the event of a positive dementia screening, physicians should conduct a further diagnostic evaluation. Although some patients may be referred to a specialist, primary care providers can also do the diagnostic workup. We will provide strategies for that evaluation in another document. To develop a tailored care plan following disclosure of a dementia diagnosis, physicians should work closely with their patients and their patient's social support system (e.g., family, close friends, care partner) to conduct a thorough assessment of the patient's unique medical and psychosocial needs.

Care planning should include referrals to local, state, and national organizations that offer services such as respite care, resources on best practices for caregiving, and community wellness centers. For instance, NYU's Alzheimer's and Related Dementias (ADRD) Family Support Program offers support and services including individual and family consultation with social workers, music and dance therapy, a memory café, as well as referrals to support groups and other community organizations.