A Scoping Review of Guidelines and Quality Measures to Screen for Social and Caregiver Support and Cognitive Impairment in Primary Care

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High-risk patients—those patients with complex health care needs who are most likely to face hospitalization or death in the following two years—are most often initially seen in the primary care setting in such health care systems as the Veterans Health Administration (VHA) in the U.S. Department of Veterans Affairs (VA). Availability of electronic methods for identifying high-risk patients in primary care settings has raised the possibility of timely enhancement of care for detected patients. However, results of studies of care enhancement for high-risk patients have been inconclusive, in large part because evidence-based guidance on caring for these patients and measures of care quality based on those guidelines are lacking. As an initial step in developing guidelines and measures, an expert panel was asked to assess the appropriateness of several measure concepts—guidelines or proposed guidelines that had not yet attained the status or specificity of being measures—with the aim of developing a measure dashboard for high-risk patients in the VA primary care setting. Among measure concepts ranked with highest priority, several have no counterparts among measures in current use in the VA. The primary aim of this study was to conduct a scoping review to identify guidelines and quality measures in use for two potential measure concepts: (1) screening for social support, need for caregiver support, and referral to social services and (2) screening for cognitive impairment.

This research was funded by the VHA—the largest single health care system in the United States—and carried out within the Access and Delivery Program in RAND Health Care to help inform the provision of quality care to high-need, complex care patients. Although funded by the VHA, the research presented here aims to identify principles applicable to the broader needs of population-based health care systems delivering primary care.

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Summary

Multiple studies have confirmed the existence of a population of patients—in the U.S. Department of Veterans Affairs (VA) health care system and across all health care systems—with complex health care needs who are at elevated risk for further morbidity, hospitalization, or mortality in the near term. This small group of patients uses a disproportionate amount of care resources. Contributing to the challenges of care planning for this population is that individuals are highly heterogeneous, both at any given time and over time. No two patients present the same set of symptoms, diagnoses, and challenges related to social determinants of health (SDOH). Furthermore, high-risk status is fluctuating in nature: Among an identified high-risk population, some will die within two years, some will remain at chronically high risk, and some (as many as two-thirds) will achieve reduced risk. In addition, approaches for identifying the appropriate patients for targeted interventions, such as those that use electronic health records, might be insufficient. Thus, attempts to define the meaning of high-quality care for high-risk patients and to establish its evidence base have been frustrating.

In late 2020 and early 2021, a team of RAND researchers conducted a study for the VA using a virtual RAND-University of California, Los Angeles, appropriateness panel to identify health care assessment priorities and associated quality-of-care measures or measure concepts for patients identified as being at high risk. When we refer to a measure, we mean the specification of how, when, and with what population an evidence-based care process guideline should be implemented such that it can be used to assess care quality at the individual and system levels. Measure concepts are those guidelines or recommendations that have not been developed into measures. The panel comprised a group of experts in the care of patients with complex health care needs, including primary care physicians, nurse practitioners, social workers, and health services administrators—most with experience working in the VA health care system—and several VA patients. The panelists were asked to assess a proposed set of evidence-based potential measure concepts and a group of existing VA measures currently in use that address many of the same measure concepts. The existing measures specified the target patients and other details, such as recommended frequency or tools.

The final ratings showed 22 measure concepts that the panelists regarded as high priority and with strong agreement. With these 22 concepts that might merit consideration for inclusion in a measure dashboard for high-risk patients in primary care clinics, the research team first compared the measure concepts to existing VA measures to identify any that had identical or very similar existing VA measures already in use, because, in such cases, no additional development or validation work would be required to incorporate them into the dashboard. It would instead be a matter of repurposing existing measures for this new use. This evaluation found that 16 highly rated measure concepts had existing VA measures that could be repurposed.
However, the remaining six highly rated measure concepts had no comparable VA measure and, therefore, are candidates for inclusion in a measure dashboard if evidence can be found that links the use of such measures to better care outcomes. Such evidence would hopefully be in the form of existing evidence-based guidelines and measures.

The primary focus of this project was to determine whether there are existing, operational quality measures for two of the remaining six measure concepts, selected by the VA, and whether these measures have been validated for use in primary care settings by primary care clinicians. The two concepts are as follows:

- identification of a patient’s need for and/or source of social and caregiver support and referral to social services if the patient has been identified as high risk and with social need (this was considered two separate measure concepts in the panel project)
- assessment of cognitive impairment (CI).

**Approach**

We conducted two scoping reviews to identify existing measures, guidelines, and tools for (1) assessing social support and the need for caregiver support and referral to social services and (2) screening for CI among patients with complex health care needs in primary care settings and the need for referral for further testing. The two reviews followed published guidance for conducting and reporting on scoping reviews.

**Key Findings**

**Social Support**

- We identified no existing measures for assessing existing social or caregiver support or the need for referral to social services in primary care settings.
- One identified guideline provided a decision support tool for assessing the need for caregiver support. Information on validation of this tool was not found.
- Social support, as conceived by the tools and other resources identified for the current report, encompasses at least two concepts: help when needed with performing activities of daily living (ADLs) and presence of emotional support (i.e., the absence of loneliness or social isolation).
- Many tools exist for assessment of ADLs and SDOH in primary care settings, and some of these tools include items to assess social support, need for further caregiver support, and need for referral. None of the tools or items was adapted for patients with complex care needs or validated using health or other important outcomes.

**Cognitive Impairment**

- We identified several measures and evidence-based guidelines for screening patients for CI in primary care settings, although routine screening of patients who do not present with evidence of CI remains controversial.
Numerous brief screening tools exist for assessment of age-related CI, and several tools exist for screening for CI associated with chronic conditions. Most of these tools have been validated against specialty assessment, and some have been compared in the same populations. No one screening tool appears to be ideal, but some candidates exist. Nevertheless, several challenges must be overcome for all CI screening. Chief among these is the lack of applicability of screening tools to patients with low education and low literacy and the lack of validation among diverse populations.

**Recommendations**

It is beyond the scope of this report to make research or practice recommendations. Nevertheless, the literature suggests the following next steps:

- Social support and caregiver screening of patients with complex care needs for referral appear feasible and necessary, but it will be important to identify brief screening tools that can be used with all patients or to identify criteria for which patients to assess further.
- Social support screening will need to undergo validation in populations of patients with complex care needs.
- Cognitive screening of patients with complex care needs in the primary care setting appears feasible, but patient factors that can affect performance and choice of screening test must be considered carefully.
- Risks, benefits, and cost-effectiveness of screening complex patients (versus screening only patients who demonstrate some signs of need for social support or present symptoms suggestive of possible CI) must be considered.
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Chapter 1. Background and Approach

This chapter begins with a brief background on issues surrounding patients with high or complex care needs and efforts to assess and improve the quality of their health care in the primary care setting. We then briefly describe the previous study that formed the basis of the current study. Finally, we describe the approaches used to conduct this study.

Background

Multiple studies have confirmed the existence of a population of patients in the U.S. Department of Veterans Affairs (VA) health care system and across all health care systems with complex health care needs, who are at elevated risk for further morbidity, hospitalization, or mortality in the near term. As described further below, these patients use a disproportionate amount of care resources.

**High-Need, High-Risk Patients**

Complex patients or high-need or high-risk patients are patients who require multiple, sometimes competing medical interventions, are associated with multiple or advanced chronic diseases, and have often-interlinked needs associated with substance use or mental health conditions and challenging social determinants of health (SDOH). These high-risk patients’ complex medical needs, which can include advanced type 2 diabetes mellitus (T2DM), heart disease, renal disease, and osteoarthritis, create multiple challenges for clinical care assessment and management. Research has identified many highly prevalent examples of the accompanying mental health and SDOH issues of concern, including limited mobility, cognitive impairment (CI), vision or hearing loss, mental health issues and/or drug dependence, food insecurity, lack of adequate finances, lack of social support, and transportation or safe housing issues.

Not surprisingly, the small proportion of patients at highest risk accounts for a disproportionately high level of use of health care resources (Stanton and Rutherford, 2006). For example, in the VA health care system, the top 5 percent of health care users use about 47 percent of care resources (Zulman et al., 2015).

Contributing to the challenges of care planning for this population is the fact that individuals are highly heterogeneous, both at any given time and over time. No two patients present the same set of symptoms, diagnoses, and disruptions in SDOH. Furthermore, high-risk status is fluctuating in nature: Among an identified high-risk population, some will die within two years, some will remain at chronically high risk, and some (as many as two-thirds) will achieve reduced risk. In addition, approaches for identifying the appropriate patients for targeted interventions, such as the use of electronic health records (EHRs), might be insufficient. Thus, attempts to
define the meaning of high-quality care for this population and to establish its evidence base have been frustrating. A guideline for the care of a patient with one disorder, such as a nutrition guideline for a patient with T2DM, might be inapplicable for a patient who also has end-stage renal disease, low vision, and lack of support in the home.

Additional considerations apply to care enhancement intervention planning and execution for this population. The synergy among multiple health conditions and contextual factors needs to be considered (Hochman and Asch, 2017). All these factors make it challenging to determine what constitutes high-quality care for the high-risk patient population.

An approach that emphasizes individually targeted clinical interventions supported by evidence on common causes of near-term adverse events among high-risk patients is needed. Achieving appropriate targeting requires attention to which conditions are common among high-risk patients and which show documented links to effective preventive care so that effective clinical management in primary or specialty care settings can be promptly initiated. At the same time, clinicians’ ability to recognize patients’ needs in real time might help distinguish those who are getting better on their own from those who need attention.

Although the best way to take care of high-risk patients as a group is not clear, we do have evidence about how to assess and manage individual conditions, and, with appropriate measurement systems in place, we might be able to influence care for those individual conditions and, thus, help improve patients’ outcomes overall. Evidence suggests that measurement of care quality can affect patient outcomes, sometimes through audit and feedback and sometimes as part of clinical support tools (Tierney, 2001; Yoon et al., 2018; Zulman et al., 2019). Useful measures for care enhancement interventions, in turn, might be most successful if linked to feasible primary care–based screening and assessment strategies that can be the basis for targeting further clinical management activities. When referring to a measure, we mean the specification of how, when, and with what population an evidence-based care process guideline should be implemented, such that it can be used to assess care quality at the individual and system levels. However, before measures can be developed and implemented, policymakers and clinicians need to know what assessment and care practices have a sufficient evidence base in terms of improving health care quality and outcomes for the intended patients cost-effectively and with minimal adverse consequences. (We termed as measure concepts those guidelines or recommendations that had not yet been developed into precise measures.) Only then can clinicians assess whether these efforts can be measured feasibly—that is, in a way that enables these efforts to be considered a critical part of care quality.

Like patients in general, patients with complex health care needs are seen initially and most often in the primary care setting (Chang et al., 2020). For this reason, and because primary health care providers are in the best position to assess the needs of the whole patient, this setting

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1 The establishment of a measure of care quality also assumes that the implementation of the care process is associated with improved health outcomes, that it is feasible, and that it is measurable.
provides the ideal context for establishing and implementing measures of care quality for patients with complex health care needs who are likely to be at high risk. In the past decade, the VA has implemented several interventions aimed at improving the quality of care for patients in the primary care setting. For example, the VA implemented the Patient Aligned Care Team (PACT) program (VA, undated), which uses a team-based approach and evidence-based quality improvement methods to assess and address the holistic needs of the patient.

However, additional efforts might be needed to identify and address the needs of high-risk patients, who constitute a disproportionate segment of the VA population. The VA has implemented a Primary Care Intensive Management program to address the needs of patients with complex health conditions who are at high risk for hospitalization. Initial findings from the implementation of this small demonstration program, which combined team-based care coordination, goal assessment, health coaching, medication reconciliation, and home visits, suggest that patients in such programs receive more outpatient care without increasing costs (Yoon et al., 2018). However, much remains to be examined regarding how best to address these patients’ needs, which processes and outcomes to measure, and even how best to identify the patients most in need of intensive services in the primary care setting.

**Phase 1 of the Quality Measures Dashboard Project**

In late 2020 and early 2021, a team of researchers at the RAND Corporation conducted a study for the VA using a virtual RAND-University of California, Los Angeles, appropriateness panel to identify health care assessment priorities and associated measure concepts for patients identified as being at high risk. The panel comprised a group of experts in the care of patients with complex health care needs, including primary care physicians, nurse practitioners, social workers, and health services administrators—most with experience working in the VA health care system—and several VA patients.

Prior to the meeting, panelists were provided a brief summary of the background literature on the high-risk patient population, including a recently completed systematic review on quality indicators for high-risk patients (Schneberk et al., 2022), and were asked to complete a survey to assess their views of the potential importance of some four dozen measure concepts for reducing the risk for near-term hospitalization or use of the emergency department and of reversing high-risk status. These measure concepts fell into three care categories:

- assessment, such as screening tests
- management, such as developing an individualized treatment plan
- other features of health care, such as care coordination.

In each category were several domains. For example, the assessment category included six domains—screening for SDOH, physical health status, mental health status, sensory impairment, medications, and patient and family values—and each domain included one to eight measure concepts, for a total of 64 unique concepts. Several measure concepts were evidence based and
already in use, and others had been identified in the systematic review. The panelists were also asked to assess a group of existing VA measures currently in use that address many of the same measure concepts. The existing measures specified the target patients and other details, such as recommended frequency or tools.

In a one-day virtual panel meeting, the panelists were provided the prepanel survey results—the median composite ratings and extent of agreement of each measure concept among the group. Panelists also received a copy of their own ratings to enable comparison with the group’s ratings. The moderator reviewed each of the ratings and encouraged discussion, particularly on concepts with wide disagreement and concepts with mostly negative ratings. Panelists were also encouraged to suggest new measure concepts or alternatives to some of the concepts presented in the survey.

During their discussion, the panelists noted that their greatest challenges were considering which measure concepts were (1) feasible for primary care; (2) relevant for the most-high-risk patients, in light of the heterogeneity of this patient population; and (3) actionable. They expressed the belief that some measure concepts might be important but that tracking their completion would be too difficult or that recording completion could become a box-checking exercise. Following the discussions, the panelists rerated the measure concepts and rated newly suggested concepts.

The final ratings showed 22 measure concepts that the panelists regarded as high priority and with strong agreement. To pinpoint measure concepts among the 22 that might merit consideration for inclusion in a measure dashboard for high-risk patients in primary care clinics, the research team compared the highest-rated measures with existing VA measures to identify any of the highly rated measure concepts that had identical or very similar existing VA measures already in use, because, in such cases, no additional development or validation work would be required. It would instead be a matter of repurposing existing measures for this new use. This evaluation resulted in 16 highly rated measure concepts having existing VA measures that could be repurposed. The remaining six highly rated measure concepts had no comparable VA measure and, therefore, were candidates for inclusion in a measure dashboard if evidence could be found that links the use of such measures to better care outcomes.

Approach

The focus of this project was to determine whether there are existing operational quality measures for two of the remaining six measure concepts, selected by the sponsor:

- identification of a patient’s need for and/or source of social support and referral to social services if the patient has been identified as high risk and with social need (these were considered two separate measure concepts in the panel project)
- assessment of CI.
To search for existing quality measures in populations comparable with the high-need VA patients, we conducted two scoping reviews.

Assessing the Need for Social Support and Referral to Social Services

Some studies have suggested the need to assess social support but note that, for a variety of reasons, patients in the primary care setting might not be assessed for needs related to SDOH, including dependable social support (O’Gurek and Henke, 2018). Primary care settings, even those with team-based care, might lack social workers; other health care providers might be too busy to address this need, or it simply might not occur to them. Yet at least one study found low social support to be the only nonmedical factor associated with frequent attendance in primary care settings among older adult patients (Welzel et al., 2017), another study reported an association between lack of social support and poorer self-care (Bayliss et al., 2003), and another reported an association between low social support and more-frequent visits to the emergency department (Bodenmann et al., 2015).

The following questions guided the search for our scoping review:

- What current guidelines and quality measures exist regarding assessment of social support of high-risk patients with complex care needs?
- What assessment questions or tools are used in primary care to quickly identify (need for) social support of high-risk patients with complex care needs?

We were also interested in knowing what kinds of steps have been taken to validate these assessment tools or questions in terms of how their results compare with other validated tools, the kinds of patients and settings involved, whether they provide actionable information for referral or match patients with needed help, ease of implementation, and whether the use of this screening results in higher quality care (better patient outcomes).

Other, related questions, such as whether patients experience social isolation or have reliable transportation, might address fragments of social need but are too focused to address the variety of needs that social and caregiver support can address.

Rapid Assessment of Cognitive Impairment

A 2019 review on the diagnosis and management of CI concluded that most dementia and CI (particularly mild cognitive impairment [MCI]) are diagnosed in the primary care setting (Arvanitakis, Shah, and Bennett, 2019). MCI has been defined as a heterogeneous clinical syndrome that reflects a change in cognitive function and deficits on neuropsychological testing but relatively intact activities of daily living (ADLs); MCI is a risk for further cognitive and functional decline, with 5 percent to 15 percent of such people developing dementia per year. However, about one-half do not progress or remain stable at five years, and, for a small group, symptoms resolve over time (Dunne et al., 2021).
The U.S. Preventive Services Task Force (USPSTF) recommends that clinicians assess cognitive function in patients who are suspected to have CI based on clinician or caregiver concern but found insufficient evidence in its 2020 review to recommend routine screening of community-dwelling older adults for CI in the primary care setting (based on a lack of evidence that screening improved outcomes) (USPSTF, 2020). Still, patients with highly complex health care needs might be at greater risk for at least MCI and, therefore, present a more-compelling case for screening. Several medical conditions, including vitamin B12 deficiency, depression, hypothyroidism, electrolyte imbalance, renal insufficiency, hepatic failure, infectious illness, and polypharmacy can cause (reversible) CI or worsen underlying CI by causing a superimposed delirium (Chow and MacLean, 2001). This suggests that those with any of these conditions might warrant screening and that those who present with sudden onset of CI might warrant clinical lab testing.

The following questions drove this scoping review:

- What guidelines and/or quality measures exist regarding screening high-need patients for CI in the primary care setting?
- What screening tools are currently used in the primary care setting to briefly screen for CI, and what is their evidence base?

Organization of the Report

In Chapter 2 of this report, we describe the approach and methods used for the two scoping reviews. In Chapter 3, we describe the findings of the review on assessing social support in the primary care setting. In Chapter 4, we describe the findings of the review on assessing cognitive function. Chapter 5 provides conclusions, limitations, and possible next steps.
Chapter 2. Approach and Methods

The two reviews followed published guidance for scoping reviews (Arksey and O’Malley, 2005; Peters et al., 2020):

- Stage 1: Define and align the objectives and questions.
- Stage 2: Develop and align the inclusion criteria with the objectives and questions.
- Stage 3: Describe the planned approach to evidence searching, study selection, data abstraction, and presentation of the evidence. Search for, select, extract, and analyze the evidence.
- Stage 4: Present the results and summarize the evidence in relation to the purpose of the review, draw conclusions, and note any implications of the findings.

The protocol was registered on Open Source Framework.

Stage 1: Objectives and Questions

Using the outcome of the expert panel conducted in 2021, the sponsor identified two measure concepts for care processes that it assigned as high priority and that were not currently assessed by VA measures. The objective of the two proposed scoping reviews was to identify processes used in primary care settings to assess high-risk patients’ social support and/or need for social or caregiver support and to assess cognitive function status in this population. The questions addressed are briefly summarized here:

1. Social support, need for caregiver support, or referral to social services.
   a. What current guidelines and/or quality measures exist regarding assessment of social support of high-risk patients with complex care needs?
   b. What assessment questions or tools are used in primary care to quickly identify (need for) social support of high-risk patients with complex care needs?

2. Cognitive impairment
   a. What current guidelines and/or quality measures exist regarding assessment of cognitive impairment among high-risk patients with complex care needs?
   b. What assessment questions or tools are used by primary care providers in the outpatient setting to assess cognitive status of high-risk patients with complex care needs?

Stage 2: Inclusion Criteria

Studies and online resources and tools (such as online clearinghouses, professional practice association sites, and patient support sites) were included if they:
• described guidelines, measures, or rapid assessment questions or tools used to quickly assess sources of social support or cognitive status
  – of high-risk adult patients with complex care needs
  – in the primary care setting
  – by primary care providers (medical doctors, nurse practitioners, physician assistants, or nurses).

We excluded the following:

• studies or sites that describe tools used primarily by social service personnel and/or in inpatient settings
• studies or tools aimed only at assessing caregiver strengths or needs
• tools and publications prior to the year 2000 unless obtained through reference mining
• non-English-language publications
• publications that were primarily commentaries or editorials.

Studies that tested the effects of an intervention to improve care management for high-risk adult patients in the primary care setting were also searched for descriptions of the methods used for assessing social support or CI for study participation.

Stage 3: Evidence Search, Study Selection and Data Abstraction, and Presentation

The overall approach was described in Chapter 1 and in a protocol that was peer reviewed.

Evidence Search

A prior review that was the source of some of the measure concepts presented to the expert panel in the first phase of the project was searched for potentially relevant references and search terms for assessment of social support and CI (Schneberk et al., 2022).

For the search on social support, a preliminary Google search was conducted using any terms identified in the literature review and “social support,” “family support,” and “caregiver support.” Website links that appeared in the first five pages were checked for potential inclusion of guidelines, needs assessment tools, measures, or lists of such resources (other websites) for adult patients with multiple chronic or complex care needs.

For the search on cognitive screening, a preliminary search was conducted to determine whether measures and guidelines identified in the original Assessing Care of Vulnerable Elders (ACOVE) publication on dementia in community-dwelling elderly (described in more detail in Chapter 4) were updated (Chow and MacLean, 2001).

An experienced librarian then searched PubMed, PsycInfo, Google Scholar, and ECRI for assessment methods and measures for social support or cognitive function (see Appendix A). In addition, as described above, the search sought trials that implemented interventions to provide or improve family or social or other caregiver support to patients with high care needs to
determine the criteria they used to determine eligibility for study participation (questions they asked and clinical criteria).

Additional searches were conducted of the websites for the Agency for Healthcare Research and Quality (AHRQ), Centers for Medicare & Medicaid Services (CMS), Health Canada, professional practice organizations, the Healthcare Effectiveness Data and Information Set, the ECRI guidelines clearinghouse, National Quality Forum (NQF), the COMET initiative, and HealthMeasures. Reference lists of relevant peer-reviewed journal articles and those included in online sites were mined for other potentially useful references.

Study Selection and Data Abstraction

Publication titles and abstracts identified by the searches were entered into the online reviewing software tool DistillerSR and screened and full-text versions of all potentially relevant articles were obtained and screened by the principal investigator. Materials identified through Google searches and focused searches of websites, clearinghouses, and other databases were also entered into DistillerSR. Sites and databases were further searched using the original search terms and/or any new (alternate) terms that the sites presented.

The following contents of each relevant source were abstracted in DistillerSR:

- description of the type of publication or site
- patient groups for which the measure, guideline, or assessment tool was developed or on whom it was tested
- settings to which the assessment and measure or measure concept applies
- the content of the assessment
- steps taken to validate the measure or assessment tool
- any other relevant study-level information for the implementation of a quality measure, guideline, or assessment tool.

Stage 4: Presentation of the Evidence, Summary, and Conclusions

Relevant material and sites are described in summary tables in Chapters 3 and 4 and in Appendix B. The tables list the included sources along with a brief narrative description of each. Sources that were searched but not included are listed in Appendix C.

In Chapter 5, we discuss the findings regarding screening tools and their readiness for use in the primary care setting. We also comment on the steps needed to create and validate measures. We followed the PRISMA extension guidelines for reporting scoping reviews (Tricco et al., 2018) and AMSTAR guidelines for any included systematic reviews (Shea et al., 2017).

Individual study quality was not assessed. However, we noted whether studies described a method for validating their assessment tool or described study-level details or findings for assessing how a tool was implemented.

The report underwent peer review and was revised in response to reviewer comments.
Potential Limitations

Because of the kinds of source materials included, we could not assess their quality. Most sources were not reports of actual studies, and studies that were included were not chosen for the intervention and exposure or the outcome but rather for their description or use of a question or tool, sometimes just for patient recruitment. Also, we did not exclude studies that failed to assess the predictive validity or reliability of a tool. Because study quality was not assessed, we could not assess the strength of the evidence base. Additional limitations of the evidence base and our assessment are described in Chapter 5.
Chapter 3. Assessing Social Support, Caregiver Support, and Need for Social Services in the Primary Care Setting

In this chapter, we describe the findings of the scoping review on measures, guidelines, tools, and other resources for assessing social support in the primary care setting.

Results of the Literature Searches

Through a combination of formal literature searches and reference mining of identified sources, we identified a total of 101 citations: Three of these items were excluded at citation screening, and 49 were excluded because they pertained to settings that were not relevant to the patient population or to primary care settings, did not mention social support or caregiver support, or did not address assessment of social support. Sixteen publications and 13 websites that addressed screening patients for social support in some way (guidelines, resources, and peer-reviewed publications) were used (AHRQ, undated; Boyd et al., 2014; British Geriatrics Society, 2019; Broadhead et al., 1988; CMS, 2021; Cohen et al., 2022; Core Quality Measures Collaborative, undated; De Maria et al., 2020; Family Caregiver Alliance, undated-a; Fischer et al., 2000; Friedman and Banegas, 2018; Goodger et al., 1999; Grinberg et al., 2016; Hahn et al., 2014; Health Leads, 2018; HealthIT.gov, 2021; Kaiser Permanente, 2020; Lin, Hirschfeld, and Margraf, 2019; Medicare Learning Network, 2021; National Association of Community Health Centers, 2016; Older Americans Resources and Services, 1975; RAND Corporation, 1993; Rennemark et al., 2009; Rural Health Information Hub, undated; Sheehan et al., 2003; Skolasky et al., 2011; Wolff et al., 2010; World Health Organization [WHO], 2019; Zimet et al., 1988). In addition, there were eight publications that reported additional information about tools or studies described in the publications cited above (see Table B.1 in Appendix B). (Boyd et al., 2007; Fillenbaum and Smyer, 1981; Gold et al., 2018; Gold et al., 2017; Hahn et al., 2010; Hanson et al., 1997; Kaiser Permanente and Social Interventions Research and Evaluation Network, 2017; Scherer et al., 2008). Figure 3.1 shows the PRISMA flowchart for the items that were identified.

In the remainder of this chapter, we describe the relevant material identified in publications and websites.
As we mentioned in Chapter 1, when referring to quality measures, we mean the specification of how, when, and with what population a guideline should be implemented, such that the exact number of patients who should receive the guidance (the denominator) and the number who do receive it (the numerator) can be determined—as a measure of care quality. Our working definition of a guideline was that it is a recommendation based on some combination of evidence regarding outcomes and expert opinion.

Our primary aim in conducting the searches was to identify existing quality measures and guidelines pertaining to assessment of patients with complex care needs in the primary care.
setting for sources of social support, sources of or need for caregiver support, and need for or referral to social services related to social and caregiver support.

**Quality Measures for Assessment of Social Support or Caregiver Support or Referral**

We identified no quality measures of assessment of social support, need for caregiver support, or referral to social services for social support needs in the literature. For example, the CMS Measures Inventory Tool includes no relevant quality measures (CMS, undated-b), and the CMS guidelines for preventive services and annual wellness visits (AWVs) include no screening for SDOH (although the CMS Accountable Health Communities Model has developed a screening tool—see below) (Medicare Learning Network, 2021). The Healthcare Effectiveness Data and Information Set (HEDIS) (National Committee for Quality Assurance, undated) and the NQF National Quality Partners SDOH Data Integration Action Team Brief (NQF, undated) also include no relevant quality measures. The Core Quality Measures Collaborative identified SDOH in general as a gap in its measure sets (Core Quality Measures Collaborative, undated). Similarly, neither Health Canada, the Public Health Agency of Canada, nor the Canadian Medical Association include measures of social support, although the Public Health Agency of Canada mentions social support networks as being important (Public Health Agency of Canada, 2016). The sites and organizations that report no social support or caregiver assessment guidance are not described further in the evidence table.

**Guidelines for Assessment of Social Support or Caregiver Support or Referral**

The closest thing to a guideline on assessing social support among patients with complex care needs in primary care settings is the WHO manual on *Integrated Care for Older People (ICOPE)* (WHO, 2019). Chapter 10 of this manual includes an 11-question screening tool to assess patients’ social support needs; each question is accompanied by a set of follow-up questions and remedies to consider (see Figure 3.2). Accompanying the manual are an implementation framework and guidance for community-level interventions. The question set assesses various potential areas of concern, including the difficulties in managing ADLs, the person’s risk for loneliness or elder abuse, and financial challenges. However, recommendations to refer for further assessment and interventions are limited to clinical referrals for medical issues, referral for financial counseling, and referral to social services for interpersonal violence victimization.
Figure 3.2 World Health Organization Social Support Assessment Questions

1. Do you have difficulty getting around indoors?
2. Do you have difficulty using the toilet (or commode)?
3. Do you have difficulty dressing yourself?
4. Do you have difficulty using the bath or shower?
5. Do you have difficulty keeping up your personal appearance?
6. Do you have difficulty feeding yourself?
7. Do you have problems with the place where you live (accommodation)?
8. Do you have problems with your finances?
9. Do you feel lonely?
10. Are you able to pursue leisure interests, hobbies, work, volunteering, supporting your family, educational or spiritual activities that are important to you?
11. Assess risk of elder abuse


Tools and Question Sets

Having identified no existing measures (and only one guideline) that pertained to assessment of social support or caregiver support, we sought to describe questions or questionnaires reported for use in assessing patients’ social support in primary care settings. We first describe questions intended for general primary care patients and then describe those intended for patients with chronic conditions and complex care needs.

Screening Questions or Tools for Average Patients in Primary Care Settings

The studies and tools described in this and the following sections are summarized briefly in Table 3.1 and in Appendix B Table B.1. Several questions, questionnaires, and tools for assessing social and caregiver support in primary care settings, dating back to the 1980s, were identified. They are described here in chronological order, including any validation the questions or tools have undergone and information reported on implementation of the tools in studies.

The Duke-University of North Carolina Functional Social Support Questionnaire is a two-domain, eight-item tool that was shortened first from a 35-item to a 14-item questionnaire in the 1980s to assess “confidant support” and “affective support” among patients in the primary care
family medicine setting (Broadhead et al., 1988). The tool has demonstrated construct, concurrent, and discriminant validity, although the population on which it was tested was small, predominantly white, female, and younger. Goodger and colleagues, 1999, subsequently developed and validated an 11-item version for use with community-dwelling older adults in Australia in a primary care setting. The instrument was reported to be simple and quick to administer and was well received by patients. Concurrent and construct validity were assessed against a longer tool developed for use in psychiatry that measured social interaction and with tools that assessed health-related quality of life (HRQOL) and loneliness.

The Multidimensional Scale of Perceived Social Support (MSPSS) is a scale that groups 12 items into three domains: family, friends, and significant others (Zimet et al., 1988). The scale is reported to have been validated in multiple languages, cultures, and patient groups against various other mental health tools (although not against another measure of perceived social support) and is likely the predecessor of the Perceived Social Support Questionnaire described below (Lin, Hirschfeld, and Margraf, 2019).

To assess factors associated with frequent use of primary care, the Swedish National Study on Aging and Care conducted a survey that adapted a Swedish screening tool developed in the 1990s to assess the association of social support with health outcomes. The original tool assessed social support using a concept called social anchorage, a term that refers to the degree to which an individual belongs to and is anchored in formal and informal groups in society. Anchorage includes membership in a club or organization for which one feels a strong affinity, feelings of strong affinity toward relatives, a sense of acceptance in the presence of neighbors, and a sense of belonging to a group of friends or acquaintances who do things together. In this study, social anchorage was not associated with frequency of use of primary care services among elderly patients (Rennemark et al., 2009). Validation of the social support questions was reported to have been conducted in developing an earlier tool. Ease of implementation of the survey was not described.

Sheehan and colleagues, 2003, described a study among 140 primary care clinic attendees 65 or over, for whom perceived social support was measured twice over ten months using one item from the COOP charts. These charts (which must be purchased) rate a subject’s HRQOL in nine areas. Item 8 asks the patient whether, in the past four weeks, help was available to them should they require it, and responses cover five levels from, “Yes, as much as I wanted” to “No, not at all.” Higher scores thus indicate lower perceived support. Higher perceived social support was associated with lower risk for somatization, and somatization has been shown across multiple studies to be associated with increased number of visits to primary care. The study also found that whereas somatization symptoms were transient, perceived poor social support was persistent. No information was reported on the validation of the single item or implementation of the screener.

In 2008, the 14-question self-report German-language Perceived Social Support Questionnaire was developed; its items refer to various aspects of experienced support
This questionnaire was validated in several German-language studies before being adapted for English- (and other) language use, shortened to six questions, and validated by Lin, Hirschfeld, and Margraf, 2019:

1. I experience a lot of understanding and security from others.
2. I know a very close person whose help I can always count on.
3. If necessary, I can easily borrow something I might need from neighbors or friends.
4. I know several people with whom I like to do things.
5. When I am sick, I can without hesitation ask friends and family to take care of important matters for me.
6. If I am down, I know to whom I can go without hesitation.

The response choice employs a five-point Likert scale ranging from 1 (not true at all) to 5 (very true) (see Table 3.1). The authors report that the tool is simple to administer, is reliable over time, and shows strong validity against other tools that assessed similar mental health constructs (such as social isolation) across genders and among multiple cultures.

Wolff and colleagues, 2010, implemented a brief (two-question) assessment tool to determine eligibility for a study of a guided care model of health care for patients and caregivers that was tested in a cluster randomized trial. The tool asked patients whether they received assistance with ADLs, and, if so, they were asked to identify the primary caregiver who helped them the most. Eligible dyads were enrolled in the study, and the guided care model improved several aspects of HRQOL in both caregivers and patients. However, the validity of the tool was not determined, nor was its implementation described.

In 2022, the VA implemented a social needs screening toolkit initiative called the Assessing Circumstances & Offering Resources for Needs (ACORN) initiative (Cohen et al., 2022). The screener uses 13 questions, including one question on social isolation and loneliness, to assess social needs in ten domains. The toolkit was adapted from an AARP survey and can be self-administered or administered by a provider or staff person. The toolkit does not provide guidance on referral except to explain that veterans who screen positive (not defined) can have the results noted in their EHR (details were not provided regarding whether the EHR has been modified to accommodate the results) and can be offered “geographically tailored resource guides, resource navigation support, and/or referrals to Social Work” (Cohen et al., 2022) Thus far, ACORN has been implemented in several clinic settings, including primary care. Results have not yet been published.

Social Support Screening Tools Incorporated into Electronic Health Records

HealthIT.gov reports that the Gravity Project is developing standard interoperable EHR data elements for 11 categories of SDOH, including social isolation (HealthIT.gov, 2021). Among the
data elements are two questions from a Kaiser screener, one of which is, “Do you have someone you could call if you needed help?”

Friedman and Banegas, 2018, reported that the EHR developed by Kaiser Permanente Northwest includes a series of items to assess SDOH to help ensure that needed resources go to patients. Among the SDOH elements collected is social support; however, the EHR calls it social isolation and describes it as the lack of support from family, friends, community groups, or agencies that would normally provide such support, and the patients spending most of their time alone.

**Screening Tools for Patients with Chronic Conditions and Complex Care Needs**

The RAND Medical Outcomes Study Social Support Survey is a widely cited self-administered tool to screen for social support among adult patients with chronic health conditions in primary care settings (RAND Corporation, 1993). The tool includes 19 items in four domains: emotional and informational support, tangible support, affectionate support, and positive social interaction. The response choice employs a five-point Likert scale. A small subset of these questions could be implemented for a rapid assessment of social support. The survey demonstrated reliability and stability over time, and construct validity was demonstrated for some measures against several mental and physical health scales and other measures of social functioning.

The Cancer and Aging Research Group developed a Modified Patient Reported Geriatric Assessment Questionnaire that contains questions on functional status, including one four-part question to assess social support in terms of help needed with ADLs and one to assess social isolation. The questions were based on questions developed by the Patient Reported Outcomes Measurement Information System Cooperative Group’s Social Health Workgroup, specifically on the instrumental support and social isolation domains. The questions were subsequently validated in a population of caregivers of veterans with traumatic brain injuries against several established mental health and social functioning scales (Hahn et al., 2014). No information was reported on implementation of the tool.

De Maria and colleagues, 2020, recently validated the 12-item MSPSS in a population of older adults with multiple chronic conditions and their caregivers in Italy. The study found good agreement between patients and their caregivers regarding perceived social support and strong association of social support with HRQOL. The publication did not report on implementation of the assessment tool.

**Web-Based Resources**

This section describes additional tools found primarily on the internet and clearinghouses and toolkits that included information on screening for social support (see Table 3.1).

AHRQ EvidenceNOW is a federal initiative to foster the dissemination and implementation of evidence-based quality improvement practices, methods, and tools in primary care settings.
The EvidenceNOW website contains a toolkit, “Identifying and Addressing Social Needs in Primary Care Settings,” aimed at helping primary care practices that are considering implementing assessment of social needs (Gerteis and Booker, 2021). The site includes links to several screening tools for various populations; guidance on choosing a tool, such as whether to use a self-administered or staff-administered tool, gathering the desired information in a sensitive and caring way, ensuring that the information is gathered and recorded in a standard fashion, and suggested uses for the information (including using the information for determining community medical complexity); and a set of suggested methods and resources for patient referral to community agencies. However, none of the information or resources included on the site explicitly mention social or caregiver support.

INTERMED is a multicomponent health assessment and screening tool designed to be self-administered by adults with a completion time of less than 15 minutes. Although the screener was not intended explicitly to identify need for social support, one of four domains, “social,” includes the following concepts: family disruption, impairment of social support (history) or residential instability, and impairment of social integration (current state) or social vulnerability (short and long term) (prognosis) (Fischer et al., 2000). The tool has been validated against other medical and psychological assessment tools in numerous populations. One study reported on the use of INTERMED to assess the role of social support in outcomes associated with T2DM: Although poorer social functioning appeared to be associated with greater medical complexity and poorer diabetic control over time, the authors did not assess associations of outcomes with individual functional domains (Fischer et al., 2000).

The Protocol for Responding to and Assessing Patients’ Assets, Risks, and Experiences (PRAPARE) is a website that provides resources for collecting patient information (National Association of Community Health Centers, 2016). The site includes a one-page patient assessment tool. Although it does not explicitly assess social support, it does ask, “How many family members, including yourself, do you currently live with?” and “How often do you see or talk to people that you care about and feel close to? (For example talking to friends on the phone, visiting friends or family, going to church or club meetings),” which could provide an entry to a more-in-depth discussion (National Association of Community Health Centers, 2016; PRAPARE, undated).

Healthleadsusa.org is a site that provides multiple patient resources, including an online Social Needs Screening Toolkit launched in 2016 and updated in 2018, and advice to providers on how to integrate SDOH screening into practice routines. The main, self-administered screener includes a single, validated question that assesses social isolation—“Do you often feel that you lack companionship?”—however, the toolkit advises that administering and following up on this question might require more-skilled staff and resources than is present in the average clinic (Health Leads, 2018). The site also refers users to additional SDOH screeners, such as PRAPARE and the Accountable Health Communities tool.
The Family Caregiver Alliance offers an online set of support tools aimed at identifying patient social support; caregiving needs; and assessment of caregiver knowledge, skills, strain, and needs for training or more-formal support (Family Caregiver Alliance, undated-a). Determination of the need to identify a caregiver is based on a single-item assessment of the patient’s existing social support—spouse, other relative or friend, or none.

The British Geriatrics Society website contains a page of resources that includes a comprehensive 20-item social questionnaire covering, for example, whether the patient is also a caregiver, drives, and owns a pet. The first two questions could be used alone to determine the need for further screening (British Geriatrics Society, 2019):

Does the patient live alone? If no, who do they live with?
What informal support is available?

Kaiser Permanente’s Washington Research Institute conducted a systematic review of tools to assess social risk and posted the results in the form of an online clearinghouse (Kaiser Permanente, 2020). Searching the term “social support systems” identified 13 tools, mostly questionnaires comprising large numbers of items. However, one questionnaire, Your Current Life Situation, developed with Social Interventions Research and Evaluation Network, is available in a longer 32-item and a shorter nine-item version. Both include one question on living situation and one question on the need for help with ADLs (Kaiser Permanente and Social Interventions Research and Evaluation Network, 2017):

Which of the following best describes your current living situation? [e.g., I live alone in my own home; I live with other people]

If for any reason you need help with activities of daily living such as bathing, preparing meals, shopping, managing finances, etc., do you get the help that you need? [e.g., I don’t need any help; I get all the help I need; I need a lot more help]

The supplemental questions include one instrumental social support question and one social connection question (Kaiser Permanente and Social Interventions Research and Evaluation Network, 2017):

[Instrumental Social Support:] Do you have someone you could call if you needed help?
[Social Connection:] How often do you see or talk to people that you care about and feel close to? (For example, talking to friends on the phone, visiting friends or family, going to church or club meetings?)

No information could be found on validation of the survey questions or studies that implemented the questions.

The Rural Health Information Hub is an online clearinghouse for tools and resources for use in working with rural populations. One area is devoted to SDOH: sites that collect and report epidemiological data on SDOH risk factors among rural populations, assessment tools, and
referral resources (Rural Health Information Hub, undated). The assessment tools listed on the site have all been described elsewhere in this report.

The CMS Accountable Health Communities Model developed a Health-Related Social Needs screening tool (CMS, undated-a). The original ten-question tool addresses interpersonal violence but does not address family and social support. However, a 16-question supplement includes one question that asks about access to help with ADLs, if needed (CMS, undated-a):

If for any reason you need help with day-to-day activities such as bathing, preparing meals, shopping, managing finances, etc., do you get the help you need? [with four response choices:] I don’t need any help . . . I get all the help I need . . . I could use a little more help . . . I need a lot of help.

And one question addresses loneliness and social isolation (CMS, undated-a):

How often do you feel lonely or isolated from those around you? [Never, Rarely, Sometimes, Often, Always]

The question that addresses need for help with ADLs is identical to a question that was included in the Your Current Life Situation tool, described above. A separate guide shows the sources for each question (including validation information, if available), requirements for using the question, and the Logical Observation Identifiers Names and Codes for each.

Table 3.1. Screening Questions, Tools, and Web Resources

<table>
<thead>
<tr>
<th>Reference or Source and Name of Tool (If Any)</th>
<th>Questions or Description of Questions</th>
<th>Was the Social Support Assessment the Entire Screening Tool or Only a Part?</th>
<th>Validation Described?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broadhead et al., 1988; Goodger, et al., 1999: Duke-University of North Carolina Functional Social Support Questionnaire</td>
<td>Eight questions in two domains: confidant support and affective support</td>
<td>Entire tool</td>
<td>Construct, concurrent, and discriminant validity in several populations of younger and older adults, compared with existing tools for mental and physical health assessment</td>
</tr>
<tr>
<td>Zimet et al., 1988: MSPSS</td>
<td>Twelve questions in three domains: family, friends, and significant others</td>
<td>Entire tool</td>
<td>Validated in multiple languages and patient groups against other mental health scales</td>
</tr>
<tr>
<td>Sheehan et al., 2003</td>
<td>In the past four weeks, was help available to you if you needed it? (five-item response)</td>
<td>Part of COOP charts for HRQOL rating</td>
<td>Scores compared with risk for somatization; no validation reported</td>
</tr>
<tr>
<td>Lin, Hirschfeld, and Margraf, 2019; Scherer et al., 2008: Perceived Social Support Questionnaire, Brief Form</td>
<td>Items referring to different aspects of experienced support (emotional support, instrumental support, and social integration); six-question version</td>
<td>Entire screening tool</td>
<td>Validated against multiple tests of positive mental health measures in four languages</td>
</tr>
<tr>
<td>Reference or Source and Name of Tool (If Any)</td>
<td>Questions or Description of Questions</td>
<td>Was the Social Support Assessment the Entire Screening Tool or Only a Part?</td>
<td>Validation Described?</td>
</tr>
<tr>
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</tr>
<tr>
<td>Rennemark et al., 2009: Swedish National Study on Aging and Care (Swedish screening tool for social support)</td>
<td>Questions related to social anchorage, which encompasses self-reported feelings of affinity towards relatives, friends, and neighbors and involvement in social activities</td>
<td>Part of a larger screening tool developed for a prior study</td>
<td>Validation against other measures of social support, but no association found with use in primary care services</td>
</tr>
<tr>
<td>Wolff et al., 2010: Guided Care Program for Family and Friends</td>
<td>Patients who reported receiving health-related assistance from another person asked to identify their primary caregiver—the person (family member or unpaid friend) who helped the most</td>
<td>Part of a tool</td>
<td>The question used to identify need for and/or receipt of caregiver support not validated</td>
</tr>
<tr>
<td>Cohen et al., 2022: ACORN</td>
<td>One item that assesses social isolation or loneliness</td>
<td>Part of a 13-item screener on SDOH developed by the VA</td>
<td>Validation not described for the question, but a similar question is included in many prior social needs tools and has been validated against tools for depression and HRQOL</td>
</tr>
</tbody>
</table>

**Social Support Screening Tools in EHR**

<table>
<thead>
<tr>
<th>Source</th>
<th>Details</th>
<th>Validation Described?</th>
</tr>
</thead>
<tbody>
<tr>
<td>HealthIT.gov, 2021</td>
<td>Gravity Project developing standard interoperable EHR data element for SDOH (Gold et al., 2018); one question addresses social support</td>
<td>Validation in process</td>
</tr>
<tr>
<td>Kaiser Permanente (Friedman and Banegas, 2018)</td>
<td>“Social isolation” assessed as part of SDOH in EHR</td>
<td>Unclear</td>
</tr>
</tbody>
</table>

**Social Support Screening Tools for Patients with Chronic Conditions**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Questions or Description of Questions</th>
<th>Validation Described?</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAND Corporation, 2003: Medical Outcomes Study Social Support Survey</td>
<td>Nineteen questions cover four domains: emotional and information support, tangible support, affectionate support, and positive social interaction</td>
<td>Construct validity demonstrated for some measures; reliability and stability shown over time</td>
</tr>
<tr>
<td>Hahn et al., 2014: Cancer and Aging Research Group's Modified Patient Reported Geriatric Assessment Questionnaire</td>
<td>A four-part question assessing need for social support in terms of help needed with ADLs and a question assessing social isolation</td>
<td>Construct and criterion validity assessed against multiple mental health and social functioning scales and reassessed in this study among caregivers of veterans</td>
</tr>
<tr>
<td>De Maria et al., 2020: 12-item MSPSS</td>
<td>Items assessing perceived social support</td>
<td>Validated; good patient caregiver agreement and association with HRQOL</td>
</tr>
<tr>
<td>Reference or Source and Name of Tool (If Any)</td>
<td>Questions or Description of Questions</td>
<td>Was the Social Support Assessment the Entire Screening Tool or Only a Part?</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
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</tr>
<tr>
<td>Fischer et al., 2000: INTERMED</td>
<td>“Social” domain assessed as a series of concepts that include family disruption, impairment of social support (history), residential instability, impairment of social integration (current state), and social vulnerability (short- and long-term prognosis)</td>
<td>One of 4 domains assessed</td>
</tr>
<tr>
<td><strong>Websites</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gerteis and Booker, 2021: AHRQ Identifying and Addressing Social Needs in Primary Care Settings</td>
<td>Toolkit of resources, including links to tools and guidance on how to choose and use tools</td>
<td>Not applicable</td>
</tr>
<tr>
<td>PRAPARE, undated</td>
<td>One question: How many family members, including yourself, do you currently live with?</td>
<td>Part of a one-page tool comprising 15 core questions; not actually intended to assess social support or need for caregiver help</td>
</tr>
<tr>
<td>Health Leads, 2018</td>
<td>Site that provides multiple patient resources, including an online self-administered Social Needs Screening Toolkit; one question assessing social isolation</td>
<td>Site that includes several SDOH screeners</td>
</tr>
<tr>
<td>Family Caregiver Alliance, undated-b</td>
<td>Toolkit that includes tools to assess patient social support, caregiver needs, and educational resources</td>
<td>Not applicable</td>
</tr>
<tr>
<td>British Geriatrics Society, undated</td>
<td>Two questions in social needs questionnaire that determine need for further social support screening</td>
<td>Part of larger social questionnaire</td>
</tr>
<tr>
<td>Kaiser Permanente Washington Research Institute, 2020: Online systematic review</td>
<td>Interactive review links to tools</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Rural Health Information Hub, undated</td>
<td>Online clearinghouse of resource and tools</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Reference or Source and Name of Tool (If Any)</td>
<td>Questions or Description of Questions</td>
<td>Was the Social Support Assessment the Entire Screening Tool or Only a Part?</td>
</tr>
<tr>
<td>---------------------------------------------</td>
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</tr>
<tr>
<td>CMS, undated-a</td>
<td>Health Related Social Needs Tool, which includes one question on access to help with ADLs and one question on social isolation and loneliness</td>
<td>Part of larger tool</td>
</tr>
</tbody>
</table>
Chapter 4. Assessing Cognitive Impairment in the Primary Care Setting

Results of the Literature Searches

Through a combination of formal literature searches and reference mining of identified sources, we identified 50 references: Nine were excluded at citation screening; nine were excluded because they pertained to settings that were not relevant to the patient population or to primary care settings, did not mention cognitive assessment, or did not address assessment of CI; and ten provided background. Nineteen studies reported in 22 publications (guidelines and peer-reviewed reports of studies) that addressed screening patients for CI in some way were used (American Academy of Family Physicians [AAFP], 2014; American Psychological Association, 2021; Aufill et al., 2019; Burton et al., 2021; CMS, 2022; Chen et al., 2018; Chow and MacLean, 2001; Cordell et al., 2013; Dementia Warning Signs Workgroup, Office of Geriatrics and Extended Care, and the National Center for Health Promotion and Disease Prevention, 2011; Feil, MacLean, and Sultzer, 2007; Fernandes, Goodarzi and Holroyd-Leduc, 2021; Ko et al., 2022; Koekkoek et al., 2016; LeRoith et al., 2019; Levell-Smith, 2020; Medicare Learning Network, 2021; Mini-Cog, 2016; Paraizo et al., 2016; Petersen et al., 2018; Thompson et al., 2021; Tokuhara et al., 2006; USPSTF et al., 2020). Figure 4.1 shows the PRISMA flowchart for the items that were identified.

The remainder of this chapter describes the relevant material identified in publications and websites. Appendix B, Table B.2 provides further information.
Figure 4.1 PRISMA Flow Diagram for Literature Search on Cognitive Impairment

Guidelines and Measures

In the late 1990s, the ACOVE initiative established a set of quality indicators for screening and diagnosis for dementia and CI among community-dwelling and hospitalized vulnerable elderly patients and for management of those diagnosed (Chow and MacLean, 2001). The quality measure set was based on systematic reviews of the literature (including existing guidelines) and an expert panel. Of 14 quality measures, five covered screening and diagnosis. The first establishes who should be screened according to the following (Chow and MacLean, 2001):

**IF** a patient is admitted to a nursing home or hospital, or is new to a physician practice,
THEN there should be documentation of a multidimensional assessment of
cognitive ability and an assessment of functional status, BECAUSE full
assessment of the patient’s self-care abilities and risk for dementia can lead to
early detection of dementia, and initiation of treatment that may delay further
progression.

This quality measure was updated in a 2007 publication to the following two measures (Feil,
MacLean, and Sultzer, 2007):

IF a vulnerable elder is new to primary care practice or inpatient service, THEN
there should be a documented assessment of cognitive ability and functional
status; and

ALL vulnerable elders should be evaluated annually for changes in memory and
function.

Seven subsequent screening and diagnosis indicators specify further cognitive evaluation,
including laboratory or imaging tests that should be conducted to rule out false positives and
clinical or psychological causes of symptoms of CI.

The rationale for the quality measure asserts that, although no direct evidence supports a role
for screening in improving clinical outcomes, indirect evidence does support the positive effect
of early clinical and social interventions.

The ACOVE indicators considered other quality measures and guidelines in existence at the
time. Therefore, we first sought to determine whether these guidelines and measures have been
updated in the intervening 20 years.

Quality Measures and Guidelines for General Populations

Although we did not identify other quality measures like ACOVE, we identified several
updated guidelines for screening for CI. Some of these specify when and on which patients
screening should be performed.

The American Academy of Neurology updated its screening guidelines for MCI in 2018
(Petersen et al., 2018):

1. For patients for whom the patient or a close contact voices concern about
memory or impaired cognition, clinicians should assess for MCI and not
assume the concerns are related to normal aging.

2. When performing a Medicare Annual Wellness Visit, clinicians should not
rely on historical report of subjective memory concerns alone when assessing
for cognitive impairment.

3. When screening or assessing for MCI, validated assessment tools should be
used.2 Various instruments have acceptable diagnostic accuracy for detecting
MCI, with no instrument being superior to another. For patients who test

2 Validation of screening tests for CI refers to comparing the findings for that test for a large, representative
population against the findings of a complete diagnostic evaluation of that population by a neurologist blinded to the
results of the screening test.
positive for MCI, clinicians should perform a more formal clinical
assessment for diagnosis of MCI.

4. For patients with MCI, clinicians should assess for the presence of functional
impairment related to cognition before giving a diagnosis of dementia.

5. For patients suspected to have MCI, clinicians who lack the necessary
experience should refer these patients to a specialist with experience in
cognition.

6. For patients diagnosed with MCI, clinicians should perform a medical
evaluation for MCI risk factors that are potentially modifiable.

7. For patients and families asking about biomarkers in MCI, clinicians should
counsel that there are no accepted biomarkers available at this time [but can
refer to sites conducting clinical trials].

8. For patients diagnosed with MCI, clinicians should perform serial
assessments over time to monitor for changes in cognitive status.

The American Academy of Neurology also provides recommendations regarding differential
diagnoses.

CMS requires assessment for CI as part of the AWV and provides brief guidelines but does
not specify a particular tool (CMS, 2022; Medicare Learning Network, 2021):

Detecting cognitive impairment is a required element of Medicare’s AWV. You
can also detect cognitive impairment as part of a routine visit through direct
observation or by considering information from the patient, family, friends,
caregivers, and others. You may also use a brief cognitive test and evaluate
health disparities, chronic conditions, and other factors that contribute to
increased risk of cognitive impairment. If you detect cognitive impairment at an
AWV or other routine visit, you may perform a more detailed cognitive
assessment and develop a care plan during a separate visit. This additional
evaluation may be helpful to diagnose a person with dementia, such as
Alzheimer’s disease, and to identify treatable causes or co-occurring conditions
such as depression or anxiety.

To operationalize screening recommendations for the Medicare AWV, the Medicare
Detection of Cognitive Impairment Workgroup of the Alzheimer’s Association developed
guideline, algorithm, and screening tool recommendations based on a series of systematic
reviews in 2013 (Cordell et al., 2013). The workgroup sought to determine whether consensus
existed regarding the best tools for brief cognitive assessment during primary care visits, not to
identify a gold-standard tool. It found that, although many tools exist, most were validated in
narrow populations. The resulting algorithm includes review of the patient Health Risk
Assessment information, patient observation, open-ended questions during the AWV, and use of
structured cognitive assessment tools for both patients and informants (i.e., family members or
other caregivers). Among 17 tools reviewed, the researchers recommended three screening tests:
the Memory Impairment Screen (MIS), General Practitioner Assessment of Cognition (GPCOG),
and Mini-Cog, based on the following criteria (Cordell et al., 2013):
• requires 5 minutes or less to administer
• is validated in a primary care or community setting
• is easily administered by medical staff members who are not physicians
• has good to excellent psychometric properties
• is relatively free from educational, language, and/or culture bias
• can be used by clinicians in a clinical setting without payment for copyrights. (This concern applies to a tool with widespread use, the Mini Mental State Examination [MMSE].)

The researchers also assessed tools intended to be used with an informant and identified the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), the Ascertain Dementia 8 (AD8), and the GPCOG.

The American Psychological Association Task Force on the Evaluation of Dementia and Age-Related Cognitive Change released a set of 16 guidelines for the Evaluation of Dementia and Age-Related Cognitive Change in 2021, updating a 1998 guideline set (American Psychological Association, 2021). Guideline 8 covers use of standardized tests, including brief screening and monitoring tests. Although it mentions the MMSE and Montreal Cognitive Assessment (MoCA) as examples, this does not appear to be an endorsement. The American Psychological Association, 2021, does recommend that brief cognitive screening tools “should be standardized and have good positive predictive values for identifying possible cognitive impairment.” The guideline also notes that clinicians must be aware of differences in sensitivity predictive values of screeners across populations of different ages, races or ethnicities, and educational levels. The positive predictive value (PPV) and negative predictive value (NPV) of a diagnostic test refer to the likelihood that a person with a positive or negative test result truly has or does not have, respectively, the condition in question, as determined by validation with a full diagnostic evaluation of CI. PPVs and NPVs take the prevalence of the condition in the group of interest into account.

In 2014 and again in 2020, the USPSTF recommended against routine screening for CI—that is, screening of individuals who have not shown signs of CI—among asymptomatic community-dwelling adults 65 years and older because the evidence for benefits (e.g., earlier initiation of treatment resulting in a better prognosis) did not outweigh the evidence for harms. However, the USPSTF states that more research is needed.

The AAFP adheres to USPSTF recommendations and does not endorse screening for MCI or dementia in patients who do not present with signs or concerns regarding CI (AAFP, 2014).

In 2011, the VA, in collaboration with other groups, developed a clinician fact sheet on recognizing signs of dementia (Dementia Warning Signs Workgroup, Office of Geriatrics and Extended Care, and the National Center for Health Promotion and Disease Prevention, 2011). The Warning Signs guideline was intended to assist adherence to the USPSTF and AAFP recommendations against routine screening of asymptomatic individuals for CI, advising instead
to rely on 11 warning signs—six clinician warning signs and five caregiver warning signs—to guide further assessment.

**Guidelines for Patients with Chronic Conditions**

Several guidelines have been issued for cognitive screening of individuals with chronic conditions that can increase the risk for CI (age related or otherwise).

A 2020 advanced practice nursing doctoral thesis presented the first guideline, based on a systematic review, for including a brief cognitive function screening tool in the assessment packet for all patients with T2DM (Levell-Smith, 2020).

Concurrently, the Endocrine Society and the American Diabetes Association released guidelines advising periodic screening of patients 65 and older with diabetes to detect undiagnosed CI (LeRoith et al., 2019).

The HIV Medicine Association of the Infectious Diseases Society of America recommends that the initial exam of a person who is HIV positive should include an assessment for CI but does not specify how the assessment should be conducted (Thompson et al., 2021).

**Tools and Question Sets**

Numerous screening tools have been developed for (relatively) rapid screening for MCI, Alzheimer’s disease, and dementia. Screening modalities tend to fall into one of several categories, based on who provides the information, that is whether the test is self-administered, provider administered, caregiver elicited, or a combination. Tests might also differ on the cognitive and functional domains most emphasized, but a review of these distinctions is beyond the scope of this report. Likewise, various studies are exploring the utility of imaging and biomarker assessment for identifying early signs of or risk for CI, but a review of these efforts is also beyond the scope of this report.

Several systematic reviews and reviews of reviews have assessed the utility, reliability, and validity of screening tools for CI in the primary care setting, and some studies have assessed their utility with patients with such chronic conditions as T2DM, kidney failure, and substance use disorders (SUDs).

This section will summarize the findings of the most-recent systematic reviews and the findings of original studies that were not included in the reviews.

**Systematic Reviews**

A 2021 systematic review of reviews on screening, diagnosis, and management of dementia in primary care settings compared the sensitivity and specificity (and PPV and NPV where relevant; again, sensitivity and specificity do not consider prevalence, only the inverse risk of a false negative and false positive, respectively) of the most-widely used and reviewed tools (high quality by AMSTAR 2) (Fernandes, Goodarzi, and Holroyd-Leduc, 2021). Nine systematic
reviews that included screening tools for use in primary care were included. They report that the Mini-Cog and the MMSE are the most-widely used tools, but the Abbreviated Mental Test Score (AMTS) could be the most-rapid, -sensitive, and -specific tool among the major tools used in primary care settings. The Mini-Cog was reported to take a minimum of 3 minutes to complete, whereas the AMTS took slightly longer (3.2 to 5 minutes). The reviewers also support use of the Mini-Cog as a rapid initial screener to identify the need for further testing, although they note that the lower sensitivity of this test might result in too many missed cases.

A 2021 Cochrane Review assessed the utility of the IQCODE, a 16- or 26-item screener, for use with patient informants in primary care settings (high quality by AMSTAR 2) (Burton et al., 2021). The review identified only one study (with high risk of bias) that met inclusion criteria. Thus, no conclusions were drawn.

A 2018 systematic review that included seven studies assessed the utility of the AD8 eight-item questionnaire in various settings, including primary care (high quality as assessed by AMSTAR 2) (Chen et al., 2018). The AD8 is a brief informant-based measure that asks about changes in performance of eight different functions and can be administered in less than 3 minutes. The tool has been translated into and validated in several languages. The reviewers were able to divide original studies into those that used the tool to discriminate MCI from more-advanced dementia and those that used the tool to discriminate those with MCI or dementia from those with no evidence of CI. The tool showed greater sensitivity in differentiating normal cognition from MCI or dementia when used in clinics or hospitals than when it was used in the community, likely because of differences in severity of CI. The reviewers note the importance of including informant perspective in screening.

A 2021 systematic review assessed screening tools for CI specifically for use in patients with SUD (high quality as assessed by AMSTAR 2) (Ko et al., 2022). Fourteen studies that met inclusion criteria identified ten cognitive screening tools. The MoCA was the most-commonly used, and two novel screening tools (Brief Evaluation of Alcohol-Related Neuropsychological Impairments and Brief Executive Function Assessment Tool) were specifically developed for use in SUD populations. The review provided both research and clinical recommendations. Research recommendations included the need for more-widespread validation, especially in patients with co-occurring conditions, and the need to clearly identify study-level characteristics (e.g., settings and patient characteristics) when evaluating tools for research publications. Clinical recommendations included endorsement of the MoCA for patients with SUD based on ease of use, validation, and other factors (e.g., the MoCA has several alternate versions, facilitating relatively frequent retesting). The authors recommended not relying on published cutoff scores when implementing tools in populations with SUD. They also noted that newer tools show promise but require further testing.
Original Studies

As indicated, numerous studies have assessed the use of screening tools for CI in primary care settings. This section reviews the findings of a very small number of newer studies that were not included in prior reviews and that focus on screening for CI in patients with chronic conditions. No studies assessed the use of screening tools in patients with multiple complex conditions.

A 2016 Netherlands study compared two rapid self-administered questionnaires for screening for CI in patients with T2DM (Koekkoek et al., 2016). The Test Your Memory (TYM) instrument is a self-administered test consisting of ten subtasks, which can be completed in 5 minutes. The tasks include orientation, ability to copy a sentence, semantic knowledge, calculation, verbal fluency, similarities, naming, visuospatial abilities (two subtasks), and recall of a copied sentence. The ability to complete the test without help represents an eleventh task. The Self-Administered Gerocognitive Examination (SAGE) is a self-administered test, completed in 10 to 15 minutes, that assesses orientation, language, memory, executive function, calculations, abstraction, and visuospatial abilities and also includes questions on demographic information, personal and family medical history, and current status. The researchers validated the two screeners against a primary caregiver–administered MMSE and full evaluation at a memory clinic, finding that both screeners showed sufficient reliability and validity for routine screening.

A 2016 study conducted in Brazil assessed several tools for use in screening for CI in nonelderly adult patients with chronic kidney disease prior to beginning dialysis (Paraizo et al., 2016). The study compared the MoCA with several simple tools for assessing executive function: the clock drawing, the digit span forward and reverse, phonemic verbal fluency and semantics (animals), fist-edge-palm, and the ten-picture memory tests. The MoCA indicated CI in 71 percent of predialysis patients: Positive screening was associated with age, diabetes, and educational attainment. A combination of the clock drawing, digit span forward and reverse, and fist-edge-palm compared well with MoCA in identifying MCI in this population. The authors do not suggest substitution of these tests for the MoCA but rather interpret the findings as indicating that executive function might be affected in patients with kidney failure.
Social Support

Despite frequent mention of the importance of social support in health and assessing patients’ need for—and existence of—social support, we found no quality measures that referred to when or how to assess social support of patients in the primary care setting, including patients with complex care needs; which patients to assess; or how or when to refer for further services.

Only one guideline, a decision aid tool created by the WHO for use with older patients with complex care needs, was identified. Although the guideline provided an implementation framework, no actual guidance was provided about how often to use the tool (to assess social support and caregiver support) or what follow-up social services to refer patients with additional need for social or caregiver support. (In contrast, the guideline provides guidance on referring patients with physical or mental health needs, violence victimization, and financial needs.)

A 2020 study examined SDOH that were already included in USPSTF primary care recommendations and proposed a process for identifying others that should be considered for inclusion, but social support was not among them (Davidson et al., 2020). However, a 2016 National Academies of Sciences, Engineering, and Medicine report on the impact of social risk factors on health care costs among the elderly noted that social risk factors encompass (and need to account for) five domains: socioeconomic position; race, ethnicity, and cultural context; gender; social relationships; and residential and community context (National Academies of Sciences, Engineering, and Medicine, 2016).

Studies that aimed to assess the role of or need for social support in patient health outcomes typically omitted mention of how they evaluated social support—either to assess whether patients met the study’s inclusion criteria or to measure exposures. For example, one study that recruited patients based on medical records and surgeon recommendations mentioned that two questions were asked to assess social support—one for the patient and one for the caregiver—but the questions were not identified (Bekelman et al., 2011). A published protocol for a trial aimed at assessing the effect of a program targeting patients with multiple chronic conditions and their caregivers to assist with managing their conditions described only age, diagnoses, and geographic location as the criteria for enrollment (Markle-Reid et al., 2020).

However, we did identify several tools, ranging from a single question to dozens of questions, that were designed to assess patients’ need for social support, and sometimes the accessibility of this support, in primary care settings. We comment further on the limitations of these tools below.

Social support, as conceived by the tools and other resources identified for the current report, encompasses at least two concepts: help when needed with performing ADLs and emotional
support (as in the absence of loneliness or social isolation). Some questions were clearly focused on identifying patients’ ADLs and instrumental ADLs (IADLs) and identifying persons who could help poorly functioning patients, whereas others were meant to assess whether the patient had social interactions and felt loved or important (and at least one screener focused only on interpersonal safety and violence, to the extent that it touched on social support at all). It is clearly possible to be surrounded by loved ones who cannot help with ADLs, just as it is possible to have all of one’s material needs but none of one’s social or emotional needs met. It is beyond the scope of this review to try to assess whether one is generally more important than the other to assess or to fulfill.

When we assessed how the social support assessment tools or questions were validated, we found that some of the questions, usually the larger question sets, were validated against other tools, such as those assessing ADLs, IADLs, HRQOL, or depression, but many reported no validation or were validated against another social support assessment tool. It has been suggested that the only appropriate validation for an assessment of social support is the determination of the association between what is being assessed and whether follow-up actions aimed at addressing deficits result in improved processes or outcomes for patients. Almost none of the studies we identified reported the association of social support, as assessed by their tool, with subsequent process implementation to address identified deficits or with changes in health outcomes.

Another concern we noted was a general lack of information on clinical implementation of assessment tools—information both on the patient populations and on how the tools were used in the primary care settings. Some study authors noted that their tools were implemented in small, nonrepresentative groups of patients.

Who assesses social support, and how are processes embedded in primary care visits? The primary goal of this review was to identify quality measures or guidelines for assessing social support among complex patients in primary care and, in the absence of those, to identify validated, brief tools or questions that a primary care provider can use to quickly ascertain a patient’s need for and access to social support. However, most publications lacked information on whether tools were self-administered or administered by a staff member or how use of tools was implemented in primary care processes, and none addressed follow-up referral. Some studies and sites emphasized that their questions or tools were intended for use by providers. However, some studies assume that social (case) workers would be conducting the assessments on referral from a provider. For example, among the very small number of VA studies we identified, a 1996 study reported on the development and use of a social needs checklist intended for use by VA social workers in the primary care setting (the publication did not provide the actual questions) (Cook et al., 1996). A recent study conducted in a group of rural VA primary care clinics assessed the effect of a Social Work PACT Staffing Initiative on three outcomes: access to social services (encounters with a social worker), hospitalization, and emergency department use. The study identified high-risk veterans using the Care Assessment Needs score (95th percentile or
higher) and used the Elixhauser score to control for the number of comorbid conditions but did not report on the assessment questions or tools that the social workers used. The results indicated that social worker assessment was associated with greater contact with social services personnel and small reductions in hospitalization and emergency department use. The authors recommended that future work examine additional impacts, including access to supportive services, such as caregiver support (Cornell et al., 2020). Neither of these studies addressed criteria that providers used or could use to determine which patients to refer to social services, and that is a critical omission for these studies. The study by Cornell and colleagues, 2020, compared hospitalization and emergency department use among high-risk (complex) patients who were seen in the clinic before and after the addition of social workers to the PACTs, whereas the study by Cook and colleagues, 1996, surveyed a convenience sample of patients in a VA primary care clinic waiting room.

A critical gap in published tools for assessing patients’ need for social support is that no criteria appear to exist for deciding whom to assess, when to assess, and when to refer for follow-up. Should all complex patients be asked about social and caregiver support, or only a subset with particular characteristics (e.g., obvious difficulty with self-care)? And how often should they be asked—at every visit? The complex and changing needs of this patient population suggest that a brief question set be used to screen all patients. However, only when the implementation of such assessment (and the resulting identification of caregivers who can provide support or, if suggested, referral to social services) can be tested to see whether assessment improves health outcomes will it be possible to begin to address who should be assessed, how often, and with what follow-up.

Once such criteria and questions are identified and validated, a step that will facilitate primary care providers’ ability to quickly screen patients for social support needs will be embedding the questions into EHR dashboards. Doing so will also make it feasible to assess whether eligible patients receive recommended screening. Several of the studies we identified were focused on developing brief social support screening questions expressly for EHR. One study canvassed several vendors with large market shares and found that most were developing products to collect SDOH data and were working with policymakers to actively address challenges associated with data standardization and interoperability (Freij et al., 2019). No nationwide policies or guidelines exist even regarding what information to collect, let alone how to collect it. The authors point out that, because of this gap, the largest vendors might end up setting those policies and standards for all health care systems.

**Cognitive Impairment**

As we found for screening for the need for social support, caregiver assistance, and referral, many tools exist for screening for CI. However, in contrast to social support, most of the screening tools for CI have been validated extensively against the gold standard of full cognitive
evaluations, some even in patients with chronic conditions, albeit not complex combinations of conditions. Still, challenges remain with screening and even with identifying patients for screening.

The USPSTF and AAFP express legitimate concerns regarding the lack of evidence that screening for CI in the absence of indications improves health outcomes. A 2022 systematic review finds that cognitive remediation interventions following a diagnosis of MCI or early-stage dementia are effective in improving IADL performance in the short term but that evidence for long-term improvement is still lacking (Tulliani et al., 2022). A screener with inadequate PPV could result in decreased quality of life by instilling worry and fear, whereas a screener with poor NPV could miss a diagnosis and opportunity for early intervention (although, admittedly, early intervention might be relevant only for those patients with CI that is due to a reversible cause such as depression, a medication [or polypharmacy], or one of several B vitamin deficiencies).

Tests that include an informant show some evidence of being more accurate than those that involve only the patient. However, this observation might need further evaluation, especially among larger, more racially and culturally diverse populations.

Multiple studies note that CI screening tools have been inadequately validated in populations and individuals with low literacy, lack of education, and poor English language skills, each of which can result in screening results suggestive of CI.

Finally, a burgeoning area of research is on alternative methods of diagnosing and predicting risk for CI and dementia. Methods include genetic screening for biomarkers and use of imaging and artificial intelligence (Levy et al., 2022; Sabbagh et al., 2020). Because of this expanding research, a group of UK clinicians and researchers issued a set of evidence-based guidelines in 2021, referred to as the Manchester consensus, on the proposed new MCI screening methods and cognitive testing, follow-up, and diagnostic terminology (Dunne et al., 2021). These guidelines urge caution in the use of newer screening methods, especially given the lack of existing data on ethnically diverse populations and the absence of clear evidence on the outcomes and value of early screening.

**Recommendations**

It is beyond the scope of this report to make research or practice recommendations. Nevertheless, the literature suggests several next steps:

- Social support and caregiver screening of patients with complex care needs for referral appear feasible and necessary, but it will be important to identify brief screening tools that can be used for all patients or to identify criteria for which patients to assess further.
- Social support screening will need to undergo validation in populations of patients with complex care needs to demonstrate association with improvement in clinical outcomes.
- Cognitive screening of patients with complex care needs in the primary care setting appears feasible, but patient factors that can affect performance and choice of screening test must be considered carefully.
Risks, benefits, and cost-effectiveness of screening complex patients (versus screening only patients who demonstrate some signs of need for social support or present symptoms suggestive of possible CI) must be considered.
Appendix A. Search Strategies

Search Strategies for Social and Caregiver Support and Referral

The following formal search strategies were used, followed by searches in Google Scholar and in additional guideline clearinghouses and sites. Searches were conducted on November 3, 2021.

**PubMed**

(“Comorbidity”[Mesh] AND “Surveys and Questionnaires”[Mesh])

AND

“Ambulatory Care”[Mesh]

AND

measure*[tiab]

AND

(gap*[tiab] OR missing*[tiab] OR need*[tiab] OR barrier*[tiab] OR vulnerab*[tiab])

**PubMed**

(“Comorbidity”[Mesh] AND “Surveys and Questionnaires”[Mesh])

AND

“Ambulatory Care”[Mesh]

AND

((gap*[tiab] OR gaps*[tiab]) AND care*[tiab])

(“Healthcare task*”[tiab] OR “health care task*”) AND (Comorbidity”[Mesh] OR multimorbid*[tiab] OR complex*[tiab]) AND “Surveys and Questionnaires”[Mesh]

**ECRI Guidelines Trust**

(caregiver* AND Support) AND (measure* OR questionnaire* OR identif*) AND (“Primary care” OR Ambulatory OR outpatient*)

(caregiver* AND Support) AND (measure* OR questionnaire* OR identif*) AND (complex OR chronic)

Search Strategies for Screening for Cognitive Impairment

Searches were conducted on February 4, 2022.
PubMed
AND
“Primary Health Care”[Mesh] OR “primary care”[tiab] OR “general practitioner*”[tiab]
AND

American Psychological Association PsycInfo
DE “Cognitive Impairment” OR TI(“cognitive impairment” OR “cognitive status” OR “cognitive decline”) OR AB(“cognitive impairment” OR “cognitive status” OR “cognitive decline”)
AND
DE “Primary Health Care” OR TI(“primary care” OR “general practitioner*”) OR AB(“primary care” OR “general practitioner*”)
AND
DE “Questionnaires” OR TI(questionnaire* OR survey* OR “practice guideline*”) OR AB(questionnaire* OR survey* OR “guideline*”)
Appendix B. Evidence Tables

This appendix comprises two evidence tables: Table B.1 displays brief details of the studies and websites that identified social support, caregiver support, and referral assessment. Table B.2 displays study-level details for the studies that reported on screening for CI and dementia.

### Table B.1. Evidence Table for Social and Caregiver Support

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Notes, Source, or Suggested References</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHRQ</td>
<td>See Gerteis and Booker, 2021, below.</td>
</tr>
<tr>
<td>Boyd et al., 2014</td>
<td>The Health Care Task Difficulty Scale tool was developed and validated for assessing older adults with multimorbidity in self-reported difficulty with eight different health care treatment tasks (treatment burden): obtaining medications, planning medication schedule, taking medications, making decisions about changing medications, managing medical bills, scheduling medical appointments, arranging transportation, and getting information. The tool could be used to assess need for support. To assess predictive ability, cross-sectional associations of the Health Care Task Difficulty Scale tool and number of chronic diseases, and conditions that add to health status complexity (falls, visual, and hearing impairment), patient activation, patient-reported quality of chronic illness care (Patient Assessment of Chronic Illness Care), and mental and physical health (SF-36: HRQOL) were tested using statistical tests for trends.</td>
</tr>
<tr>
<td>British Geriatrics Society, 2019</td>
<td>The website contains a page of resources, including a comprehensive 20-item social questionnaire covering, for example, whether the patient is also a caregiver, drives, and owns a pet. The first two questions could be used alone to determine the need for further screening: (1) &quot;Does the patient live alone? If no, who do they live with?&quot; and (2) &quot;What informal support is available? Questions do not seem to have been validated.&quot;</td>
</tr>
<tr>
<td>Broadhead et al., 1988</td>
<td>The Duke-University of North Carolina Functional Social Support Questionnaire is a two-domain, eight-item tool that was shortened from a 35-item to a 14-item questionnaire in the 1980s to assess &quot;confidant support&quot; and &quot;affective support&quot; among patients in the primary care family medicine setting. The tool has demonstrated construct, concurrent, and discriminant validity.</td>
</tr>
<tr>
<td>CMS, undated-a</td>
<td>The original ten-question tool addresses interpersonal violence but does not address family and social support. However, a 16-question supplement includes one question that asks about access to help with ADLs, if needed, and one question that addresses loneliness and social isolation. The citation guide includes sources for each question, requirements for using the question, and Logical Observation Identifiers Names and Codes.</td>
</tr>
<tr>
<td>CMS, undated-b</td>
<td>This website is a clearinghouse for Medicare treatment guidelines.</td>
</tr>
<tr>
<td>Cohen et al., 2022</td>
<td>ACORN is a 13-item screening tool for assessing ten domains of SDOH, developed by the VA for use with all VA patients. The tool has been implemented and is being tested in several VA clinical settings, including primary care, women's health, mental health, social work, and peer support. One item asks about loneliness and social isolation (response options are always, sometimes, and never). The question has been used and validated in other screening tools, typically against measures of depression. The tool can be self-administered before or during visits or administered by providers or other staff with results recorded in EHRs (it is unclear whether any VA health care system has already inserted the tool into its EHR system). The tool developers state that results of the tool can be used to guide providers to give appropriate information: &quot;Veterans who screen positive [criteria not clarified] are provided with geographically tailored resource guides, resource navigation support, and/or referrals to social [services].&quot;</td>
</tr>
<tr>
<td>Core Quality Measures Collaborative, undated</td>
<td>The Core Quality Measures Collaborative identified social support as being a gap in its measure sets.</td>
</tr>
<tr>
<td>Study ID</td>
<td>Notes, Source, or Suggested References</td>
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<tr>
<td>De Maria et al., 2020</td>
<td>The 12-item MSPSS was validated in a population of older adults with multiple chronic conditions, and their caregivers, in Italy. There was good agreement regarding perceived social support in patient-caregiver dyads and strong association with HRQOL.</td>
</tr>
<tr>
<td>Duke Aging Center, undated; Fillenbaum and Smyer, 1981</td>
<td>This Duke University School of Medicine’s Duke Aging Center website provides access to a survey that was developed, validated, and reliability tested to assess the impact of service provision on the functional status of older adults. The survey, which must be purchased, takes 45 minutes to administer. The questionnaire assesses individual functional status in five dimensions, including social resources, and then determines extent, intensity of utilization, and perceived need for each of 24 nonoverlapping, broadly encompassing generic services.</td>
</tr>
<tr>
<td>Family Caregiver Alliance, undated-a</td>
<td>Caregivers Count Tool website and toolkit include assessments for clinicians to determine patient needs, which family members should be assessed and how, caregiver resources and strengths, and additional caregiver needs.</td>
</tr>
<tr>
<td>Fischer et al., 2000</td>
<td>INTERMED is a multicomponent health assessment and screening tool designed to be self-administered by adults with a completion time of less than 15 minutes. Although the screener was not intended explicitly to identify need for social support, one of four domains, “social,” includes the following concepts: family disruption, impairment of social support (history), residential instability; impairment of social integration (current state), social vulnerability (short- and long-term) (prognosis). The tool has been validated in numerous populations. This study reported on the use of INTERMED to assess the role of social support in outcomes associated with T2DM.</td>
</tr>
<tr>
<td>Friedman et al., 2018</td>
<td>Kaiser Permanente Northwest developed a risk stratification system to prioritize community resource referral follow-up. One element that is recorded in the EHR is the patient’s social support, which it calls social isolation (code Z62.4), and it describes using the system if patient has “lack of or limited availability of family, friends, community groups, or agencies to provide routine social support, member spends most of time alone (in home or facility).” However, no information is provided on how this is assessed.</td>
</tr>
<tr>
<td>Gerteis and Booker, 2021</td>
<td>This online resource helps guide primary care clinicians on whether to screen for social needs, tools to use (including links to three additional sites that provide tools), and recommendations on gathering and implementing information obtained from patients. The site does not refer specifically to screening for social support or caregiver assistance.</td>
</tr>
<tr>
<td>Goodger et al., 1999</td>
<td>An 11-item version of the Duke-University of North Carolina Functional Social Support Questionnaire was developed and validated among older adults in Australia.</td>
</tr>
<tr>
<td>Grinberg et al., 2016</td>
<td>To assess predictive ability, cross-sectional associations of the Health Care Task Difficulty Scale tool and number of chronic diseases and conditions that add to health status complexity (falls, visual, and hearing impairment), patient activation, patient-reported quality of chronic illness care (Patient Assessment of Chronic Illness Care), and mental and physical health (SF-36) were tested using statistical tests for trends among a population of adults with frequent hospitalizations to aid in implementation of care management.</td>
</tr>
<tr>
<td>Hahn et al., 2014; Hahn et al., 2010</td>
<td>The Cancer and Aging Research Group developed a Modified Patient Reported Geriatric Assessment Questionnaire that contains questions on functional status, including a four-part question to assess social support in terms of help needed with ADLs and a question to assess social isolation. The questions were based on questions developed by the Patient Reported Outcomes Measurement Information System’s Cooperative Group’s Social Health Workgroup using on the Instrumental Support and Social Isolation domains. The questions were subsequently validated in a population of caregivers of veterans with traumatic brain injuries.</td>
</tr>
<tr>
<td>Health Leads, 2018; Gold et al., 2017; Gold et al., 2018</td>
<td>The Health Leads screening toolkit includes a single question that assesses social isolation: “Do you often feel that you lack companionship?” Validation is uncertain.</td>
</tr>
<tr>
<td>HealthIT.gov, 2021</td>
<td>Official website of the Office of the National Coordinator for Health Information Technology focuses on four key areas for using health IT to advance the interoperability and use of SDOH data: standards and data, infrastructure, policy, and implementation. The site reviews recent standards and efforts to incorporate SDOH measures and screening questions into EHR and provides links to professional practice organization resources.</td>
</tr>
<tr>
<td>ICOPE</td>
<td>See WHO, 2019 (ICOPE), below.</td>
</tr>
<tr>
<td>Study ID</td>
<td>Notes, Source, or Suggested References</td>
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</tr>
<tr>
<td>Kaiser Permanente, 2020; Kaiser Permanente and Social Interventions Research and Evaluation Network, 2017</td>
<td>This website is an online systematic review of tools for social needs screening and related resources. The site provides links to the actual tools.</td>
</tr>
<tr>
<td>Lin, Hirschfeld, and Margraf, 2019; Scherer et al., 2008</td>
<td>The Brief Perceived Social Support Questionnaire (also known as F-SozU K-6), is a six-item test of perceived social support that consists of the following questions (assessed on a 5-point Likert scale): 1. I experience a lot of understanding and security from others. 2. I know a very close person whose help I can always count on. 3. If necessary, I can easily borrow something I might need from neighbors or friends. 4. I know several people with whom I like to do things. 5. When I am sick, I can without hesitation ask friends and family to take care of important matters for me. 6. If I am down, I know to whom I can go without hesitation. This study examined the validity of the scale (originally written in German) in English, Chinese, and Russian in the United States, China, and Russia among students and older adults and found good correlations and validity (negative correlations with depression, anxiety, and stress and positive correlations with positive mental health measures) among all populations.</td>
</tr>
<tr>
<td>National Association of Community Health Centers, 2016</td>
<td>The PRAPARE website provides resources for collecting patient information. A one-page assessment tool is intended for assessing SDOH; it does not explicitly address social support but includes 1 question that asks how many family members the patient currently lives with. Validation is unknown.</td>
</tr>
<tr>
<td>RAND Corporation, 1993</td>
<td>This is a tool to screen for social support among adult patients with chronic health conditions. It includes 19 items in four domains: emotional and information support, tangible support, affectionate support, and positive social interaction. The response choice employs a five-point Likert scale. The tool demonstrates good reliability and stability, and validity was shown for several the items.</td>
</tr>
<tr>
<td>Rennemark et al., 2009; Hanson et al., 1997</td>
<td>This study used a Swedish screening tool developed in the 1990s to assess the association of social support with health outcomes. The tool assesses structural and functional aspects of social networks and social support based on concepts deduced from a theoretical framework of social resources. The tool also added an item to assess a concept called control, defined as the relationship between the demands of daily life and the resources the individual possesses to handle these demands. The tool demonstrated good reliability in older individuals but less reliability among younger adults, especially females. The tool showed an association of social anchorage with less use of health resources. Hanson and colleagues assessed social anchorage based on: (1) membership in a club or organization for which one feels a strong affinity, (2) feelings of strong affinity toward relatives, (3) experiencing a sense of anchorage and acceptance in the presence of neighbors, and (4) belonging to a group of friends or acquaintances who do things together. In this study, social anchorage was not associated with frequency of use of primary care services among elderly.</td>
</tr>
<tr>
<td>Rural Health Information Hub, undated</td>
<td>The site includes a list of tools and other resources for assessing SDOH and other health risks and databases of regional demographic and health information. Tools are similar to those on other sites.</td>
</tr>
<tr>
<td>Sheehan et al., 2003</td>
<td>Among 140 primary care clinic attenders 65 or over, perceived social support was measured twice over ten months using one item from the COOP charts. These charts rate a subject’s health-related quality of life in nine areas. Item eight asks the subject whether, in the past four weeks, help was available to them should they require it. Responses cover five levels from “Yes, as much as I wanted” to “No, not at all.” Higher scores thus indicate lower perceived support. Higher perceived social support was associated with lower risk for somatization, and somatization has been shown across multiple studies to be associated with increased number of visits to primary care. It was also noted that somatization symptoms were transient, whereas perceived poor social support was persistent.</td>
</tr>
<tr>
<td>Skolasky et al., 2011; Boyd et al., 2007</td>
<td>This study aimed to assess the validity of the Patient Activation Measure among older adults with multiple morbidities who were at risk of using large amounts of health resources and who were enrolled in Guided Care, an intervention based on a model of comprehensive health care for older adults with multimorbidities. The intervention was based on a four-stage model of patient activation. The study used latent class analysis to assess a theoretical four-stage model of patient activation. Self-reported social</td>
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<td>Study ID</td>
<td>Notes, Source, or Suggested References</td>
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<td>support was assessed at baseline in the Guided Care program using the response to the following statement: “Could [you] have used more support with household activities or health care in the last six months?” In this context, activity referred to usual household or recreational activities, such as housecleaning or grocery shopping; participation in hobbies; and health care activities, such as attending appointments or managing medications. Response choices were: “A lot,” “Some,” and “No, none.” Reporting “a lot” or “some” was associated with lower Patient Activation Measure scores and activation stage.</td>
</tr>
<tr>
<td>WHO, 2019 (ICOPE)</td>
<td>This book-length guide does not provide a measure or measures but provides assessment tools and guidelines for caring for older adults in primary care settings worldwide. Chapter 10, Social Care and Support, provides an assessment tool for ADLs and IADLs that includes an assessment of sources of and need for social support, loneliness, and need for various kinds of social support. Assessments should include “support for their living condition, financial security, loneliness, access to community facilities and public services, and support against elder abuse.” Guidance is provided on how to assess loneliness, what kinds of social contact the person desires, whether a pet would help, what kinds of activities the person considers important to engage in for a meaningful life, and what barriers might be preventing the person from engaging in those activities and when referrals to other services might be beneficial and the kinds of referrals.</td>
</tr>
<tr>
<td>Wolff et al., 2010</td>
<td>A cluster-randomized trial of 14 primary caregiver-patient teams assessed the effects of a Guided Care model of health care for older adults with multiple morbidities on primary caregivers. The 18-month program did not affect caregivers’ depression, strain, or productivity but improved their—and their care recipients’—perceptions of the quality of care that their care recipient was receiving. Patients were recruited based on Hierarchical Condition Category score predictions of need for health services in the coming year. Patients who reported receiving health-related assistance from another persons were asked to identify their primary caregiver—the person (family member or unpaid friend) who helped the most.</td>
</tr>
<tr>
<td>Zimet et al., 1988</td>
<td>MSPSS is a scale that groups 12 items into three domains: family, friends, and significant others. It has been validated in multiple languages, cultures, and patient groups, and is likely the predecessor of the Perceived Social Support Questionnaire.</td>
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<tr>
<td>Study ID</td>
<td>Study Type, Study Content, and Organization Information</td>
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<tr>
<td>AAFP, 2014</td>
<td>Article reports on: Guideline Content of measure or guideline: Clinical preventive service recommendations do not recommend routine screening of primary care patients for CI or dementia. Organization that sponsored or developed the guideline, measure, or test: AAFP</td>
</tr>
<tr>
<td>American Psychological Association, 2021</td>
<td>Article reports on: Guideline Content of measure or guideline: Guideline on evaluation of age-related CI and dementia Organization that sponsored or developed the guideline, measure, or test: American Psychological Association</td>
</tr>
<tr>
<td>Aufill et al., 2019</td>
<td>Article reports on: Empirical assessment of a screening test or tool Content of measure or guideline: N/A Organization that sponsored or developed the guideline, measure, or test: N/A</td>
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<tr>
<td>Study ID</td>
<td>Study Type, Study Content, and Organization Information</td>
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<tr>
<td>Burton et al., 2021; Tokuhara et al., 2006</td>
<td>Article reports on: Empirical assessment of a screening test or tool, systematic review Content of measure or guideline: N/A Organization that sponsored or developed the guideline, measure, or test: N/A</td>
</tr>
<tr>
<td>CMS, 2022</td>
<td>Article reports on: Quality measure, guideline Content of measure or guideline: CMS measure on requirement for yearly screening for CI as part of the AWV Organization that sponsored or developed the guideline, measure, or test: CMS</td>
</tr>
<tr>
<td>CMS, 2022</td>
<td>Article reports on: Guideline Content of measure or guideline: Guidance on required content of the AWV Organization that sponsored or developed the guideline, measure, or test: CMS</td>
</tr>
<tr>
<td>Chen et al., 2018</td>
<td>Article reports on: Empirical assessment of a screening test or tool, systematic review Content of measure or guideline: N/A Organization that sponsored or developed the guideline, measure, or test: Washington University in St. Louis</td>
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<td>Study ID</td>
<td>Study Type, Study Content, and Organization Information</td>
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<td>from normal cognition and very good diagnostic accuracy in differentiating dementia from nondementia. Sensitivity exceeded specificity in all studies and settings (suggesting more false positives than false negatives). Additional comments: The AD8 questionnaire is a brief informant-based measure and is considered to be better than performance-based tools for the primary care setting. It can be administered in less than 3 minutes. The systematic review identified seven trials that assessed the validity of the AD8 among patients in community or primary care settings. Two U.S. trials, one UK trial, and the remainder in Brazil, Singapore, Japan, and China. Individual studies defined dementia and MCI differently and used different cutoff scores. The AD8 had greater sensitivity in differentiating normal cognition from MCI or dementia when used in clinics or hospitals than when it was used in the community, likely because of differences in severity of CI. The tool’s informant-based nature suggests need for caregiver input.</td>
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| Cordell et al., 2013 | Article reports on: Guideline, empirical assessment of a screening test or tool Content of measure or guideline: Guideline operationalizes screening recommendations for Medicare AWV Organization that sponsored or developed the guideline, measure, or test: Alzheimer’s Association | Intended population or setting for the measure: Medicare patients’ AWV in primary care setting Tool questions: Authors assessed available tools reviewed in six systematic reviews: “To narrow the search to tools more applicable to the Annual Wellness Visit, the workgroup sought to determine whether the literature offered a consensus regarding brief cognitive assessment during time-limited primary care visits.” The aim was not to identify a gold-standard tool but to identify tools most suitable for use in the PC setting. Measure, guideline, or tool validated: The recommended tools were validated but only in narrow populations. Validation is lacking in low-education and low-literacy populations. Additional comments: An algorithm was developed to assess Medicare patients in the primary care setting to comply with Medicare requirement. The resulting Alzheimer’s Association Medicare AWV algorithm for assessment of cognition includes a review of patient Health Risk Assessment information, patient observation, unstructured queries during the AWV, and structured cognitive assessment tools for both patients and informants. Among 17 tools reviewed, the researchers identified three recommended screening tests: MIS, GPCOG, and Mini-Cog, based on the following criteria:  
  • Requires 5 minutes or less to administer  
  • Is validated in a primary care or community setting  
  • Is easily administered by medical staff members who are not physicians  
  • Has good to excellent psychometric properties  
  • Is relatively free from educational, language, and/or culture bias  
  • Can be used by clinicians in a clinical setting without payment for copyrights. |
<table>
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<tr>
<th>Study ID</th>
<th>Study Type, Study Content, and Organization Information</th>
<th>Intended Population or Setting, Tool Questions, Validation, and Additional Comments</th>
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<tr>
<td>Dementia Warning Signs Workgroup, Office of Geriatrics and Extended Care, and the National Center for Health Promotion and Disease Prevention, 2011</td>
<td>Article reports on: Guideline Content of measure or guideline: VA guideline—Clinician Fact Sheet on Detection of Dementia that emphasizes use of warning signs of dementia as a decision aid Organization that sponsored or developed the guideline, measure, or test: VA Dementia Warning Signs Workgroup</td>
<td>The researchers also assessed tools intended to be used with an informant and identified the IQCODE, the AD8, and the aforementioned GPCOG. Authors recommend the stepwise process that incorporates a screening tool and further validation of existing and newer tools.</td>
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<tr>
<td>Feil et al., 2007 Chow and MacLean, 2001</td>
<td>Article reports on: Quality measure Content of measure or guideline: ACOVE measure, which provided indicators for screening, diagnosing, and managing community-dwelling and hospitalized vulnerable elderly patients for CI and dementia (Among 14 measures in the original 2001 measure set, five covered screening and diagnosis. The measure set was updated in 2007 to contain 16 measures, nine of which cover screening and diagnosis, including differential diagnosis.) Organization that sponsored or developed the guideline, measure, or test: Pfizer and RAND Health</td>
<td>Intended population or setting for the measure: Vulnerable elderly patients who are community dwelling, hospitalized, or long-term care residents Tool questions: N/A Measure, guideline, or tool validated: The measures were based on systematic review and expert panel consensus. Additional comments: Of the nine measures that cover screening and diagnosis, the first two are (1) IF a vulnerable elder is new to a primary care practice or inpatient service, THEN there should be a documented assessment of cognitive ability and functional status, and (2) ALL vulnerable elders should be evaluated annually for changes in memory and function. The other seven screening and diagnostic measures specify clinical, neurological, lab, or...</td>
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<tr>
<td>Study ID</td>
<td>Study Type, Study Content, and Organization Information</td>
<td>Intended Population or Setting, Tool Questions, Validation, and Additional Comments</td>
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| **Fernandes et al., 2021; Mini-Cog, 2016** | Article reports on: Empirical assessment of a screening test or tool, systematic review  
Content of measure or guideline: N/A  
Organization that sponsored or developed the guideline, measure, or test: N/A | Imaging tests that should be conducted to confirm the diagnosis and rule out clinical causes of CI.  
Intended population or setting for the measure: Primary care patients  
Tool questions: The questions differed for each screening tool  
Measure, guideline, or tool validated: The tools reported in the review were validated.  
Additional comments: Nine systematic reviews described tools to assess CI or dementia in primary care. Most used the MMSE as the reference standard for validation, with the Mini-Cog (which takes 3 minutes) being the most-frequently used tool. The AMTS (which took 3.16 to 5 minutes in the primary care setting) had better sensitivity and specificity than the Mini-Cog. (The AMTS was first fielded in 1972 as a ten-item screener.) The reviewers suggest the Mini-Cog as a rapid initial screener to identify the need for further testing, although the sensitivity might not be high enough, and too many cases might be missed. |
| **Ko et al., 2022**           | Article reports on: Empirical assessment of a screening test or tool, systematic review  
Content of measure or guideline: N/A  
Organization that sponsored or developed the guideline, measure, or test: N/A | Intended population or setting for the measure: Patients with SUD in any clinical setting  
Tool questions: Systematic review that assessed multiple tools  
Measure, guideline, or tool validated: Most of the studies attempted to validate the tool on which they reported in the population of interest. The MoCA showed the strongest validation, but all of the tools would benefit from greater validation.  
Additional comments: 14 studies that met inclusion identified ten cognitive screening tools. The MoCA was the most common, and two novel screening tools (Brief Evaluation of Alcohol-Related Neuropsychological Impairments and Brief Executive Function Assessment Tool) were specifically developed for use within SUD populations. Research recommendations primarily consisted of the need for more-widespread validation, especially using patients with co-occurring conditions, and the need to identify study-level characteristics (e.g., settings and patient characteristics). Clinical recommendations included the following: “Of the tools reviewed, the MoCA was the most studied and demonstrated the most-consistently adequate diagnostic classification accuracy in this population. Practically, the MoCA is brief to administer, evaluates a broad variety of cognitive domains, and is used widely across healthcare settings, which might aid in effective communication of health information. It also has alternate versions available, which facilitate re-testing over short periods of time.” The MMSE failed to show adequate classification accuracy. Newer tools show promise but require further testing. Authors also advise not relying on tools’ absolute published cutoff scores when applying to SUD populations. |
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<tr>
<th>Study ID</th>
<th>Study Type, Study Content, and Organization Information</th>
<th>Intended Population or Setting, Tool Questions, Validation, and Additional Comments</th>
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</table>
| Koekkoek et al., 2016 | Article reports on: Empirical assessment of a screening test or tool  
Content of measure or guideline: N/A  
Organization that sponsored or developed the guideline, measure, or test: Not reported | Intended population or setting for the measure: The Cognitive Impairment in Diabetes study examined a stepped diagnostic procedure to detect undiagnosed CI in patients aged ≥70 years with T2DM. The aim of this follow-up study was to validate the two screeners used.  
Tool questions: (1) The TYM instrument is a self-administered test consisting of ten subtasks, which can be filled out in five minutes. The tasks include orientation, ability to copy a sentence, semantic knowledge, calculation, verbal fluency, similarities, naming, visuospatial abilities (two subtasks), and recall of a copied sentence. The ability to complete the test without help represents an 11th task. The maximum score is 50 points. A score <40 is suggestive of dementia.  
(2) The SAGE is a self-administered test, filled out in 10–15 minutes, that examines orientation, language, memory, executive function, calculations, abstraction, and visuospatial abilities. It includes questions on demographic information, medical and family history, and current status. The maximum score is 22 points. A score <15 is suggestive of dementia.  
Measure, guideline, or tool validated: The tools were validated in a two-step process for patients with T2DM and no prior dementia diagnosis or testing. First, they took the two tests during a home visit. Then an independent general practitioner assessed the patients for suspected CI based on an interview and the MMSE. Patients who scored positively on any of those three assessments and a random sample who did not score positively on any were referred for full evaluation at a memory clinic. The TYM instrument and the SAGE questionnaires had negative predictive values of 81 percent and 85 percent, respectively (compare the memory clinic full exam). Positive predictive values were 39 percent and 40 percent, respectively. The general practitioner evaluation had a negative predictive value of 83 percent and positive predictive value of 64 percent.  
Additional comments: Authors conclude that either the TYM instrument or the SAGE, preferably the SAGE, could be used by the general practitioner to screen T2DM patients for CI to enable tailoring of diabetic treatment. |
| LeRoith et al., 2019 | Article reports on: Guideline  
Content of measure or guideline: Clinical practice guidelines for the treatment of diabetes in older adults, which recommend routine screening for known diabetes complications, including CI  
Organization that sponsored or developed the guideline, measure, or test: Endocrine Society | Intended population or setting for the measure: Diabetes patients 65 and over receiving routine care  
Tool questions: N/A  
Measure, guideline, or tool validated: Not described  
Additional comments: No further comments |
<p>| Levell-Smith, 2020 | Article reports on: Guideline | Intended population or setting for the measure: Patients with T2DM in primary care |</p>
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<th>Study ID</th>
<th>Study Type, Study Content, and Organization Information</th>
<th>Intended Population or Setting, Tool Questions, Validation, and Additional Comments</th>
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<td>Content of measure or guideline: Early screening for dementia assessment performed on patients diagnosed with T2DM at the primary care setting upon each admission and annually. Organization that sponsored or developed the guideline, measure, or test: Not reported</td>
<td>Tool questions: N/A Measure, guideline, or tool validated: The guideline was evaluated by a panel and determined to be evidence based. Additional comments: The guideline emphasizes early routine preliminary screening but does not specify the question(s) to use for that screening. Because this was an unpublished Doctor of Nursing Practice thesis, results might be best as background or discussion. (If the patient answers yes to any of the risk assessment questions to the early screening assessment, the provider will be informed; the provider will decide on the best next step, which might include a cognitive assessment using a brief structured tool such as the Mini-Cog [see Cordell et al., 2013, the Alzheimer's screening questions], laboratory tests, CT [computerized tomography], and/or MRI [magnetic resonance imaging]. Alternatively, the provider might refer the patient to a memory clinic for a multidisciplinary evaluation and treatment between neurologists and diabetologists for early dementia.)</td>
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<tr>
<td>Paraizo et al., 2016</td>
<td>Article reports on: Empirical assessment of a screening test or tool Content of measure or guideline: N/A Organization that sponsored or developed the guideline, measure, or test: N/A</td>
<td>Intended population or setting for the measure: Nonelderly adult patients (mean age 56) with kidney failure in Brazilian clinic Tool questions: Study compares the MoCA with several simple executive function assessment tools: the clock drawing, the digit span forward and reverse, phonemic verbal fluency and semantics (animals), the fist-edge-palm, and the ten-picture memory tests. Measure, guideline, or tool validated: The executive function tools were validated against the MoCA. Additional comments: The MoCA indicated CI in 71 percent of predialysis patients. Positive screening was associated with age, diabetes, and educational attainment. A combination of the clock drawing, digital span reverse, and phonemic verbal fluency and semantics (animals) compared well with MoCA in identifying MCI in this population. The authors do not suggest that these tests should be substituted for the MoCA but that the findings indicate that executive function is affected.</td>
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<tr>
<td>Petersen et al., 2018</td>
<td>Article reports on: Guideline Content of measure or guideline: Updated guideline on assessment and management of MCI, which focuses on “presumed idiopathic or neurodegenerative MCI—particularly relating to AD [Alzheimer’s Disease]—rather than mild cognitive changes relating to potentially reversible causes” or to Parkinson’s (update to the guideline includes assessment and treatment)</td>
<td>Intended population or setting for the measure: It is unclear whether the guidelines are intended for primary or specialty care clinicians, but the implication is that they apply to all care providers. Tool questions: N/A Measure, guideline, or tool validated: The update is based on a systematic review and metaanalysis of prevalence, prognosis, and treatment. Additional comments: Recommendations related to screening are (1) For patients for whom the patient or a close contact voices concern about memory or impaired cognition, clinicians should assess for MCI and not assume the concerns are related to normal aging. (2) When performing a Medicare AWV,</td>
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<tr>
<td>Study ID</td>
<td>Study Type, Study Content, and Organization Information</td>
<td>Intended Population or Setting, Tool Questions, Validation, and Additional Comments</td>
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<td>Thompson et al., 2021</td>
<td>Article reports on: Guideline Content of measure or guideline: Guideline that describes routine preventive care and screening tests that people who are HIV [human immunodeficiency virus] positive should receive, recommending that the initial exam of a person who is HIV positive should include an assessment for CI but not specifying how the assessment should be conducted Organization that sponsored or developed the guideline, measure, or test: HIV Medicine Association of the Infectious Diseases Society of America</td>
<td>Intended population or setting for the measure: HIV-positive individuals in primary care settings Tool questions: N/A Measure, guideline, or tool validated: Not described Additional comments: No further comments</td>
</tr>
<tr>
<td>USPSTF et al., 2020</td>
<td>Article reports on: Guideline Content of measure or guideline: Guideline addressing screening for CI in older adults Organization that sponsored or developed the guideline, measure, or test: USPSTF</td>
<td>Intended population or setting for the measure: Adults 65 and older in primary care settings Tool questions: N/A Measure, guideline, or tool validated: The guideline is based on a systematic review of the literature. Additional comments: The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for CI in older adults. &quot;Screening instruments can adequately detect cognitive impairment. There is no empirical evidence, however, that screening for cognitive impairment improves patient or caregiver outcomes or causes harm. It remains unclear whether interventions for patients or caregivers provide clinically important benefits for older adults with earlier detected cognitive impairment or their caregivers.&quot; Instead, it recommends implementing screening when there is reason to believe the patient might have CI.</td>
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</table>
Appendix C. Excluded Studies and Background Literature

This appendix provides citations for all the studies that were excluded at the full-text review stage (the reasons for the decision to exclude are in italics) and citations for the identified background literature.

Excluded Studies


Systematic review or toolkit for reference mined—cognitive impairment


No information on social support assessment—social and caregiver support


No reference to social support—social and caregiver support


No reference to social support—social and caregiver support


No information on social support assessment—social and caregiver support


No information on social support assessment—social and caregiver support

No information on social support assessment—social and caregiver support


No information on social support assessment—social and caregiver support


No reference to social support—social and caregiver support


No information on social support assessment—social and caregiver support


https://www.cma.ca/

No reference to social support—social and caregiver support


No information on social support assessment—social and caregiver support


Caregiver assessment only social and caregiver support


Not primary care setting—social and caregiver support

*Caregiver assessment only—social and caregiver support*


*Caregiver assessment only—social and caregiver support*


https://www.canada.ca/en/health-canada.html

*No reference to social support—social and caregiver support*


*No information on social support assessment—social and caregiver support*


*No reference to social support—social and caregiver support*

HealthBegins, “Strategies & Investments,” webpage, undated. As of June 23, 2022:

https://healthbegins.org/

*No reference to social support—social and caregiver support*


*Systematic review or toolkit for reference mined—social and caregiver support*


*No information on social support assessment—social and caregiver support*

No information on social support assessment—social and caregiver support


Study design—cognitive impairment


Duplicate—cognitive impairment


Caregiver assessment only—social and caregiver support


Systematic review or toolkit for reference mined—cognitive impairment


Systematic review or toolkit for reference mined—social and caregiver support


No reference to social support—social and caregiver support


Study design—cognitive impairment


No reference to social support—social and caregiver support

*No information on social support assessment—social and caregiver support*


*Duplicate—social and caregiver support*

National Alliance to Impact the Social Determinants of Health, “Screening Tools and Tool Kits,” webpage, undated. As of September 13, 2022:
https://nasdoh.org/screening-tools-and-tool-kits/

*No information on social support assessment—social and caregiver support*

National Association of Community Health Centers, “NACHC,” website, undated. As of September 13, 2022:
https://www.nachc.org/

*No information on social support assessment—social and caregiver support*

National Committee for Quality Assurance, “Care for Older Adults (COA),” webpage, undated. As of September 13, 2022:
https://www.ncqa.org/hedis/measures/care-for-older-adults/

*No reference to social support—social and caregiver support*

———, “Transitions of Care (TRC),” webpage, undated. As of September 13, 2022:
https://www.ncqa.org/hedis/measures/transitions-of-care/

*Not primary care setting—social and caregiver support*

———, “Proposed Changes to Existing Measure for HEDIS 2020: Care for Older Adults (COA),” Washington, D.C., 2019.

*Not cognitive screening—cognitive impairment*


*Not primary care setting—social and caregiver support*


*No reference to social support—social and caregiver support*
National Quality Forum, “National Quality Partners,” webpage, undated. As of September 13, 2022:
No information on social support assessment—social and caregiver support

Not primary care setting—social and caregiver support

Caregiver assessment only—social and caregiver support

Public Health Agency of Canada, “Social Determinants of Health,” webpage, June 27, 2016. As of July 17, 2022:
No reference to social support—social and caregiver support

No reference to social support—social and caregiver support

Caregiver assessment only—social and caregiver support

Study design—cognitive impairment

No reference to social support—social and caregiver support

Study design—cognitive impairment
United Hospital Fund, “Next Step in Care,” webpage, 2015. As of September 13, 2022:
https://www.nextstepincare.org/

Caregiver assessment only—social and caregiver support


*Systematic review or toolkit for reference mined—Social and Caregiver Support*


*No information on social support assessment—social and caregiver support*


*No reference to social support—social and caregiver support*


*Duplicate—social and caregiver support*


*No reference to social support—social and caregiver support*


*No reference to social support—social and caregiver support*


*Not primary care setting—social and caregiver support*

**Background**


U.S. Department of Veterans Affairs, “Patient Aligned Care Team (PACT)” website, undated. As of July 13, 2022:
http://patientcare.va.gov/primarycare/PACT.asp


## Abbreviations

<table>
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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>AAFP</td>
<td>American Academy of Family Physicians</td>
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<tr>
<td>ACORN</td>
<td>Assessing Circumstances &amp; Offering Resources for Needs</td>
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<tr>
<td>ACOVE</td>
<td>Assessing Care of Vulnerable Elders</td>
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<tr>
<td>AD8</td>
<td>Ascertain Dementia 8</td>
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<td>ADLs</td>
<td>activities of daily living</td>
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<td>AMTS</td>
<td>Abbreviated Mental Test Score</td>
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<td>AWV</td>
<td>annual wellness visit</td>
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<td>CI</td>
<td>cognitive impairment</td>
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<td>CMS</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
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<td>EHR</td>
<td>electronic health records</td>
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<tr>
<td>GPCOG</td>
<td>General Practitioner Assessment of Cognition</td>
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<tr>
<td>HRQOL</td>
<td>health-related quality of life</td>
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<tr>
<td>IADLs</td>
<td>instrumental activities of daily living</td>
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<tr>
<td>IQCODE</td>
<td>Informant Questionnaire on Cognitive Decline in the Elderly</td>
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<tr>
<td>MCI</td>
<td>mild cognitive impairment</td>
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<tr>
<td>MIS</td>
<td>Memory Impairment Screen</td>
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<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
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<td>MoCA</td>
<td>Montreal Cognitive Assessment</td>
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<td>MSPSS</td>
<td>Multidimensional Scale of Perceived Social Support</td>
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<tr>
<td>NPV</td>
<td>negative predictive value</td>
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<td>NQF</td>
<td>National Quality Forum</td>
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<td>PACT</td>
<td>Patient Aligned Care Team</td>
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<td>PPV</td>
<td>positive predictive value</td>
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<td>PRAPARE</td>
<td>Protocol for Responding to and Assessing Patients’ Assets, Risks, and Experiences</td>
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<td>SAGE</td>
<td>Self-Administered Gerocognitive Examination</td>
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<td>SDOH</td>
<td>social determinants of health</td>
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<td>SUD</td>
<td>substance use disorder</td>
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<td>T2DM</td>
<td>type 2 diabetes mellitus</td>
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<td>TYM</td>
<td>Test Your Memory</td>
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<td>USPSTF</td>
<td>U.S. Preventive Services Task Force</td>
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<td>VA</td>
<td>U.S. Department of Veterans Affairs</td>
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<td>WHO</td>
<td>World Health Organization</td>
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