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Alzheimer's Disease

Minnesota Department of Health Report to the Minnesota Legislature 2013

January 31, 2013

Alzheimer's Disease

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Protecting, maintaining and improving the health of all Minnesotans

January 31, 2013

Dear Legislators:

Alzheimer's disease and related dementias are estimated to affect 94,000 people in Minnesota and that number is increasing. The costs of caring for people affected by these dementias are also increasing. Most people with Alzheimer's disease are also affected by other chronic conditions like heart disease, diabetes and arthritis; and dementias make it more difficult and costly to treat these conditions.

While the economic impact of Alzheimer's disease and related dementias is large; caregivers, families and friends of people with Alzheimer's disease experience great emotional, physical and financial stress as their loved ones are progressively impacted by the disease. With the aging of the baby boomers, the population of older adults will increase. More of us will be faced with Alzheimer's disease or other dementias in ourselves or our family members.

New and effective ways to prevent, delay and treat Alzheimer's disease are urgently needed. There is research worldwide to find these answers. There is increasing attention being directed at identifying practices to support people, families and caregivers so they have the best quality of life possible. Minnesota's research institutions and care systems are leaders in these important efforts. There is good reason for hope as we look at the array of efforts underway. We need to continue to monitor these efforts and work to implement evidence-based and best practices as they become available.

Sincerely,

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Edward P. Ehlinger, M.D., M.S.P.H. Commissioner P.O. Box 64975 St. Paul, MN 55164-0975

Alzheimer's Disease Table of Contents

Executive Summary	1
Introduction	3
Background: Alzheimer's Disease and Related Dementias	3
Literature Review: Synthesis of the Current State of Evidence	4
Quality Measures Review	10
Learning Collaborative	11
Current Efforts and Future Opportunities	12
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Appendices:

Appendix 1: Annotated Bibliography of Selected Studies

Appendix 2: The Alzheimer's Disease Supportive Services Program (ADSSP) and Minnesota's Participation

Appendix 3: Alzheimer's Quality Measures Inventory and Feasibility Plan

Appendix 4: Preparing Minnesota For Alzheimer's 2020 and ACT on Alzheimer's

Appendix 5: Learning Collaborative Curriculum

Appendix 6: The National Plan to Address Alzheimer's Disease

Alzheimer's Disease Report to the Minnesota Legislature 2013

Executive Summary

Minnesota Statutes 62U.15 Alzheimer's Disease: Prevalence and Screening, directs the Commissioner of Health to 1) review currently available quality measures for identification and care of people with Alzheimer's disease and related dementias and make recommendations for future measurement, 2) develop a health care homes learning collaborative curriculum related to best practices regarding identification and management of Alzheimer's disease and related dementias, and 3) review the literature to estimate differences in the outcomes and costs comparing current practice to practice with earlier identification, improved support of family caregivers; and improved collaboration between medical care management and community-based supports.

This report summarizes the work conducted to fulfill this charge. In summary, our review of the evidence suggests that the state of the science does not currently support concrete recommendations for achieving cost savings in care for people with Alzheimer's disease and related dementias as envisioned by the legislation.

Published literature was reviewed to determine the current state of the science related to potential cost savings and improved care outcomes that might be achieved with changes in usual care for people with Alzheimer's disease and related dementias. As directed by the legislation, practices related to earlier identification, improved support of caregivers and improved collaboration between medical care and community-based supports were evaluated.

There is consensus among health care providers and researchers that people who present to a primary care provider with symptoms related to cognitive health that they identify themselves or that are identified by those close to them should be screened for cognitive impairment, Alzheimer's disease and related dementia. However, it is not clear that the benefits of screening all people at a certain age outweigh the costs and potential risks associated with diagnosis or misdiagnosis. The benefits of early identification of cognitive impairment by screening are related to screening being followed by further assessment and effective intervention for patients and their families and caregivers.

There is consensus that community-based interventions to support patients, families and caregivers in the day-to-day demands of care for people with cognitive impairment can provide significant benefits to patients and families in meeting these challenges. Data are not currently available to assess costs and potential cost saving of implementing these interventions and it is not clear at this time which interventions are cost effective and for whom.

Supporting individuals through transitions to different levels and locations of care have been shown to lead to smoother transitions and better health outcomes. At this time, there is still insufficient evidence available about the costs and potential cost savings of various interventions to make specific recommendations regarding care transitions practice. Also, given the changes in use of different levels and locations of care, more specific definition of appropriate use of care settings for people with Alzheimer's disease and related dementias is necessary.

An environmental scan of quality measures and assessment tools was conducted for the Minnesota Department of Health by Minnesota Community Measurement. None of the identified quality measures for Alzheimer's disease and related dementia are endorsed by the National Quality Forum or other bodies that formally endorse quality measures and no national standards for evaluating quality measures have been developed to date. Delineation of best dementia care practices and evidence based guidelines that can serve as a foundation to the development of metrics that promote high-quality dementia care in all settings is also identified as a priority action in the National Plan to Address Alzheimer's Disease.(1) Therefore, the adoption of a state quality reporting measure for

Alzheimer's and related dementia is not recommended at this time.

The Patient Protection and Affordable Care Act will likely drive consensus development on appropriate tools as experience is gained with the use of cognitive screening in the Medicare annual wellness visits. At this time it is more appropriate to monitor this experience and reassess the state of the science as standards for assessment tools and quality measures are developed, standardized and implemented.

A health care home learning collaborative curriculum was developed by the Minnesota Department of Health, Health Care Home Team in collaboration with members of the Prepare Minnesota for Alzheimer's 2020 (PMA 2020) Early Identification Committee. The first session of an ongoing series of sessions was offered in November, 2012. The curriculum is being refined based on detailed analysis of the pre-assessments completed by participating health care homes. Additional evaluation will provide information needed to optimize ongoing educational support for providers.

Identifying and implementing effective strategies to address Alzheimer's disease and related dementias are high priorities for the research and practice communities at the state and national level. Considerable effort is underway at many levels to identify best and most cost-effective practice, set practice guidelines, and identify the roles of various care settings, health care providers and care-givers as well as identify the means to treat, halt or prevent the disease.

The Act on Alzheimer's collaboration of more than 150 individuals and 50 organizations the developed from the Alzheimer's Disease Working Group created by the 2009 legislation continues to work to address the challenges to families from these life changing conditions. They have produced specific tools and approaches for clinicians, families and communities to address identification and improved care. Four of Minnesota's health systems, HealthPartners, CentraCare, Essentia and Allina, are engaged in adoption part or all of the guidelines. As efforts like these are funded, implemented and evaluated, the next few years are likely to provide more specific information that will help address issues raised about cost and quality of care, support for patients with Alzheimer's disease and related dementias, their families and caregivers, and the health care providers who work with them.

Alzheimer's Disease Report to the Minnesota Legislature 2013

Introduction

Legislation passed in 2011 (Minnesota Statutes 62U.15) directs the Commissioner of Health to 1) review currently available quality measures for identification and care of people with Alzheimer's disease and related dementias and make recommendations for future measurement. 2) develop a health care homes learning collaborative curriculum which includes best practices regarding identification and management of Alzheimer's disease and related dementias, and 3) review the literature to estimate differences in the outcomes and costs comparing current practice to practice with earlier identification, improved support of family caregivers; and improved collaboration between medical care management and communitybased supports.

This report summarizes the work conducted to date to fulfill this charge.

Background: Alzheimer's Disease and Related Dementias

Alzheimer's disease is an age-related brain disorder that gradually destroys a person's ability to remember, think, learn and carry out even simple tasks. "Dementia" is a broad term describing a variety of diseases and conditions that damage brain cells and impair brain function. Alzheimer's disease is the most common type of dementia and accounts for an estimated sixty to eighty percent of cases. It is often difficult to distinguish among the types of dementias in clinical presentation and in diagnosis. Some of the neurodegenerative processes are common across conditions. Consequently people with dementia and their families face many similar challenges across the spectrum of types of dementia. (1, 2, 3) As it is for physical health, cognitive health can be viewed along a continuum from no impairment to mild cognitive impairment to severe dementia. There are no standardized definitions of the various gradations of cognitive health, but most agree that the components of healthy cognitive functioning include language, thought, memory, ability to plan and carry out tasks, judgment, attention, perception, remembered skills (such as driving), and the ability to live a purposeful life. Some people never develop a serious decline in cognitive function and not all who develop mild cognitive impairment develop dementia. Some people with mild cognitive impairment regain normal cognitive functioning. (4, 5)

The causes of Alzheimer's disease are not currently known, but research suggests a combination of genetic, environmental and lifestyle factors. The relative importance of any one of these factors to any given individual's risk of developing Alzheimer's disease differs from person to person. The most recognized risk factor for developing cognitive decline and dementia is advancing age. More than ninety percent of Alzheimer's disease and related dementia cases occur in people age sixty and older, with studies showing the prevalence increases dramatically after age eighty. A small number of people, age thirty to sixty years, develop "early-onset" Alzheimer's disease. This "earlyonset" form of the disease often runs in families. It is not known how the Alzheimer's disease process begins, and research indicates that damage to the brain starts a decade or more before symptoms appear. Generally diagnosis is not made until symptoms occur. Currently there are no medications or other interventions that definitively prevent, treat. or cure these conditions and we are unable to diagnose the disease before symptoms occur. (3)

Alzheimer's disease and related dementias are a major public health issue because they affect a large number of people and have a profound impact on their health and that of their caregivers. Also, the related costs are large, and dementias will continue to affect the health and well-being of a growing segment of the population. Over 5.4 million Americans were estimated to be affected by Alzheimer's disease and related dementias in 2012. This estimate was developed by extrapolating from studies that had evaluated all the individuals in a community to determine how many of the total population were affected by dementias. In American communities, only about half of the people who would meet the diagnostic criteria for Alzheimer's disease or related dementias have been diagnosed, so it is likely that half of the estimated 5.4 million Americans with Alzheimer's disease and related dementias do not know they are affected. Unless something can be done to delay the onset or to intervene to halt or reverse the course of the condition, researchers predict as many as 16 million Americans will have Alzheimer's disease and related dementias by 2050. (3)

The rising prevalence of Alzheimer's disease and related dementias has profound social and economic implications. Alzheimer's disease and related dementias place large emotional, physical, and financial stresses both on individuals who are affected and on their family members. Informal care givers, such as family members and friends, provide an estimated eighty percent of care in the community. The demands of supporting a person with Alzheimer's disease or related dementia can affect the emotional and physical health of the caregiver, their employment status, income and family finances. Moreover, when the person with dementia moves to a skilled nursing facility to receive 24-hour care, the financial costs increase considerably. (3)

People affected by Alzheimer's disease and related dementias use more health resources than those without these conditions. Medicare and Medicaid cover about seventy percent of the health care, longterm care and hospice payments for people with Alzheimer's disease and related dementias. In 2008, total per person payments from all sources for health care and long term care for Medicare beneficiaries with Alzheimer's disease and related dementias (\$43,847) were triple the costs for other Medicare beneficiaries in the same age group (\$13,879). Twenty-nine percent of older people with Alzheimer's disease and related dementias also had Medicaid coverage compared to 11 percent of older people without dementia. Those with Alzheimer's disease and related dementias have more than three times as many hospital stays as

those without dementia and have more skilled nursing facility stays and home health care visits.

Ninety-five percent of people with Alzheimer's disease and related dementias have one or more additional chronic conditions. Studies have shown that people with coronary heart disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, stroke or cancer, who also have Alzheimer's disease or related dementias, have greater use and costs of health care compared to people with those conditions but no coexisting dementia. (3, 6)

Literature Review: Synthesis of the Current State of Evidence

MN Statutes 62U.15Subd3. Comparison Data. The commissioner, with the Commissioner of Human Services, the Minnesota Board on Aging and other appropriate state offices shall jointly review existing and forthcoming literature on order to estimate differences in the outcomes and costs of current practices for caring for those with Alzheimer's disease and other dementias, compared to the outcomes and costs resulting from: 1) earlier identification of Alzheimer's and other dementias; 2) improved support of family caregivers; and 3) improved collaboration between medical care management and community-based supports.

Effective comparison of cost differences resulting from changes in care practice requires a common definition of current care practice, a standardized method to measure cost and agreement on a common set of outcome measures used by researchers across studies. Presently there is neither a consistent definition for current care practice nor a sound description of the baseline of usual care cost used in published studies. Moreover, there is no consensus on the appropriate strategies for early identification, the desired outcomes for care and care management, caregiver support or for community support. Standardized measurement approaches for both cost and outcomes are lacking.

A large volume of published research describes care strategies for Alzheimer's disease and related

dementia. However, studies focus on varying aspects of care and with different outcome goals thus hampering direct comparisons. Few studies of program interventions address cost of the intervention or the other costs of care.

The following sections summarize key considerations for each of the three areas outlined in 62U.15 Subd. 3 regarding comparison data and will guide future consideration of these questions. An annotated bibliography of selected studies is included in Appendix 1.

Earlier Identification of Disease

Diagnosing Alzheimer's disease and related dementias early in the disease process has been identified as an urgent need by policy makers, researchers and multiple stakeholder groups. Screening and early diagnosis have a number of potential benefits. Patients identified with Alzheimer's disease and other dementias could access new treatments as they become available. New treatments would likely provide the greatest benefit if they were provided to patients at earlier stages of disease. Patients could enroll in clinical trials testing new treatments and prevention measures.

At present, studies show mixed results regarding the value of lifestyle interventions related to physical activity, eating patterns, stress management, social contact and cognitive activity as prevention or treatment measures for people with dementia. As these relationships become clearer, patients with earlier diagnosis could benefit most from initiating lifestyle interventions. (7)

Earlier diagnosis of Alzheimer's disease and other dementias could potentially enable health care providers to pro-actively and comprehensively manage care of affected individuals and to anticipate problems in understanding and adherence to recommended treatment. Active clinical management has been shown to improve health outcomes, decrease hospitalizations and may help to delay or avert institutional care. Included in this active clinical management is greater attention to involving family and caregivers to support the patient's health needs related to their dementia and other chronic conditions, address safety issues, address depression and other psychological or behavioral issues, address end-of-life care and to document preferences and decisions in advanced directives. (8, 9)

Early diagnosis could potentially enable patients, family members and caregivers to address financial and other legal issues, plan for care needs, and access available community interventions and supports for both the patient and the caregiver. Finally, screening might identify people with reversible causes of dementia and ensure prompt treatment.

There are potential negative outcomes from screening for dementia, but these have not been systematically examined. Adverse effects could occur from both an individual being identified as having dementia who does not actually have the disease (misdiagnosis) or to someone who is accurately diagnosed. (5)

Misdiagnosis of Alzheimer's disease or a related dementia (false positive), is possible particularly in the earlier stages of mild cognitive impairment. This could result in unnecessary psychological distress and potentially financial cost to the patient and the family. Misdiagnosed individuals might be treated with medications that have potential harm.

There is also concern that among those with early Alzheimer's or related dementia, some may not want to know their diagnosis or may not want it known to family members. A diagnosis of dementia could also affect a person's autonomy unnecessarily. (10, 14)

The assumption that early identification and diagnosis of Alzheimer's disease and other dementias will reduce health care costs from a societal perspective stems from the idea that early diagnosis, improved treatment and enhanced medical and social support systems will delay or avert hospital and/or long term care costs. These costs accrue to a variety of payers including patients their families, health or long term care insurance providers and Medicare and Medicaid.

Estimating potential cost savings from early identification of Alzheimer's disease and related dementias is problematic. It is complicated by the inconsistency in the published research in how and what costs are assessed, the impact of the timing of diagnosis on the treatment strategies, the impact of the spectrum of co-existing chronic conditions on the costs for any individual and the impact of other strategies including caregiver support and clinical management on the overall cost. Measuring the health care costs associated with Alzheimer's disease and other dementias is difficult and methods vary across studies. Those that standardize across the multiple variables to factor out only the impact of early identification on cost and outcome are technically difficult and costly to conduct. At the present time, neither controlled trials nor metaanalyses assessing the impact of early identification on health care costs are available. The most comprehensive studies are modeling studies that use existing data from clinical trials, usually one to two years in duration, to project potential cost savings over a much longer time. These studies have significant limitations in that they are based on presumed as opposed to actual population experience and use limited evidence from specific settings that may not be easily generalizable to broad contexts.

Researchers working in this area remain divided in their support for population-based cognitive screening programs that would screen all persons at a particular age to promote early identification and intervention for people with Alzheimer's disease and related dementias. Two key studies included cost projections for potential savings from early identification of dementias. Getsios, et. al. conducted a simulation study using data from studies of people with Alzheimer's disease who were treated with medication in clinical trials in the United Kingdom. They projected the costs over the patients presumed lifespan. Their study projected a cost savings of \$5300 in medical costs and \$11,400 in societal costs per patient. Cost savings were attributed primarily to a delay in institutional care. They concluded that "although early assessment has significant up-front costs, identifying Alzheimer's disease patients at an early stage results in cost savings and health benefits compared with no

6

treatment or treatment in the absence of early assessment." (11)

Weimer and Sager from the University of Wisconsin performed a cost analysis of the potential benefits of early diagnosis and treatment using best estimates of the effects of available pharmacological and non-pharmacologic therapies and projecting the costs over time. Their analysis suggests that early recognition and management of people with Alzheimer's disease will generate cost savings, with the greatest benefit seen when cases were identified at earlier stages and when drug therapy was combined with a caregiver intervention program. They found greater potential savings to federal payers rather than payers at the state level, but savings to Wisconsin were projected to be approximately \$10,000 per diagnosed patient. In order to show meaningful cost savings, the cost of the early identification program must be small enough per person to balance the cost of the interventions. They concluded that screening across the population is not the best use of resources at this time since Medicare does not currently support the cost of caregiver interventions, and access to dementia diagnostic services is limited. They also noted that the cost savings they projected assumed that physicians would act on the results of the diagnostic process to provide drug or caregiver interventions and suggest they may be overestimating the physician action. They concluded that if cost savings are to be realized, any screening must be accompanied by increased access to effective therapies. That will require changes in current policy related to Medicare and Medicaid support of interventions and the practice of health care providers in connecting diagnosed patients with appropriate interventions. (12) It will also require clearer delineation of best dementia care practices and evidence based guidelines.(1)

Assessing the impact of early identification is further complicated by the introduction of new criteria for the defining and diagnosing the Alzheimer's disease and dementia spectrum. The 2009 international workgroup formed by the National Institute on Aging and the Alzheimer's Association to revise the diagnostic criteria for Alzheimer's disease released updated guidelines in 2011. These updated guidelines add criteria for diagnosing mild cognitive impairment and expand the conceptual framework to include a "preclinical" stage characterized by biological changes that would be measured by biomarkers, and that occur years before disruptions in memory, thinking and behavior are apparent. The clinical criteria are currently in use, but the new guidelines do not yet specify which biomarkers should be used to define preclinical disease. (13)

The Diagnostic and Statistical manual of Mental Disorders (DSM) published by the American Psychiatric Association will release a new version, DSM-5, in May of 2013. It is anticipated that the dementia chapter will be retitled "Neurocognitive Disorders" from the previous version which described "Delirium, Dementia, Amnestic and Other Cognitive Disorders" and represent a change to a broader continuum of severity and a range of dementias based on their underlying cause. (14) Both new classifications offer improvements in the specificity of diagnosis and differentiation among types of dementia, however the lack of a single common set of diagnostic criteria and diagnostic tests will make evaluation of the impact and utility more complex and comparison across studies will continue to be difficult.

Different diagnostic criteria and definitions, particularly for earlier stages of cognitive impairment are currently used in research and practice in the absence of consensus on definitions and standards. It is in this area of diagnosing early cognitive changes that there is the greatest potential for misdiagnosis.

A number of assessment tools are currently used in clinical practice to assess cognitive status. Further research and evaluation of implementation in practice is needed to define those that are most useful and how and when they should be used. The Patient Protection and Affordable Care Act (ACA) includes cognitive assessment as part of the annual wellness visit under Medicare. The ACA directs the physician to assess an individual's cognitive function during the annual wellness visit by direct observation, with due consideration of information obtained from the patient, as well as concerns raised by family members, friends, caretakers or others. Specific assessment tests are not defined for this benefit, but seven instruments were identified for recommended use by the Advisory Council of the National Plan in October of 2012. (15)

The Medicare Detection of Cognitive Impairment Workgroup of the Alzheimer's Association also recently published recommendations for operationalizing the cognitive assessment component in primary care settings. Their recommendations include a different list of tools with some overlap compared to the National Plan Advisory Council recommendations. (16) They also describe the iterative process that is needed to move from detection of cognitive impairment through initial screening with a structured assessment using a validated tool to further evaluation as indicated by screening results and a more specific diagnosis. Evaluating these instruments over the next several years as they are used in the large national population will provide more information to guide and refine best practice in assessment of cognitive impairment at the population level as well as in clinical practice. Additionally, the US Preventive Services Task Force is reviewing and updating their 2003 recommendation on screening for dementia. At that time they concluded that there was insufficient published evidence of better clinical outcomes as a result of routine screening for cognitive impairment in older adults. Their update is expected to be available for review and comment in March, 2013. (5)

Research is underway in Minnesota and elsewhere that will add to understanding of how best to conduct of cognitive assessment and follow-up. (15, 17)

Conclusion: There is no consensus that the benefits of screening of all people at a certain age for cognitive status outweigh the costs and potential risks. There is consensus that screening is useful for individuals who present to a primary care provider with self-identified symptoms of concern related to cognitive health or symptoms identified by those close to them. The benefits of early identification can be realized only when assessment is followed by appropriate intervention that will mitigate the impact of the disease for patients and their caregivers. Work remains to be done to evaluate

when screening or assessment are appropriate and to delineate the interventions and community supports that are effective.

Improved Support of Caregivers

Caregivers play a crucial role in managing individuals with Alzheimer's disease and related dementias and a high level of care is required compared to those who care for people with chronic conditions without dementia. Family caregivers provide the majority of day-to-day care. The high demands in caregiving contribute to chronic health and psychosocial issues among caregivers. Interventions to support caregivers have been directed at multiple goals. Some address the needs of caregivers in supporting their own health and psychosocial wellbeing, others aim to reduce the burden of caregiving by providing respite care and some provide education and support to develop coping skills to assist with the caregiving role. Some programs combine pharmacological and nonpharmacological approaches for both caregivers and patients. Most have multiple components that address several goals and the outcomes assessed in the evaluation of these programs, particularly with respect to cost, vary widely. The lack of consistent outcome and cost measurement makes comparison across models difficult. To adequately evaluate the cost-effectiveness of interventions it is also necessary to assess both caregiver outcomes and costs and patient outcomes and costs. (18)

Several reviews of the literature on caregiving and caregiver support have been conducted examining effective and cost-effective interventions. (18, 19, 20) Though a number of effective interventions have been identified and recommended for community implementation (including under the funding programs of the Administration on Aging), few published studies report costs in sufficient detail to provide evidence of both effectiveness and cost-effectiveness of interventions for supporting caregivers. The studies point out the difficulty of evaluating outcomes in randomized control trials or other designs as the needs of caregivers and patients vary widely and change over time. Some of the most successful programs provide individualized strategies, and this adds significantly to the complexity of assessing cost outcomes.

The New York University Counseling and Support Intervention (NYUCI) has been under study since 1987 and represents the intervention with the strongest research base. This intervention provides counseling and support for spouse caregivers and has shown that improving social support for spouse caregivers decreases caregiver depression, decreases negative caregiver appraisals of behavior problems in the person with dementia and delays nursing home placement of the person with dementia. The intervention is currently being tested with adult children caregivers. While the published studies on this project do not include sufficient information to assess total costs against benefits and cost savings, the delay in nursing home placement of 1.5 years represents sizable cost savings to be matched against program costs. (21)

This intervention is currently being implemented in Minnesota and preliminary evaluation results are trending in the direction of the NYU studies. Final evaluation of the full five years of implementation of the intervention in Minnesota will be available in mid-2013. Additional information about the federal funding program for state implementation of community interventions and the participation by Minnesota Board on Aging is included in Appendix 2.

Additional research is needed to evaluate the costeffectiveness looking across the range of support services that may benefit caregivers. The current literature provides many constellations of caregiver supports and interventions with mixed results. Careful design that sorts out the relative merits of different types and combinations of interventions and considers the changing needs of caregivers related to their health status and the health status of the patient and assesses intervention cost against health and social service costs for both caregivers and patients is needed and not currently available. (22)

Conclusion: There is consensus that communitybased interventions to support patients and their caregivers in the day-to-day demands of care for people with cognitive impairment can provide significant benefits in the success of managing these demands. Data are not currently available to assess costs and potential cost saving of implementing these interventions and it is not clear at this time which interventions are cost effective and for whom.

Improved Collaboration Between Medical Care and Community Supports

Work is underway in Minnesota and around the nation to build new models of health and primary care including patient-centered care, team-based care and health care homes. While many efforts focus on improving care for those with complicated health status and multiple chronic conditions, most are not specifically directed toward care of patients with Alzheimer's disease and other dementias. New care models have not been in place long enough to realistically assess costs of implementation and cost savings resulting from improved care outcomes.

Work done by the Indiana University Center for Aging Research has demonstrated the effectiveness and feasibility of implementing a collaborative dementia care model that includes care coordination and coordination with community resources for respite care and social support. This work does not quantify costs. (23) Additionally, their work examining transitions in care for people with dementia among home, hospital and nursing facilities underscores the complexity of assessing the best approach to achieving cost savings and quality of care.

Efforts to decrease cost of care for older adults have focused on reducing or delaying use of nursing facility care. However, current patterns of care for people with dementia include multiple transitions between home, hospital and nursing facility. In addition, the care in nursing facilities varies in format across residential care with varying levels of services provided and care in transitional care units intended for short stay. Callahan and colleagues found that a large percentage of those moving from hospital to nursing facility returned home with various levels of home health care. (24) Analysis of cost and cost savings needs to include an assessment of the quality of care, appropriate use of care settings and levels of care within those settings and appropriate management of transitions between care levels and care settings. Increasingly, nursing facility care is a transitory site of care in a "transitional care unit" and an extension of acute care. A reduction in nursing facility use is commonly used as an outcome indicator for intervention and care coordination efforts, but this may not be appropriate without understanding the varied reasons for use.

Transitional care has emerged as a strategy for achieving higher quality of care at reduced cost. It entails a broad range of time-limited services to ensure continuity of care, promote safe and timely transfer of patients from one level or type of care setting to another and to decrease hospital admissions and readmissions. Naylor and colleagues conducted a systematic review of randomized clinical trials of transitional care interventions. They focused on care for chronically ill adults and not those with Alzheimer's disease or related dementia, specifically. Research by this group on transitional care interventions for those with Alzheimer's disease or related dementia is underway and publication is expected soon.

Patients with dementia have among the highest level of care transitions, and these transitions are frequently related to their other, co-existing health conditions. Consequently, it is necessary to determine whether transitional care strategies for those with Alzheimer's disease and related dementia need to be specifically tailored. While most studies reviewed by Naylor and colleagues included economic analyses, cost measures varied and often did not include all relevant health costs. This made it difficult to compare the effects of the successful interventions on cost and cost savings. Similarly, the interventions included varying components of transitional care. (25)

In order to determine the most cost-effective strategies for collaboration between clinical care and community supports and to assess care models and patterns of transition against standards for identifying the most appropriate level and setting for care, consistent measures are needed for cost accounting and intervention outcomes. Costs and outcomes must be determined specifically for those with Alzheimer's disease and related dementia. Ideal models of high value care will also need to be assessed against the varying availability of community resources across Minnesota.

An initiative is underway in Minnesota to address effective care transitions. The Reducing Avoidable Readmissions Effectively (RARE) campaign is being conducted by the Institute for Clinical Systems Improvement (ICSI), the Minnesota Hospital Association and Stratis Health. Although this project is not directed specifically at patients with Alzheimer's disease and related dementias, the outcome of this effort should provide valuable information about the experience of supporting care transitions for those with dementia-related conditions.

Conclusion: It is clear that specific efforts to support individuals through transitions to different levels and locations of care are important to successful care transitions and health outcomes. Currently there is insufficient information available about the costs and potential cost savings of various interventions to make specific recommendations. The use of different levels and locations of care is changing and more specific definitions for the appropriate use of different care settings are needed.

Quality Measures Review

MN Statutes 62U.15 Subd. 1. **Data from Providers**. (a) By July 1, 2012 the commissioner shall review currently available quality measures and make recommendations aimed at improving assessment and care related to Alzheimer's disease and other dementia diagnoses, including improved rates and results of cognitive screening, rates of Alzheimer's and other dementia diagnoses and prescribed care and treatment plans.

Minnesota's 2008 Health Reform Law requires the Commissioner of Health to establish a standardized set of quality measures for health care providers across the state. The goal is to create a uniform approach to quality measurement in order to enhance market transparency. The quality measures,

to be reviewed annually, must be based on medical evidence, and are developed through a participatory process with health care providers. Measures must include uniform definitions and submission formats and, to the extent possible, avoid increasing the administrative burden on health care providers. Initial measures must be based on existing quality indicators for physician and hospital services, measured and reported publicly by quality measurement organizations. Quality reporting must incorporate measures for primary care, including preventive services, coronary artery and heart disease, diabetes, asthma, depression, and other measures as determined by the Commissioner. Currently, the State Quality Reporting and Measurement System does not include measures related to screening and treatment for Alzheimer's disease and related dementias.

To review potential quality measures related to Alzheimer's disease and other dementias, Minnesota Department of Health contracted with Minnesota Community Measurement (MNCM), to conduct an environmental scan of relevant clinical quality measures and surveillance systems. MNCM is nonprofit organization in Minnesota that works with a variety of stakeholders in the state, including MDH, to accelerate provider quality improvement through measure development, data collection and public reporting health care quality information. MNCM also made recommendations regarding the feasibility of developing and implementing statewide quality measures pertaining to screening for Alzheimer's disease and related dementias. This report is included in Appendix 3.

Thirty-one quality measures pertaining to dementia screening or other relevant aspects of care provided to people with dementia were identified but none were specific to Alzheimer's. None of these measures have the endorsement of the National Quality Forum or other such bodies and no national standards for evaluating quality measures for dementia care are available. Forty-seven cognitive assessment tools were also identified but there are no national standards to evaluate these assessment tools or criteria for comparing their relative effectiveness. Of the forty-seven tools included, only ten are open source and widely available. This raises the prospect of added costs for providers who choose – or would be mandated- to use such tools for all patients.

Conclusion: Given the current lack of standards for quality measures and assessment tools for Alzheimer's disease and related dementias, the lack of standard methodology for evaluating costs and outcomes of care, and the changing definitions of stages of cognitive impairment; it is premature to recommend a specific state screening program or the adoption of quality measures at this time. The Patient Protection and Affordable Care Act is likely to drive development of consensus on appropriate tools as experience is gained with use of cognitive screening in the Medicare annual wellness visits. It would be more logical to monitor this experience and as the state of the science evolves and new criteria for assessment and treatment are developed and implemented to revisit recommendations for quality measures for screening and treatment of Alzheimer's disease and related dementias.

Learning Collaborative

MN Statutes 62U.15 Subd2. Learning

Collaborative. By July 1, 2012 the commissioner shall develop a learning collaborative curriculum that includes screening and education on best practices regarding identification and management of Alzheimer's and other dementia patients under section 256B.0751, subdivision 5, for providers, clinics, care coordinators, clinic administrators, patient partners and families, and community resources including public health.

The goals established for this activity were to develop learning collaborative curriculum and accompanying tools to support implementation of care coordination for health care homes (HCH). The learning collaborative curriculum is based on the following:

• Clinics complete a baseline assessment of their current status for coordinating care for dementia patients; progress is measured year to year and clinics are provided with feedback.

- Providers, team members, community supports and patients and family members are active teachers at each session.
- Learning modules are grounded in evidence based guidelines, tools and expert documentation to support learning.
- Caregiver support and care coordination elements are included in each teaching module.
- Active evaluation of the learning methods and learning of participants is integrated into future planning.

The Minnesota Department of Health, Health Care Home Team collaborated with members of the PMA 2020 Early Identification Committee to develop the initial draft of the health care home learning collaborative curriculum for patients with dementia. (More information on the PMA 2020 work and organizational development is available in Appendix 4.) The team also developed an Alzheimer's HCH Standards document with a cross walk between the HCH standards and the best practices treatment, care coordination and care giver supports to help HCHs understand how to integrate care coordination of people with dementia into the systems of the HCH.

Team members developed the longitudinal high level curriculum from the PMA 2020 Curriculum Outline. The goal of this curriculum is to address main components in the first three learning collaborative sessions and re-evaluate. Detail on the curriculum content is available in Appendix 5.

The first learning collaborative session, Implementing the HCH for Patients with Alzheimer's: Early Identification, Care Coordination and Care Giver Support, was included in the Health Care Homes Learning Day, November 1, 2012 and provided an introduction to the topic. The objectives for this session were to:

- Understand the importance of early diagnosis and identifying patients with dementia such as Alzheimer's in the HCH.
- Identify key elements to effective management of Alzheimer's patients in the HCH.

- Define care coordination structures that improve the quality of care for patients and families.
- Understand the tools that support the work of the health care team in caring for Alzheimer's patients.

One hundred sixty-seven HCH team members participated in the session. Two physicians, a care coordinator, the Alzheimer association representative and a patient and her husband served as panelists and presenters in the education session. Evaluations from participants were very positive. The initial pre-assessment indicated that there is wide variation among HCHs as to the level of implementation of dementia related care coordination methods implemented in the health care home. Additional clinical guidelines and tools are in development for use at future learning collaborative sessions. The next face to face learning session is planned for May 1 and 2, 2013.

Further Development: Further refinement and development of the learning collaborative curriculum will be completed based on a comprehensive analysis of the pre-assessments completed by participating health care homes. Focused planning will be based on learning needs and additional evaluation strategies will be developed. The HCH is collaborating with DHS Aging and Adult Services Division in the development of the Alzheimer's/dementiacompetent Health Care Home that will be implemented in pilot sites in the next year. The experience gained from these pilots will also inform development of future learning collaborative activities.

Current Efforts and Future Opportunities

Major research institutions in Minnesota, including the University of Minnesota, Mayo Clinic, and Veteran's Administration Health Care System, are actively involved in research initiatives to develop new strategies for differential diagnosis of dementias and cognitive impairment and earlier diagnosis of Alzheimer's disease and related dementias. These will be crucial to establishing baseline measures to assess the efficacy of various treatment strategies. Work is also underway to describe the sources of excess cost of care for people with Alzheimer's disease and related dementias and assess the impact of co-existing chronic diseases. This may provide clearer direction for cost-saving interventions related to dementias or the other co-existing chronic conditions.

Minnesota is on the cutting edge of efforts to reform primary care and effectively implement health care home models. The pilot implementation of an Alzheimer's/dementia-competent Health Care Home will provide an opportunity to evaluate the care model with an assessment of the factors which affect cost of care in actual populations in real time. This is data that is currently lacking in the estimated cost methods used in much of the published research.

The Act on Alzheimer's collaboration of more than 150 individuals and 50 organizations the developed from the Alzheimer's Disease Working Group created by the 2009 legislation continues to work to address the challenges to families from these life changing conditions. (See Appendix 4.) They have produced specific tools and approaches for clinicians, families and communities to address identification and improved care. The Act on Alzheimer's Provider Practice Tool developed for clinicians offers practice guidelines for the implementation of screening, diagnosis and care management for patients with Alzheimer's disease and related dementias. Four of Minnesota's health systems, HealthPartners, CentraCare, Essentia and Allina, are engaged in adoption part or all of the guidelines. Their work in developing a Dementia Capable Communities Toolkit for community leaders and influencers is currently being tested and is expected to be instrumental in guiding communities through the process of addressing community needs to support those affected by Alzheimer's disease and related dementias.

Work is underway elsewhere implementing new models of care, coordinating clinical and community care and providing community programs to support caregivers and systems of support for people with Alzheimer's disease and related dementias which will inform the initiatives conducted in Minnesota. Collectively, these initiatives provide significant opportunities to evaluate cost and effectiveness across settings using various models of care. The Minnesota organization known as Act on Alzheimer's collaboration will continue to work on community engagement, professional education and definition of models for evaluating cost-effectiveness and projecting cost.

In addition to work specifically designed to evaluate the care of people with Alzheimer's disease and related dementias, efforts directed toward populations with complicated health issues and multiple chronic conditions include people with Alzheimer's disease and related dementias. With robust evaluation, they provide a unique opportunity to evaluate broader models for their specific benefits to people with Alzheimer's disease and related dementia. As Minnesota's health reform efforts evolve and with attention to achieving the triple aim through reforms in payment and health care delivery, there is an opportunity to evaluate efforts particularly as they pertain to subpopulations with high utilization of health care including those with Alzheimer's disease and related dementias.

While the RARE Campaign to reduce avoidable hospital readmissions targets the general population of patients, people with dementia are overrepresented among those requiring readmission. RARE will add to the knowledge base of effective strategies to manage multiple conditions and set priorities for intervention.

The National Plan to Address Alzheimer's Disease provides a framework to address the challenges of Alzheimer's disease and related dementias. Their aggressive work plan will direct needed efforts to address the issues. More information on the National Plan is included in Appendix 6. Designed to coordinate the work of federal agencies, the National Plan also provides direction to other stakeholders. Strategies and agency-specific actions are included that address many of the issues raised in this report including best models for early diagnosis, care guidelines and models of care and care coordination, development of a dementiacapable workforce, expansion of family supports, and development of effective methods for surveillance and monitoring of Alzheimer's disease and related dementias and their impact. The National Plan brings together resources across federal agencies and builds on nation-wide efforts to address the issues facing Minnesota and all states.

Conclusion

Identifying and implementing effective strategies to address Alzheimer's disease and related dementias is a high priority for the research and practice communities at the state and national level. Considerable effort is underway at many levels to identify best and most cost-effective practice, set practice guidelines, and identify the roles of various care settings, health care providers and care-givers as well as identify the means to treat, halt or prevent the disease. The next few years are likely to provide more specific information that will help address issues raised about cost and quality of care and support for patients with Alzheimer's disease and related dementia and their caregivers.

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Appendices

Appendix 1: Annotated Bibliography of Selected Studies

Appendix 2: The Alzheimer's Disease Supportive Services Program (ADSSP) and Minnesota's Participation

Appendix 3: Alzheimer's Quality Measures Inventory and Feasibility Plan

Appendix 4: Preparing Minnesota For Alzheimer's 2020 and ACT on Alzheimer's

Appendix 5: Learning Collaborative Curriculum

Appendix 6: The National Plan to Address Alzheimer's Disease

Appendix 1: Annotated Bibliography of Selected Studies and Other Reports

Study or Report	Study Subjects and Design	Results and Discussion
Boustani MA, Sachs GA, Alder CA, Munger S, Schubert CC, Guerriero Austrom M, Hake AM, Unverzagt FW, Martin M, Mathews BR, Perkins AJ, Beck RA, and Callahan CM. Implementing innovative models of dementia care: The healthy aging brain center. Aging and Mental Health. 2011;15(1):13-22.	A collaborative dementia care delivery model in a safety net health care system serving the resident of Marion Co, Indiana was developed and implemented. Interventions for 208 patients with dementia and their caregivers included telephone support, patient and caregiver education, active case-finding and treatment for depression, psychoses, behavioral disturbances and hazardous activities, medications, management of vascular disease and other co-morbid conditions.	Within one year, 208 patients received 528 clinic visits in the new model. Results showed fewer ER visits and decreased length of hospital stay, fewer readmissions within 30 days and better management of vascular conditions and diabetes compared to usual care patients.
Callahan CM, Arling G, Wanzhu Tu, Rosenman MB, Counsell SR, Stump TE, and Hendrie HC. Transitions in care for older adults with and without dementia. JAGS. 2012;60:813-820.	Data from several databases was evaluated for 4,197 community dwelling older adults, including 1,523 participants with dementia. Rates and types of transitions in care among those with and without dementia were described, particularly those involving nursing facilities.	Participants with dementia had greater health care utilization, nursing facility use, hospital care, home health care and more transitions between and among care settings compared to those without dementia. Nursing facilities were part of a dynamic network of care characterized by frequent transitions.
Callahan CM, Boustani MA, Unverzagt FW, Austrom MG, Damush TM, Perkins AJ, Fultz BA, Hui SL, Counsell SR, and Hendrie HC. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized control trial. JAMA. 2006;295:2148- 2157.	Controlled clinical trial of 153 older adults with Alzheimer's disease and their caregivers who were randomized to receive collaborative care management (n=84) or augmented usual care (n=69). Intervention patients received one year of care management by an interdisciplinary team.	Patients and caregivers receiving intervention had significantly fewer behavioral and psychological symptoms. Caregivers in the intervention group reported significant improvements in distress and improvement in depression compared with those in the usual care group.
Centers for Disease Control and Prevention and the Alzheimer's Association. The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health: Chicago, IL: Alzheimer's Association; 2007. (available at www.cdc.gov/aging)		A public-private collaborative workgroup developed a framework to guide a coordinated public health response to address cognitive health.
Clark PA, Bass DM, Looman WJ, McCarthy CA, and Eckert S. Outcomes for patients with dementia from the Cleveland Alzheimer's managed care demonstration. Aging and Mental	Evaluation of the effects of care consultation delivered within a partnership between a managed health care system and Alzheimer's Association chapter among 121	Overall findings show that care consultation was a promising strategy for improving outcomes for people with memory problems as demonstrated by reduced utilization of health care

Appendix 1: Annotated Bibliography of Selected Studies and Other Reports		
Study or Report	Study Subjects and Design	Results and Discussion
Health. 2004;8(1):40-51.	patients.	services, and improved psychosocial outcomes.
Cordell CB, Borson S, Boustani M, Chodosh J, Rueben D, Verghese J, Thies W, Fried LB, the Medicare Detection of Cognitive Impairment Workgroup. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. Alzheimer's and Dementia, in press, available at www.alzheimersanddementia.org/inpress		Workgroup developed an algorithm for assessment of cognition including recommended tools for assessment for both patients and caregivers to provide primary care physicians with guidance on cognitive assessment during the Medicare Annual Wellness Visit.
Freiman, MP, Brown D, Maier J, O'Keefe C, and Wiener JM, ADSSP National Resource Center. Innovative interventions for persons with Alzheimer's disease and their caregivers. Prepared for the Office for Planning and Policy Development, Administration on Aging, US Department of Health and Human Services, April, 2010		Summary of a representative sample of the available literature describing evidence-based interventions or promising practices in 4 categories: persons with Alzheimer's disease and related dementias; caregiver/care receiver dyads; caregivers; administrative interventions, care coordination and screening.
Getsios, D, Blume S, Ishak KJ, Maclaine G, and Hernandez L. An economic evaluation of early assessment for Alzheimer's disease in the United Kingdom. Alzheimer's and Dementia, 8(2012)22-30.	A simulation of Alzheimer's disease progression and the effect of treatment interventions was developed from patient level data collected in drug evaluation trials.	17 patients need to be assessed to diagnose one patient with Alzheimer's disease at an average assessment cost of \$6,000 per patient diagnosed. Early assessment reduced health care costs by an estimated \$5,300 in health care costs and \$11,400 in societal costs.
Jones C, Edwards RT, and Hounsome B. A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. International Psychogeriatrics. 2012;24(1):6-18.	A range of electronic databases were searched. Studies were evaluated for quality using a checklist for economic evaluations. Twelve studies were included in the review.	Only 4 of the 12 studies reported a significant difference in the outcome measure for caregivers. Review indicated that few studies report costs in enough detail to provide evidence of the effectiveness and cost-effectiveness of both pharmacological and non- pharmacological approaches.
Kutschenko, LK. Diagnostic misconceptions? A closer look at clinical research on Alzheimer's disease. J Med Ethics. 2012;38:57-59.		A brief report of the ethical issues raised by inclusion of persons indentified with mild cognitive impairment and cognitive problems not reaching the criteria for dementia as participants in early intervention trials in Alzheimer's disease

research.

Appendix 1: Annotated Bibliography of Selected Studies and Other Reports

Study or Report	Study Subjects and Design	Results and Discussion
Mauskopf J, and Mucha LA review of the methods used to estimate the cost of Alzheimer's disease in the United States. Am J Alzheimers Dis Other Demen. 2011;26(4):298- 309.	Systematic literature review of cross-sectional, survey and other observational studies on the costs of care for Alzheimer's disease patients at different stages of the disease. Studies included data on direct medical, direct nonmedical, indirect and informal costs of care; this review had the goal of evaluating the utility of these data for future economic evaluations of new AD treatments.	This analysis highlights the complexity and difficulty of quantifying these various health costs. Authors concluded that this body of literature was of limited utility for use in economic evaluations due to variation in time periods assessed, types of costs included, analysis methods, specific patient groups included/excluded, and methods to characterize disease severity.
McCarten JR, Anderson P, Kuskowski MA, McPherson SE, Borson S, and Dysken MW. Finding dementia in primary care: the results of a clinical demonstration project. JAGS. 2012;60:210-217.	Descriptive/feasibility program evaluation was conducted in 7 Veterans Affairs Medical Centers offering cognitive screening tests in the primary care clinic to veterans 70 years or older who did not have a prior diagnosis of cognitive impairment. Those failing the cognitive screen were offered a more complete diagnostic evaluation to identify dementia or cognitive impairment.	Of 8,342 veterans offered screening, 8,063 accepted, 2,081 failed the screen, 580 agreed to further evaluation and 540 were diagnosed with cognitive impairment, including 432 with dementia. Total newly documented cognitive impairment in all screens was 11% as compared to 4% in similar clinics without this screening program.
Mittelman MS, Haley WE, Clay OJ, and Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. Neurology. 2006;67:1592-1599.	406 Spouse caregivers were randomized into a counseling and support intervention or usual care.	Patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls. The median delay in placement was 557 days, or approximately 1.5 years.
National Plan to Address Alzheimer's Disease. US Department of Health and Human Services. 2012. http://aspe.hhs.gov/daltcp/napa/natlplan.shtml		National plan completed as directed by the National Alzheimer's Project Act (2011). The plan includes a detailed listing of current federal activities and initial recommendations for priority actions to expand, eliminate, coordinate or condense programs. The plan also addresses ensuring coordination of the implementation of the National Plan with implementation of other HHS-wide plans and strategies. More detail on the plan is included in Appendix 5.

Appendix 1: Annotated Bibliography of Selected Studies and Other Reports

Study or Report	Study Subjects and Design	Results and Discussion
Naylor MD, Aiken LH, Kurtzman ET, Olds DM, and Hirschman KB. The importance of transitional care in achieving health reform. Health Affairs. 2011;30(4):746-754.	Systematic review of the research literature and summary of twenty- one randomized clinical trials of transitional care interventions to prevent rehospitalization among chronically ill adults discharged from hospitals to home or to long- term care facilities.	Two types of multicomponent interventions have been shown more effective in reducing all-cause readmissions: comprehensive discharge planning with follow-up interventions that incorporate patient and caregiver goal setting, individualized care planning, educational and behavioral strategies, and clinical management; and a telehealth-facilitated intervention emphasizing daily home videophone or telephone monitoring and transmission of physiological measurements, self-care instruction, and symptom management.
US Preventive Services Task Force Screening for Dementia, Recommendations and Rationale, Agency for Healthcare Research and Quality. Pub. No. 03-520A, 2003.	Task force review of available research on the potential benefits and harms of routine screening for dementia in older adults. Updates the 1996 review.	The task force concluded that there is insufficient evidence to determine whether the benefits of screening for dementia outweigh the harms.
Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, DeMonte RW, Chodosh J, Cui X, Vassar S, Duan N, and Lee M. The effect of a disease management intervention on quality and outcomes of dementia care. Ann Intern Med. 2006;145:713-726.	Evaluated the effectiveness of a dementia guideline-based disease management program on quality of care and outcomes for patients with dementia. Study was a clinic-level randomized control trial among 18 primary care clinics and 408 patients with dementia 65 years or older paired with 408 informal caregivers. Intervention lasted 12 months.	The guideline-based disease management program led to substantial improvements in quality of care for patients with dementia.
Weimer, DL and Sager, MA. Early identification and treatment of Alzheimer's disease: Social and fiscal outcomes. Alzheimer's and Dementia 2009;5:215-226.	Cost-benefit analysis was based on estimates available in the medical literature and assuming early intervention with drug treatment, a program for caregivers, or both these interventions. A Monte Carlo model was used. Potential cost savings to the state of Wisconsin and the federal government were estimated.	In this estimate, the net fiscal benefits of the combined intervention would be expected to generate savings of approximately \$10,000 per patient diagnosed with Alzheimer's disease. The analysis also assumes that physicians would initiate interventions based on the results of a diagnostic screening.

Appendix 2: The Alzheimer's Disease Supportive Services Program (ADSSP) and Minnesota's Participation

Congress created the Alzheimer's Disease Supportive Services Program (ADSSP) in 1992 to encourage states to develop models of assistance for persons with Alzheimer's disease and related dementias and their family caregivers. The goal of the program is to expand the availability of community-level supportive services for persons with Alzheimer's disease and related dementias as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard-to-reach and underserved persons and their family caregivers using proven and innovative models. A number of evidence-based programs that improve the health and wellbeing of persons with Alzheimer's disease and related dementias and/or their caregivers are currently being implemented in communities through the ADSSP. (1)

Beginning in 2007, the Administration on Aging (AoA) began funding states through cooperative agreements to implement evidence-based or innovative projects under a number of ADSSP program announcements. The ADSSP National Resource Center was created to provide technical assistance to ADSSP grantees. Currently, the ADSSP program has three types of grants: Evidence-based, Innovative Practices, and Systems Integration/Dementia Capability. (2) The Minnesota Board on Aging has been funded through these grant programs.

Minnesota has participated in numerous federally funded initiatives over the past two decades that have advanced policy and practice around addressing needs of persons with Alzheimer's disease and their caregivers including:

- Medicare Alzheimer's Disease Demonstration (1989-1995),
- Chronic Care Networks for Alzheimer's Disease Demonstration (1997-2003),
- AoA National Family Caregiver Support Program (2001-present) and
- Aging and Disability Research Center development (2003-present).

In addition, the state has funded local initiatives through a legislated grant program, the Community Services/Service Development (CS/SD) grants since 2003 to fund efforts directed at supporting people living in the community and delaying nursing home placement. Caregiver education and support has been a central focus of all these initiatives involving both changes and innovations in practice, and modifications in policy and public program features. Through the National Family Caregiver Support Program, Minnesota is creating an expanded network of trained dementia capable consultants statewide. (3)

The Minnesota Board on Aging (MBA) has been awarded three ADSSP grants and two Systems Integration grants under the AoA programs described above. Since 2007, MBA was awarded three ADSSP Evidence-Based grants for implementation the New York University Caregiver Intervention (NYUCI), one of the evidence-based interventions identified by AoA for translation to community settings. Based on previous work, the NYUCI intervention was chosen for implementation because it was a multi-component intervention that included a range of services and could be tailored to the diverse needs of each family. It enhances the state's ongoing pursuit of the formal Minnesota policy directives to "rebalance long-term care" from facilities into community settings and advances its progress toward the AoA vision of choices for independence. The original research conducted by New York University demonstrated delayed nursing home placement of an average of 18 months. In the initial phase of the Minnesota project in 2007 to 2009, the MBA worked with four project sites. Results from this phase demonstrated that similar outcomes were achieved in Minnesota with caregivers experiencing less depression and stress and enhanced caregiver support networks. Caregivers indicated they were satisfied with the program and would recommend it to others. The Memory Care Consultants, similarly,

stated that they believed the program significantly enhanced the services offered to caregivers. The ADSSP Evidence-Based grants allowed expansion to additional sites and populations. (3,4)

The MBA was also awarded ADSSP Innovation Grants in 2008 and 2009 to develop and expand Early Memory Care sites and augment the state's infrastructure for identifying and supporting individuals with early stage dementia and their caregivers through embedding practices that build upon the medical home clinical model in both clinic and community agency practice. The goal of Minnesota's proposal is to give people in the early stages of dementia and their caregivers optimal control over their lives to help sustain cognitive function, reduce premature decline and reduce the negative impacts on caregivers. The approach will be to integrate practices that support the health care home (HCH) into the state's framework for identification, diagnosis, joint medical/community care planning, and caregiver support, to include Minnesota's effectiveness in reaching people with early stage dementia. Project objectives include: 1) screen an additional 3,000 individuals for dementia, including an additional 150 hard to reach individuals; 2) reductions in premature cognitive decline and caregiver depression; 3) adoption of HCH Early Stage Dementia practice guidelines in health care organizations; 4) consistent implementation of HCH Early Stage Guidelines across participating memory care sites; and 5) the embedding of Early Stage Dementia Practice Guidelines in the MinnesotaHelp Network (ADRC), community medical clinics, Minnesota Caregiver Consultant practice, state policy, and exported to other states. (4) MBA was awarded a Systems Integration /Dementia Capable Systems grant in 2011. With this project, MBA will integrate a dementia capable long-term services and supports system with state-certified health care homes to maximize individuals' choice, independence and responsibility through risk management, self-direction and care transition support.

To achieve this goal, Minnesota will: 1) integrate a statewide set of services/supports through a fully coordinated dementia capable single entry point with a particular focus on care transitions in cooperation with health care homes; and 2) ensure seamless regional access to a consistent set of high quality, sustainable, dementia capable evidence-based/informed supports for persons with dementia and their caregivers. The intervention will be disseminated statewide with special emphasis on the Native American and African American populations. Outcomes include: 1) identification of people with possible dementia and their caregivers at initial risk management screening, 2) increased dementia capability of health care homes and LTC services/supports, 3) earlier diagnosis of Alzheimer's disease, 4) successful care transitions for people with dementia, 5) reduced number of persons with dementia depression and increased quality of life, and 6) reduced symptoms of depression among caregivers, reduced caregiver reactions to problem behaviors and enhanced caregiver support networks.

Endnotes

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- 3. Mittleman, M, et. al. A Guide to Implementing the New York University Caregiver Intervention and the Minnesota Experience. Alzheimer's Disease Support Services Program, November, 2010
- 4. Aging and Disability Resource Center, ADSSP Grantee Profiles, <u>http://www.adrc-tae.org/tiki-index.php?page=adsspmap</u>

Appendix 3: Alzheimer's Quality Measures Inventory and Feasibility Plan

Alzheimer's Disease Prevalence and

Screening Measures

5/1/2012

Prepared for the MN Department of Health

2011 Minnesota State Legislation 62U.15 Section 4 Subdivision 1

Created by Nathan Hunkins & Collette Pitzen MN Community Measurement

Table of Contents (TOC)

Summary & Background	3
Methods	4
Feasibility Recommendation	5
Alzheimer's & Dementia Clinical Quality Measures (TOC)	8
Cognitive Assessment Tools (TOC)	.40
National Dementia & Alzheimer's Strategies and Surveillance Systems	.88
Appendix A: MN Statute 62U.15. Alzheimer's Disease: Prevalence and Screening Measures	.89
Appendix B: Proposed Alzheimer's Measure Development Work Plan	.90
Appendix C: Proposed Alzheimer's Measure Development Timeline	.91

Summary & Background National Dementia & Alzheimer's Strategies and Surveillance Systems

At the request of the MN Department of Health in response to Minnesota State Legislation 62U.15 *Alzheimer's Disease: Prevalence and Screening Measures* Section 4 Subdivision 1 (Appendix A), MN Community Measurement conducted an environmental scan of clinical quality measures and surveillance systems relating to Alzheimer's disease and dementia. An additional aspect of the request was to create a feasibility recommendation for developing and implementing statewide quality measures pertaining to screening, diagnosing, and treating Alzheimer's disease, as well as other forms of dementia.

Summary of Environmental Scan Findings

- Thirty-one clinical quality measures were identified
 - One measure from the Australian Council on Healthcare Standards pertains to screening healthy patients
 - o All thirty-one measures pertain to dementia and are NOT specific to Alzheimer's
 - No measures have been endorsed by the National Quality Forum
 - Six measures are included in the Centers for Medicare and Medicaid Services' proposed measures for Stage 2 of the Electronic Health Record Incentive Program (Meaningful Use: Stage 2)
 - Nine measures are included in the Centers for Medicare and Medicaid Services' 2012 Physicians Quality Reporting System (PQRS)
 - Due to the availability of detailed measure specifications, the most feasible clinical quality measures are a set of 10 measures recently developed by a collaboration of the American Medical Association, American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, and the Physician Consortium for Performance Improvement[®] (PCPI[™])
 - One health plan measure was identified (page 10) from the National Committee for Quality Assurance (NCQA) Healthcare Effectiveness Data and Information Set (HEDIS)
- Forty-seven cognitive assessment tools were identified
 - The Preparing MN for Alzheimer's 2020 Early Identification and Quality Health Care Leadership Group recommended eight assessment tools. The same group identified three tools for initial screening. Those were the Mini-Cog, the General Practitioner assessment of Cognition (GPCOG) and the Family Questionnaire. If the Mini-Cog score is less than four, if the GPCOG score is less than nine, or if the Family Questionnaire score is greater than two, the group recommends using one of the following tools; St. Louis University Mental Status Examination (SLUMS), Kokmen Short Test of Mental Status Montreal Cognitive Assessment (MoCA), Short Test of Mental Status, Mini-Mental State Examination (MMSE), Mini-Mental State Examination-2 (MMSE-2)
 - Ten of the tools are open source and thus widely available
- Three national dementia & Alzheimer's Strategies and Surveillance Systems were identified across the world (United States, Canada, England)

METHODS

A combination of methods was used to identify the various quality measures and cognitive screening tools found in the inventory. The primary method was internet research through different sources of academic and grey literature. Secondary methods included meeting with a subgroup from the Preparing MN for Alzheimer's 2020 (PMA 2020) and conducting a key informant interview with Katie Maslow, an Alzheimer's measurement expert from the Institute of Medicine. MNCM met with Katie Maslow and the PMA 2020 subgroup titled *Early Identification and Quality Health Care Leadership Group* to explore if there were any additional quality measures or cognitive screening tools not included in the initial draft of the inventory. The PMA subgroup offered their list of recommended cognitive screening tools which are labeled in the table of contents on page 41. As an expert on Alzheimer's quality measurement, Katie Maslow helped identify the RAND-Assessing Care of Vulnerable Elders (ACOVE) measures, which were missing from the initial draft of the inventory. Table 2 below is a list of the search results from the various internet searches conducted by MNCM.

Table 2: Summary of Search Results

Source	Clinical Quality Measures
National Quality Forum (NQF) Search- Alzheimer's	<u>Results: 0</u>
NQF Search-Dementia	Results: 18 http://www.qualityforum.org/Measures_List.aspx?#k=dementia
	Summary: No search results were relevant to dementia or Alzheimer's measurement.
National Quality Measures Clearinghouse (NQMC) Search- Alzheimer's	<u>Results: 0</u>
NQMC Search-Dementia	Results: 34 http://www.qualitymeasures.ahrq.gov/search/search.aspx?term=dementia
	Summary: Three dementia-related measures were identified. See pages 10, 39, and 40 for descriptions.
American Academy of	Results: 10
Neurology: Dementia & Alzheimer's Measures	http://www.aan.com/globals/axon/assets/9493.pdf
	Summary: All 10 measures pertain to dementia; they are not Alzheimer's specific
CMS: Physician Quality	Results: 9
Reporting System	http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment- Instruments/PQRS/AlternativeReportingMechanisms.html
	Summary: The nine dementia measures used in the PQRS program are taken directly from a collaboration of measure developers (American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician

	Consortium for Performance Improvement [®] (PCPI™)). However, the PQRS measures limit the denominator to Medicare patients.
CMS: Meaningful Use	<u>Results: 0</u>
Stage 1	
CMS: Meaningful Use	<u>Results: 6</u>
Proposed Stage 2	
	Summary: The dementia measures in the proposed stage 2 Meaningful Use program are taken directly from a collaboration of measure developers (American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement [®] (PCPI [™]))
CMS: Accountable Care	<u>Results: 0</u>
Organizations	

Feasibility Recommendation

Measuring the quality of care pertaining to Alzheimer's and other forms of dementia is a new area of measurement for both the state of MN and nationally. One indicator of this is the lack of nationally endorsed quality measures. However, the HEDIS measure and the measures developed by the collaboration lead by the American Medical Association (AMA) were the most detailed and robust measures. These measures have detailed specifications and a subset of the AMA et al. measures are currently being used by the Center's for Medicare and Medicaid Services for the Physician Quality Reporting System and are included in the list of proposed Stage 2 quality measures for the EHR Incentive Program (Meaningful Use). Currently, MNCM is not aware of any large scale data collection and measurement programs that are reporting Alzheimer's quality measures. This is a new area and is quickly becoming ripe for measurement given the local and national attention.

On the national level, MNCM has connected with a national collaboration titled the Alzheimer's disease Measurement Improvement (AD-MI) Working Group. The goal of the workgroup is to establish a "megacommunity" around improving quality of care and outcomes by improving measurement in Alzheimer's disease. MNCM is a participant on the AD-MI Measurement subgroup that is currently working on a landscape of Alzheimer's measures similar to the inventory of measures in the following pages of this report.

The dementia screening measure developed by the Australian Council on Healthcare Standards is the only measure which pertains to screening healthy patients. The rest of the measures identified in the environmental scan pertain to patients that have already been diagnosed with Alzheimer's or some other form of dementia. However, as identified by the Alzheimer's Association, Preparing MN for Alzheimer's 2020 and several other research institutions, early detection (screening) and diagnosis is one of the most important steps to treating and helping patients with dementia or Alzheimer's. The lack of a defined screening measure for Alzheimer's or dementia represents a gap in the current landscape of available measures. This is a potential area for measure development, however, prior to proceeding with measure development MN Community Measurement recommends the following:

• Submit Alzheimer's and Dementia as a measure concept to be developed during the Minnesota Department of Health's and MN Community Measurement's call for clinical quality measure concepts. When submitted for the call for measures, the document should include the
following types of documentation as a part of suggesting a measure concept: current gap in performance, suggested potential measure/s, evidence supporting a potential measure, willingness to serve on a measure development technical advisory workgroup and potential funding sources for measure development.

• If selected as a measure concept for further exploration follow MNCM's process for measure development outlined in Appendix B.

Pros & Cons of Developing an Early Screening and Diagnosis Measure

Alzheimer's and other forms of dementia have received a lot of local and national attention due to the increasing size of our aging population. The benefits of developing an early screening and diagnosis measure include giving patients and families more time to prepare for the latter stages of Alzheimer's and dementia and facilitating the alignment of local and national initiatives that support this type of measurement work. Developing an Alzheimer's measure for providers in Minnesota to report also carries risks. For example, clinical quality measurement can be very burdensome on clinics, demanding a lot of resources and affecting work flow. The extra work to collect and report data varies among clinics, so it is difficult to quantify the impact. Another challenge associated with developing this type of measure is the lack of consensus in the provider community regarding the recommended clinical actions for detecting and diagnosing dementia and Alzheimer's. The most effective and widely accepted clinical quality measures are developed using evidence-based clinical guidelines. For further considerations regarding the pros and cons pertaining to the development of an early screening and diagnosis measure, see Table 2 below.

Table 2: Pros & Cons of Developing a Measure

Pros	Cons
Local support from Preparing MN for Alzheimer's 2020 (PMA 2020). A PMA 2020 subgroup, <i>Early Identification and Quality</i> <i>Health Care Leadership Group,</i> identified three areas in need of measurement: detection (screening), diagnosis, and treatment.	Potential burden: Any screening measure will require adoption of screening tools by all eligible clinics in Minnesota. Early detection would require a measure of screening, which would involve a large population base, i.e. all patients age 65 and older. The burden on primary care clinics is especially sensitive as there are many primary care direct data submission measures for the Statewide Quality Reporting and Measurement System
Federal quality measurement initiatives have recognized Alzheimer's and dementia as a key topic for improvement and measurement.	Opportunity cost: Alzheimer's disease is not curable, so measurement resources could be allocated where the impact of curing or reducing disease burden is higher
Minnesota can use its existing Statewide Quality Reporting and Measurement System framework for collecting dementia and or Alzheimer's quality measures.	Stigma: Alzheimer's disease and dementia carry a certain stigma, and measurement may make providers and or patients uncomfortable
Early detection of dementia provides opportunity for treatment to slow disease progression and gives families more time to	

prepare for the more difficult stages of the
disease, both emotionally and financially.

Addressing Measurement Challenges

Developing a standard quality measure for clinics in MN requires support from key stakeholders such as providers affected by the potential measure, payers interested in improving quality in this area, and consumers interested in finding quality information pertaining to Alzheimer's and dementia care. If there is community-wide support for measurement the next task is to develop a feasible measure that is valid and reliable. This presents a host of technical and practical challenges which can place significant burden on the providers attempting to carry-out a new measure. The most important factor in addressing these challenges is to maintain community support and allow clinics adequate time to plan for any new technical and clinical changes that are required as a result of the new measure.

Alzheimer's & Dementia Clinical Quality Measures Table of Contents

Name of Measure	Page #	Name of Measure	Page #
Dementia: Potentially harmful drug-		Dementia: Neurological	
disease interactions in the elderly	10	Examination	26
Dementia: Staging of Dementia	11	Dementia: Laboratory Testing	27
Dementia: Cognitive Assessment	12	Dementia: HIV Testing	28
Dementia: Functional Status			
Assessment	13	Dementia: Depression Screening	29
Dementia: Neuropsychiatric		Dementia: Cholinesterase Inhibitor	
Symptom Assessment	14	Discussion	30
Dementia: Management of			
Neuropsychiatric Symptoms	15	Dementia: Stroke Prophylaxis	31
Dementia: Screening for Depressive		Dementia: Caregiver Support and	
Symptoms	16	Patient Safety	32
Dementia: Counseling Regarding		Dementia: Behavioral Symptoms-	
Safety Concerns	17	Screening	33
Dementia: Counseling Regarding		Dementia: Behavioral Symptoms-	
Risks of Driving	18	Intervention	34
Dementia: Caregiver Education and		Dementia: Behavioral Symptoms-	
Support	19	Medication Risk	35
Dementia: Palliative Care Counseling			
and Advance Care Planning	20	Dementia: Driving	36
Dementia: Cognitive and Functional			
Assessment	21	Dementia: Restraints	37
Dementia: Cognitive and Functional			
Assessment Annual Review	22	Dementia: Care Reviwed-15months	38
Dementia: Cognitive Evaluation	23	Dementia: Tracking and Registry	39
Dementia: Medication Review	24	Elderly Care: Cognition Assessment	40
Dementia: Medication Adjustment	25		

Measure Profile

Name of Measure: Dementia: Potentially harmful drug-disease interactions in the elderly.

Measure Type: Process

Source/Developer: National Committee for Quality Assurance (NCQA). HEDIS® 2011

Measure Description: Percentage of Medicare members 65 years of age and older who have a diagnosis of dementia and a prescription for tricyclic antidepressants or anticholinergic agents.

Target Population: Patients diagnosed with dementia

Provider Type: Managed Care Plans

Measure Usage: HEDIS 2011

Link to Measure:

http://www.qualitymeasures.ahrq.gov/content.aspx?id=34034&search=dementia#Section615

Measure Profile

Name of Measure: Dementia: Staging of Dementia

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia whose severity of dementia was classified as mild, moderate or severe at least once within a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012, Proposed Stage 2 Meaningful Use(MU)

Link to Measure:

Measure Profile

Name of Measure: Dementia: Cognitive Assessment

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results reviewed at least within a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012, Proposed Stage 2 Meaningful Use (MU)

Link to Measure:

Measure Profile

Name of Measure: Dementia: Functional Status Assessment

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of functional status is performed and the results reviewed at least once within a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012, Proposed Stage 2 Meaningful Use (MU)

Link to Measure:

Measure Profile

Name of Measure: Dementia: Neuropsychiatric Symptom Assessment

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia and for whom an assessment of neuropsychiatric symptoms is performed and results reviewed at least once in a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012

Link to Measure:

Measure Profile

Name of Measure: Dementia: Management of Neuropsychiatric Symptoms

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia who have one or more neuropsychiatric symptoms who received or were recommended to receive an intervention for neuropsychiatric symptoms within a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012

Link to Measure:

Measure Profile

Name of Measure: Dementia: Screening for Depressive Symptoms

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: The percentage of patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012

Link to Measure:

Measure Profile

Name of Measure: Dementia: Counseling Regarding Safety Concerns

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia or their caregiver(s) who were counseled or referred for counseling regarding safety concerns within in a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012, Proposed Stage 2 Meaningful Use (MU)

Link to Measure:

Measure Profile

Name of Measure: Dementia: Counseling Regarding Risks of Driving

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia or their caregiver(s) who were counseled regarding the risks of driving and the alternatives to driving at least once within a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012, Proposed Stage 2 Meaningful Use (MU)

Link to Measure:

Measure Profile

Name of Measure: Dementia: Caregiver Education and Support

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes AND referred to additional resources for support within a 12 month period.

Target Population: Patients diagnosed with dementia

Provider Type: All PQRS Eligible Professionals

Measure Usage: PQRS 2012, Proposed Stage 2 Meaningful Use (MU)

Link to Measure:

Measure Profile

Name of Measure: Dementia: Palliative Care Counseling and Advance Care Planning

Measure Type: Process

Source/Developer: American Academy of Neurology, American Geriatrics Society, American Medical Directors Association, American Psychiatric Association, Physician Consortium for Performance Improvement[®] (PCPI[™])

Measure Description: Percentage of patients, regardless of age, with a diagnosis of dementia or their caregiver(s) who received 1) comprehensive counseling regarding ongoing palliation and symptom management and end of life decisions AND 2) have an advance care plan or surrogate decisions maker in the medical record or documentation in the medical record that the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan within two years of initial diagnosis or assumption of care.

Target Population: Patients diagnosed with dementia

Provider Type: Family practice, eligible specialties that treat for dementia

Measure Usage: Unknown

Link to Measure: http://www.aan.com/globals/axon/assets/9493.pdf

Measure Profile

Name of Measure: Dementia: Cognitive and Functional Assessment

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a dementia patients is new to a primary care practice or inpatient service, then there should be a documented assessment of cognitive ability and functional status.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Cognitive and Functional Assessment Annual Review

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: All dementia patients that are evaluated annually for changes in memory and function.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Cognitive Evaluation

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a dementia patient screens positive for dementia, then a physician should document an objective cognitive evaluation that tests two or more cognitive domains, because a clinical cognitive evaluation will diagnose dementia more precisely by excluding patients without dementia and identifying dementia subtypes.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Medication Review

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a dementia patient screens positive for dementia, then the physician should review the patient's medications (including over the counter) for any that may be associated with mental status changes, because medications can increase cognitive, physical, or functional disability; hasten decline; or necessitate institutionalization.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Medication Adjustment

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient screens positive for dementia and is taking medications that are commonly associated with mental status changes in older people, THEN the physician should discontinue or justify continuing these medications, because removing or decreasing medications that affect cognition can improve cognitive status and function in vulnerable elders.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Neurological Examination

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient is newly diagnosed with dementia, then a physician should perform a neurological examination that includes evaluation of gait, motor function, and reflexes, because positive findings on a neurological examination may identify treatable conditions that cause or exacerbate cognitive impairment or that provide further evidence in support of a dementia subtype.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Laboratory Testing

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient is newly diagnosed with dementia, then a complete blood count, thyroid testing, electrolytes, liver function tests, glucose, blood urinary nitrogen, serum B12, and a syphilis test should be performed, because abnormalities in these laboratory tests may identify common and treatable conditions that can manifest as and contribute to cognitive impairment.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: HIV Testing

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a VE is newly diagnosed with dementia and has risk factors for human immunodeficiency virus (HIV), then HIV testing should be offered, because HIV is a communicable disease, and treatment of HIV can potentially slow the rate of or reverse cognitive impairment.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Depression Screening

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient is newly diagnosed with dementia, then he or she should be screened for depression during the initial evaluation period, because the recognition and treatment of depression will improve symptoms of dementia.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Cholinesterase Inhibitor Discussion

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient has been diagnosed with mild to moderate Alzheimer's disease, mild to moderate vascular dementia, or Lewy body dementia, then there should be a documented discussion with the patient or caregiver about cholinesterase inhibitor (AChI) treatment, becuase these agents have been shown to slow the progression of cognitive and functional decline.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Stroke Prophylaxis

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient has mild to moderate vascular or mixed dementia, THEN he or she should receive stroke prophylaxis, because vascular risk factors and comorbid cerebrovascular disease can worsen cognitive impairment and increase mortality.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Caregiver Support and Patient Safety

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a vulnerable elder with dementia has a caregiver, then the patient or caregiver should be given information on dementia diagnosis, prognosis, and associated behavioral symptoms; home occupational safety; and community resources, BECAUSE the patient's nursing home placement can be delayed and quality of life for the caregiver can be improved through educational interventions and comprehensive support and counseling.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Behavioral Symptoms-Screening

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient has dementia, then he or she should be screened annually for behavioral symptoms of dementia, because these symptoms increase patient morbidity; contribute to physical injury, and may increase the risk of early nursing home admission, caregiver burden, and depression.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Behavioral Symptoms-Intervention

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient with dementia has behavioral symptoms, then specific target symptoms should be documented and behavioral interventions instituted first or concurrently with pharmacotherapy, or if treating first with a pharmacological intervention, then severe symptoms or safety concerns should be present and documented, because targeted treatment provides optimal benefits and minimizes risks to the dementia patient.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Behavioral Symptoms-Medication Risk

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient with dementia and behavioral symptoms is newly treated with an antipsychotic, then there should be a documented risk–benefit discussion, because individual perceptions of risk and benefit may differ, and for some, the risks may outweigh the benefits of treatment.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Driving

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patinet is newly diagnosed dementia, then (consistent with state law) the patient should be advised not to drive a motor vehicle, should be referred to the Department of Motor Vehicles to test driving ability, or should be referred to a driver's safety course that includes assessment of driving ability, because patients with dementia are at greater risk of motor vehicle accidents, which increases risk of disability and death to the patient and others.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: Restraints

Measure Type: Process

Source/Developer: RAND-Assessing Care of Vulnerable Elders (ACOVE)

Measure Description: If a patient with dementia is physically restrained in the hospital, then the target behavioral disturbance or safety concern justifying the use of restraints should be documented in the medical record and communicated to the patient, caregiver, or guardian.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: Developed to help health plans, physicians and medical groups that assess the quality of care in the elderly

Measure Profile

Name of Measure: Dementia: the percentage of patients diagnosed with dementia whose care has been reviewed in the previous 15 months.

Measure Type: Process

Source/Developer: British Medical Association, National Health Service Confederation

Measure Description: This measure is used to assess the percentage of patients diagnosed with dementia whose care has been reviewed in the previous 15 months.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: UK's Pay for Performance Program

Link to Measure: http://www.qualitymeasures.ahrq.gov/content.aspx?id=27210&search=dementia+and+alzheimer

Measure Profile

Name of Measure: Dementia: the practice can produce a register of patients diagnosed with dementia.

Measure Type: Structure

Source/Developer: British Medical Association, National Health Service Confederation

Measure Description: This measure is used to assess whether a practice can produce a register of patients diagnosed with dementia.

Target Population: Patients diagnosed with dementia

Provider Type: Family Practice

Measure Usage: UK's Pay for Performance Program

Link to Measure: http://www.qualitymeasures.ahrq.gov/content.aspx?id=27209

Measure Profile

Name of Measure: Elderly Care: Cognition Assessment

Measure Type: Process

Source/Developer: Australian Council on Healthcare Standards

Measure Description: Aged care: percentage of medical patients 65 years and older who have had their cognition assessed using a validated tool such as the Abbreviated Mental Test Score (AMTS) or Mini Mental State Examination (MMSE), during the 6 month time period.

Target Population: Patients 65 or older

Provider Type: Family Practice

Measure Usage: Australian Healthcare Quality measure

Link to Measure: http://www.achs.org.au/cireports

Cognitive Assessment Tools

Name of Tool	Page #	Name of Tool	Page #
Alzheimer's Disease Cooperative Study Activities of			
Daily Living	42	Functional Assessment Questionnaire	66
Alzheimer's Disease Cooperative Study Prevention			
Study	43	Gottfries-Brane-Steen Scale (GBS)	67
		Interview for Deterioration in Daily Living	
Alzheimer's Association's Family Questionnaire*	44	Dementia	68
Alzheimer's Disease Functional Assessment of Change			
Scale (ADFACS)	45	Kokmen Short Test of Mental Status*	69
Ascertain Dementia 8 (AD8) Questionnaire	46	Late-Life Dementia Risk Index	70
Behavior Rating Inventory of Executive Function - Adult		Mail-In Cognitive Function Screening	
version (BRIEF-A)	47	Instrument	71
Blessed Dementia Scale	48	MCI-Screen	72
Blessed Orientation-Memory-Concentration Test			
(BOMC)	49	Memtrax	73
Brief Dementia Risk Index	50	Mid-life Dementia Risk Index	74
Brief Interview of Mental Status (BIMS) [Note: Validated			
for use with nursing home patients only]	51	Mindstreams	75
CAMCI	52	Mini-Cog*	76
		Mini-Mental State Examination (MMSE) [Note:	
		The MMSE has not been well validated for non-	
CANS-MCI	53	Alzheimer's dementias. *	77
CANTAB	54	Montreal Cognitive Assessment (MoCA)*	78
		Multidimensional Assessment of	
Clinical Dementia Rating Scale	55	Neurodegenerative Symptoms questionnaire	79
C C		Patient-Reported Outcomes in Cognitive	
CNS Vital Signs	56	Impairment (PROCOG)	80
Cognitive Abilities Screening Instrument (CASI)	57	Perceived Deficits Questionnaire (PDQ)	81
Cognitive Difficulties Scale (CDS	58	Physical Self-Maintenance Scale	82
Cogstate	59	Progressive Deterioration Scale	83
		Resource Utilization in Dementia	
Computer Self-Test	60	Questionnaire Scale (RUD)	84
		Short Informant Questionnaire on Cognitive	
CST	61	Decline in the Elderly (IQCODE)	85
		St. Louis University Mental Status Examination	
Dependence Scale in Alzheimer's Disease	62	(SLUMS) *	86
		The General Practitioner assessment of	
Disability Assessment for Dementia Scale	63	Cognition (GPCOG) *	87
Everyday Cognition (ECog)	64	WebNeuro	88
Frontal Systems Behavior Scale	65		

Table of Contents

* Recommended by Preparing MN for Alzheimer's 2020 Early Identification and Quality Health Care Leadership Group

Cognitive Assessment Tool Profile

Assessment Tool Name: Alzheimer's Disease Cooperative Study Activities of Daily Living (ADL)

Description: 23-item inventory of ADL, rated based on extent of assistance the patient requires (independently, with supervision, with physical help): 0 (total independence in performing an activity) to 4 (total inability to act independently). Each question varies in the number of options to chose. Total score range: 0 to 78; higher scores indicate less functional impairment. ADCS ADL-MCI: 18 item and 24 item versions.

Validated: Item content developed by a subcommittee of the ADCS Initial item pool included ADL items from existing scales and novel items based on clinical experience Items refined following pretesting ADCS ADL-MCI: 24 item version demonstrated superior sensitivity and specificity for a MCI discrimination from controls.

Proprietary or Open Source: Unknown

Date accessed: 4/9/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pubmed/9236950
Cognitive Assessment Tool Profile

Assessment Tool Name: Alzheimer's Disease Cooperative Study Prevention Study

Description: 20-item measure of ADLs and physical functioning. Five difficulty-based response options from 'as well as usual/no difficulty' to 'a lot of difficulty'; with 'not at all' option. Total score ranges from 0 to 45; higher scores indicate less functional impairment.

Validated: Items selected based on discrimination between MCI and normal subjects discriminated between CDR 0 and 0.5. Scores related to cognitive performance moderate correlation of ADL-MCI patient rating with informant rating; although most scores near ceiling.

Reliability: Test-retest reliability acceptable to good (3-month interval)

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pubmed/9236950

Cognitive Assessment Tool Profile

Assessment Tool Name: Alzheimer's Assocciation's Family Questionaire

Description: This family questionaire is designed to solicit responses from family members who are living or spending time caring for other family members with Alzheimer's or dementia. Family members are often times more aware of the the symptons and can be very effective in helpful to identify the early warning signs of cognitive impairment.

Validated: Unknown

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: www.alz.org/national/documents/brochure_toolsforidassesstreat.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: Alzheimer's Disease Functional Assessment of Change Scale (ADFACS)

Description: The ADFACS is a 16-item functional assessment instrument based on both basic ADLs and IADLs. A trained clinician or research assistant obtains information directly from both the patient and the caregiver. Each of the basic ADL items is scored on a scale of 0 (no impairment) to 4 (severe impairment) and each IADL item is scored on a scale ranging from 0 (no impairment) to 3 (severe impairment). The total score for the 16-item scale ranges from 0 to 54.

Validated: Unknown

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/books/NBK42774/

Cognitive Assessment Tool Profile

Assessment Tool Name: Ascertain Dementia 8 (AD8) Questionnaire

Description: Washington University researchers developed the two-minute "Ascertain Dementia 8" (AD8) eight-question screen to test for the probability of a person having a dementia such as Alzheimer's. The AD8 Test relies on a friend or family member who knows the person well, known as an informant, to evaluate whether cognitive changes have caused the individual to have difficulties in performing everyday activities.

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://www.emaxhealth.com/1506/ad8-questionnaire-can-help-family-friends-identify-dementia-symptoms

Cognitive Assessment Tool Profile

Assessment Tool Name: Behavior Rating Inventory of Executive Function - Adult version (BRIEF-A)

Description: 75-item measure of executive functioning in adults composed of two index scores: the Behavioral Rating Index (BRI) and the Metacognitive Index (MI). The BRI has four subscales: inhibit, shift, emotional control, and self monitor. The MI has five subscales: working memory, initiate, plan/organize, task monitor, and organization of materials. An overall score is obtained as a composite of two index scores. There are also three 'validity' scales used to screen for factors other than executive functioning that could explain scores on the main measure: negativity, infrequency, and inconsistency.

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www4.parinc.com/Products/Product.aspx?ProductID=BRIEF-A

Cognitive Assessment Tool Profile

Assessment Tool Name: Blessed Dementia Scale

Description: The Blessed Dementia Scale (DS) is a brief behavioral scale based on the interview of a close informant.

Validated: Its validity as a screening test was evaluated in 105 demented patients and 123 community residents. The DS proved to be a sensitive and specific screening test for dementia, especially when items related to personality changes were omitted by constructing a revised DS (RDS). Both the DS and RDS correlated with the patients' neuropsychological test performance.

Proprietary or Open Source: Unknown

Date accessed: 4/9/2012

Accessed from: http://onlinelibrary.wiley.com/doi/10.1002/gps.930030406/abstract

Cognitive Assessment Tool Profile

Assessment Tool Name: Blessed Orientation-Memory-Concentration Test (BOMC)

Description: The BOMC is a screening tool allowing family members, caregivers, or health care professionals to check for suspected dementia in an elderly. Dementia is described as the progressive loss of memory and at least of one other cognitive area, such as language or behavior.

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: https://www.dysmd.com/staticContent/quizzes/en/TheBlessedOrientation.htm

Cognitive Assessment Tool Profile

Assessment Tool Name: Brief Dementia Risk Index

Description: A framework for the evaluation and comparison of different methods for identification of asymptomatic individuals with a high dementia risk index.

Validated: In development

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2909695/

Cognitive Assessment Tool Profile

Assessment Tool Name: Brief Interview of Mental Status (BIMS)

Description: Cognitive assessment instrument

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.aan.com/globals/axon/assets/9493.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: The Computer Assessment of Mild Cognitive Impairment

Description: The Computer Assessment of Mild Cognitive Impairment (CAMCI[®]) is a computerized screening tool designed to provide a valid assessment of abnormal cognitive decline in older individuals at an early stage. The CAMCI battery of tasks, consisting of 8 sub-tasks testing multiple cognitive domains, and a series of self-report questions to gain information from the patient, is self-administered via tablet computer using touchscreen technology for response input

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.camci.us.com/

Cognitive Assessment Tool Profile

Assessment Tool Name: CANS-MCI

Description: The tests that comprise the CANS-MCI are automated tasks which test ability on multiple cognitive dimensions, not just memory. All dimensions tested have been found in multiple independent studies to be those cognitive dimensions most predictive of Alzheimer's Disease (AD). Impairment on these dimensions can be caused by factors other than impending Alzheimer's, so the tests are best used longitudinally in primary care offices before referral for full neuropsychological evaluation.

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.screen-inc.com/

Cognitive Assessment Tool Profile

Assessment Tool Name: CANTAB

Description: Simple computerized tests which provide information about patients' visual memory, function, attention, semantic/verbal memory, decision making/response control, and social cognition.

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.cantab.com/

Cognitive Assessment Tool Profile

Assessment Tool Name: Clinical Dementia Rating Scale

Description: The CDR a global measure of 6 domains, including memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. Its total score ranges from 0 (no impairment) to 3 (severe impairment).

Validated: Unknown

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://rgp.toronto.on.ca/dmcourse/toolkit/app5.htm

Cognitive Assessment Tool Profile

Assessment Tool Name: CNS Vital Signs

Description: CNS Vital Signs designs and developes neurocognitive and behavioral assessment tools and technologies.

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.cnsvs.com/

Cognitive Assessment Tool Profile

Assessment Tool Name: Cognitive Abilities Screening Instrument (CASI)

Description: The Cognitive Abilities Screening Instrument (CASI) has a score range of 0 to 100 and provides quantitative assessment on attention, concentration, orientation, short-term memory, long-term memory, language abilities, visual construction, list-generating fluency, abstraction, and judgment.

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pubmed/8054493

Cognitive Assessment Tool Profile

Assessment Tool Name: Cognitive Difficulties Scale (CDS

Description: Multiple versions (original was 39-item self-report; 26- item version and 38-item version; family report version available). The 38-item self report version includes items related to difficulties in attention, concentration, orientation, memory, praxis, domestic activities and errands, facial recognition, task efficiency, and name finding. Items are rated on a five-point Likert scale on frequency of difficulty over prior month, from 0 (not at all) to 4 (very often)

Validated: Derived and adapted from existing measures Profile of Mood States, Inventory of Psychic and Somatic Complaints, and Minnesota Multiphasic Personality Inventory Item content also based on expert clinical opinion 38-item self-report version: moderate to high correlation with performance on neuropsychological measures of memory and attention.

Reliability: Test-retest reliability acceptable in original 39-item version as well as in 26-item version

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://neuro.psychiatryonline.org/article.aspx?articleID=102743

Cognitive Assessment Tool Profile

Assessment Tool Name: Cogstate

Description: CogState tests use simple but effective technology to detect cognitive change in subjects. The tests begin by taking a baseline measurement from a subject who is then periodically retested in order to detect cognitive change. CogState testing utilises culture-neutral stimuli, which ensures that a wide range of subjects can be tested regardless of their ethnicity, socio-economic background or education.

Validated: The CogState computerized tasks have been validated across a wide range of pathophysiological conditions and demonstrate construct validity.

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.cogstate.com

Cognitive Assessment Tool Profile

Assessment Tool Name: Computer Self Test

Description: Unlike existing paper and pencil based Alzheimer's tests, the Computerized Self Test (CST), is an early warning assessment of cognition which:

- Screens all six cognitive domains (a critical step to accurately assess cognitive health)
- Can be taken in 8 10 minutes
- May be self-administered (help may be provided for those lacking computer skills)
- Provides immediate and objective, computer-based scoring

Validated: Demonstrated over 98% accuracy rates in ongoing clinical trials

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: https://alzselftest.com/media/files/91lag43v56x63sa2n92v8ud3c.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: CST

Description: HeadMinder is a series of web-based cognitive tests that facilitate the management of diseases and injuries associated with the central nervous system.

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.headminder.com/site/cst/home.html

Cognitive Assessment Tool Profile

Assessment Tool Name: Dependence Scale in Alzheimer's Disease

Description: The Dependence Scale (DS) is a 13-item questionnaire completed by an AD patient's primary caregiver. It measures the amount of assistance needed by the patient but not necessarily how much assistance he or she actually receives. The DS is a series of yes or no questions such as: Does the patient need reminders or advice to manage chores, shop, cook, play games, or handle money? Does the patient need to be escorted when outside? Does the patient wear a diaper or a catheter?

Validated: It shows good construct validity in relating the level of patients' dependence to their need for institutionalization. (Almost all patients with a DS score greater than 12 were institutionalized.)

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.agingwellmag.com/news/ex_112211_03.shtml

Cognitive Assessment Tool Profile

Assessment Tool Name: Disability Assessment for Dementia Scale

Description: The Disability Assessment for dementia (DAD) Scale was developed to fulfill the need for a disability measure designed specifically for community-dwelling individuals with dementia of the Alzheimer type (DAT). The instrument helps clinicians and caregivers make decisions regarding the choice of suitable interventions and to monitor disease progression. Additionally, the tool can be used to describe the functional characteristics of populations with DAT, the course of the disease and also as an outcome variable in intervention studies and clinical trials.

Validated: Validity: Content validity was established by a panel of experts and caregivers. Criterionrelated (concurrent) validity has been established with the Rapid Disability Rating Scale-2 (r = -.85, n = 59) and known-groups procedure. Results of the known-groups procedure indicated that severity of dementia, according to the GDS level, had an effect on DAD scores (F ratio = 21.24, p<, .05), n = 57. .Construct validity has been established with the MMSE (r = .54), n = 55.

Reliability: .Test-retest reliability: ICC = .96 (n = 45), Interrater reliability: ICC = .95 (n = 31, Internal consistency: Cronbach's alpha = .96 (n = 59)

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://www.dementia-assessment.com.au/function/DAD_manual.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: Everyday Cognition (ECog)

Description: 39-item measure of neuropsychological functioning related to cognitive impairment. Items are rated on a four-point scale: 1, better or no change compared to 10 years earlier; 2, questionable/occasionally worse; 3, consistently a little worse; 4, consistently much worse. Higher scores represent worse daily function.

Validated: Developed through clinical input with reference to literature; designed to address key memory and cognition symptoms that can be linked to specific neuropsychological deficits. Data support six domain factors and one global factor: everyday memory, everyday language (which includes everyday semantic knowledge), everyday visuospatial abilities, and the executive domains of everyday planning, organization, and divided attention Psychometric performance acceptable, with discrimination by clinical severity level and discrimination by different MCI subtypes. Low correlation with age and educational level (r = 0.19 and -0.16, respectively), suggestive of minimal education level bias. Convergent validity supported based on magnitude of correlation to the clinical measures and relationship to diagnostic category.

Reliability: Test-retest reliability was (r = 0.82) based on 2 day to 113 day interval

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2877034/

Cognitive Assessment Tool Profile

Assessment Tool Name: Frontal Systems Behavior Scale

Description: 46-item behavior scale rates the frontal impairments of apathy, disinhibition, and executive dysfunction, on a five-point Likert scale ranging from almost never (1) to almost always (5) for a maximum score of 240. Higher scores indicate more abnormal behavior.

Validity & Reliability: High intrascale reliability (0.95) in normal and pathological populations, subscale reliabilities of 0.78 or higher, Adequate internal consistency reliability (Cronbach's alpha: 0.92), and construct and criterion-related validity in multiple studies.

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www4.parinc.com/Products/Product.aspx?ProductID=FRSBE

Cognitive Assessment Tool Profile

Assessment Tool Name: Functional Assessment Questionnaire (FAQ)

Description: The FAQ includes 10 items and has been developed from the IADL scale. It assesses shopping, handling finances, preparing a meal and travelling (which are also in the IADL scale), remembering appointments, and paying attention to, understanding and discussing television, a book or a magazine. The total score ranges from 0 (independent) to 30 (dependent).

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.alz.washington.edu/NONMEMBER/UDS/DOCS/VER1_2/b7.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: Gottfries-Brane-Steen Scale (GBS)

Description: The Gottfries-Brane-Steen (GBS) scale is a 27-item global scale for rating dementia symptoms based on a semi-structured interview by the clinician, with both the patient and the caregiver. The GBS assesses 4 domains: intellectual impairment (orientation, memory, concentration [12 items]), self-care motor function (6 items), emotional reaction (3 items), and behavioral symptoms (6 items). A 7-point scoring system from 0 to 6 is used for each of the 27 items of this scale, giving a total score range of 0 to 162 points, with an increase in score representing clinical deterioration.

Validated: Unkown

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/books/NBK42774/

Cognitive Assessment Tool Profile

Assessment Tool Name: Interview for Deterioration in Daily Living Dementia

Description: This scale assesses functional disability in basic ADLs (16 items) and IADLs (17 items) of patients living in the community. The caregiver assesses patients' severity of impairment in each item on a 7-point scale, where 1 to 2 points denotes no or slight impairment, 3 to 4 points denotes mild impairment, 5 to 6 points denotes moderate impairment, and 7 points denotes severe impairment. The total score range is 33 to 231 points.

Validated: Unknown

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pubmed/9447438

Cognitive Assessment Tool Profile

Assessment Tool Name: Kokmen Short Test of Mental Status

Description: The Short Test of Mental Status can be administered to patients in approx. 5 minutes, and it contains items that test orientation, attention, immediate recall, arithmetic, abstraction, construction, information, and delayed recall.

Validated: Validated: Using an age-adjusted approach, sensitivity of the test to identifying dementia is 86.4 with a specificity of 93.5.

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://archneur.ama-assn.org/cgi/reprint/60/12/1777.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: Late-Life Dementia Risk Index

Description: It uses a combination of demographic, cognitive, behavioral, functional, medical, genetic, cerebral MRI, and carotid artery ultrasound measures to predict risk of developing dementia within 6 years

Validated: The c statistic was 0.81, which was slightly higher than that observed for the Mid-Life Dementia Risk Score. In addition, the Late-Life Dementia Risk Index achieved greater separation between the low- and high-risk groups in terms of actual dementia risk; 4% of subjects with low scores developed dementia within 6 years compared with 23% of subjects with moderate scores and 56% of subjects with high scores.

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2909695/

Cognitive Assessment Tool Profile

Assessment Tool Name: Mail-In Cognitive Function Screening Instrument

Description: 14-item brief screening instrument assessing cognitive and functional decline; prior year recall period. Response options are 'yes' (1), 'no' (0), or 'maybe' (0.5). Total scores range from 0 to 14; higher score indicate worse status.

Validated: Patient scores associated with clinical measures. Patient /informant core difference associated with mMMSE, NYU Paragraph immediate and delayed recall; free and cued reminder test. Trend toward relationship to APOE genotype group (none, at least one) for patient but not informant score.

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pubmed/17135810

Cognitive Assessment Tool Profile

Assessment Tool Name: MCI-Screen

Description: The MCI Screen is a brief neuropsychological test derived from the protocol of the CERAD 10-word recall test. The protocol consists of an immediate recall task, a triadic comparison task, a judgment task, a delayed free recall task, a cued-recall task, and a rehearsed recall task. It is scored using correspondence analysis and sophisticated statistical methods that yield high accuracy for differentiating normal cognitive function from Mild cognitive impairment.

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.mybraintest.org/tag/mci-screen/

Cognitive Assessment Tool Profile

Assessment Tool Name: Memtrax

Description: MemTrax.net is a scientifically validated memory game that can detect learning and memory problems.

Validated: Unknown

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://memtrax.net/

Cognitive Assessment Tool Profile

Assessment Tool Name: Mid-life Dementia Risk Index

Description: Designed to be administered to middle-aged adults (40– 64 years) [41]. This tool uses a combination of age, gender, education, physical inactivity and history of obesity, hypertension and hypercholesterolemia to predict risk of dementia 20 years later.

Validated: The accuracy of the Mid-Life Dementia Risk Score based on the statistical measure of accuracy in which 1.0 is perfect and 0.5 is no better than guessing (c statistic) was 0.77.

Proprietary or Open Source: Unknown

Date accessed: 4/10/2012

Accessed from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2909695/

Cognitive Assessment Tool Profile

Assessment Tool Name: Mindstreams

Description: MindStreams[®] is an advanced computerized cognitive testing system that is a practical way to evaluate a patient's cognitive health.

Validated: Unkown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.neurotrax.com/

Cognitive Assessment Tool Profile

Assessment Tool Name: Mini-Cog

Description: The Mini-Cog test is a 3-minute instrument to screen for cognitive impairment in older adults in the primary care setting. The Mini-Cog uses a three-item recall test for memory and a simply scored clock-drawing test (CDT). The latter serves as an "informative distractor," helping to clarify scores when the memory recall score is intermediate. The Mini-Cog was as effective as or better than established screening tests in both an epidemiologic survey in a mainstream sample and a multi-ethnic, multilingual population comprising many individuals of low socioeconomic status and education level.

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://geriatrics.uthscsa.edu/tools/MINICog.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: Mini-Mental State Examination (MMSE)

Description: The mini–mental state examination (MMSE) or Folstein test is a brief 30-point questionnaire test that is used to screen for cognitive impairment. It is commonly used in medicine to screen for dementia. It is also used to estimate the severity of cognitive impairment at a specific time and to follow the course of cognitive changes in an individual over time, thus making it an effective way to document an individual's response to treatment.

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.minimental.com/

Cognitive Assessment Tool Profile

Assessment Tool Name: Montreal Cognitive Assessment (MoCA)

Description: The Montreal Cognitive Assessment, MoCA, was created in 1996 (Copyright: Dr Z. Nasreddine) in Montreal, Canada. It was validated in the setting of mild cognitive impairment, and has subsequently been adopted in numerous other settings clinically. The MoCA test is a one-page 30-point test administered in approximately 10 minutes. The test and administration instructions are freely accessible for clinicians at www.mocatest.org. The test is available in 35 languages or dialects. There are 3 alternate forms in English, designed for use in longitudinal settings.

Validated: Validated for Screening: Acceptable Test for the PQRS Dementia Cognitive Assessment Measure

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://www.mocatest.org/
Cognitive Assessment Tool Profile

Assessment Tool Name: Multidimensional Assessment of Neurodegenerative Symptoms questionnaire

Description: Developed as a multidimensional measure permitting early detection and patient and informant comparison and applicable from mild severity onward. Developed to measure cognitive personality, functional, and motor symptoms. Items are rated on a five-point frequency scale from 0 (never) to 4 (routinely) with once/occasionally/more than monthly as intermediate anchors.

Validated: Four subscales supported by exploratory factor analysis. Construct validity supported through moderate to high correlation with clinical measures

Reliability: High internal consistency (alpha = 0.98)

Proprietary or Open Source: Unknown

Date accessed: 4/10/2012

Accessed from: http://alzres.com/content/3/6/35/table/T1

Cognitive Assessment Tool Profile

Assessment Tool Name: Patient-Reported Outcomes in Cognitive Impairment (PROCOG)

Description: 55-item measure of cognitive impairment symptoms and their impact in patients with MCI and mild to moderate AD. There are seven subscales: affect, skill loss, semantic memory, short-term memory, cognitive functioning, social impact, and long-term memory. Items are rated on a five-point Likert scale. Total scores range from 0 to 220. Higher scores indicate greater impact of cognitive impairment

Validated: Developed based on clinician input and focus groups with patients and informants. Subscale and total scores were lowest for controls and highest for AD patients, with MCI patients intermediate. Highest correlations with the PROCOG were observed for the QOL-AD (r = -0.53) and CES-D (0.60) PROCOG Aff ect subscale was most highly correlated to the CES-D. Correlations with the europsychological measures were low to moderate MCI and DAT scores differed signifi cantly ($P \le 0.05$ for total and subscale scores with the exception of 'social impact') 'Long-term memory' item did not distinguish among the three groups 'Skill loss' and 'memory for recent events' subscales showed the most separation between MCI and DAT patients.

Reliability: Internal consistency: Cronbach's alpha for all subscales was above 0.82. Test-retest: no statistically significant differences across 14 day retest ICCs ranged from 0.49 (for the single-item 'long-term memory' subscale) to 0.90

Proprietary or Open Source: Unknown

Date accessed: 4/10/2012

Accessed from:

http://www.health.fgov.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2divers/19074284.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: Perceived Deficits Questionnaire (PDQ)

Description: The PDQ is a part of the Multiple Sclerosis Quality of Life Inventory that assesses selfperceived cognitive difficulties. It consists of 20 items that address cognitive difficulties in four dimensions (attention/ concentration planning/organization, retrospective memory and prospective memory). Items are rated on a five-point scale ranging from 1 (never) to 5 (almost always)

Validated: Unknown

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.nationalmssociety.org/for-professionals/researchers/clinical-study-measures/pdq/index.aspx

Cognitive Assessment Tool Profile

Assessment Tool Name: Physical Self-Maintenance Scale

Description: The Physical Self-Maintenance Scale was developed to gauge disability in a elderly people currently in a community or institution for use in planning and assessing treatment. Items in the scale specifically target observable behaviors.

The format the PSMS is first a six item based on the ADL and then eight-items based on the IADL scale. A 5-point scale for responses ranges from total independence to total dependence. Ages recommended for the test are 60 and over. There is a rating version of instrument and a selfadministered version.

Reliability and Validity: The first half of the test (6 items) was investigated with a Guttman scale, giving a reproducibility coefficient of 0.96 and second half (eight items) coefficient of 0.93. A test-retest reliability of 0.94 was reported for the first section of test and 0.88 for the second half. In order to test validity, the scores of two nurses whom rated 36 patients were compared producing Pearson correlation of 0.91. The PSMS has been correlated with several instruments with a sample of elderly people in an institution or a home. A rating of 0.62 reported for physician's rating, 0.61 with the IADL scale, 0.38 with Kahn Mental Status Questionnaire, 0.38 with a behavioral rating of social adjustment.

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://www.aging.ufl.edu/files/pdf/tools/ADLTable.pdf

Cognitive Assessment Tool Profile

Assessment Tool Name: Progressive Deterioration Scale

Description: The PDS is a self-administered scale for caregivers that examines the ability of patients to accomplish basic ADLs and IADLs in 11 areas. 192 Each item is scored using a 100 mm bipolar visual analogue scale, then a total score range from 0 to100 is derived from the average.

Validated: Unknown

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/books/NBK42774/

Cognitive Assessment Tool Profile

Assessment Tool Name: Resource Utilization in Dementia Questionnaire Scale (RUD)

Description: The RUD scale is completed by caregivers and compiles data on the use of social services, frequency and duration of hospitalizations, unscheduled contacts with health care professionals, use of concomitant medications by both the caregiver and the patient, amount of time the caregiver spends caring for the patient and missing work, and patients' use of study medication.

Validated: Unknown

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.ncbi.nlm.nih.gov/books/NBK42774/

Cognitive Assessment Tool Profile

Assessment Tool Name: Short Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)

Description: The IQCODE lists 26 everyday situations where a person has to use their memory or intelligence.[2] Examples of such situations include: "Remembering where to find things which have been put in a different place from usual" and "Handling money for shopping", each situation is rated by the informant for amount of change over the previous 10 years, using the following scale: 1. Much improved, 2. A bit improved, 3. Not much change, 4. A bit worse, 5. Much worse.

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Unknown

Date accessed: 4/12/2012

Accessed from: http://www.patient.co.uk/doctor/Informant-Questionnaire-on-Cognitive-Decline-in-the-Elderly-(IQCODE).htm

Cognitive Assessment Tool Profile

Assessment Tool Name: St. Louis University Mental Status Examination (SLUMS)

Description: The Saint Louis University Mental Status Examination (SLUMS) is a brief oral/written exam given to people that are suspected to have dementia or Alzheimer's Disease. The exam serves as a tool to indicate whether a doctor should consider further testing to diagnose dementia. The SLUMS was created by the Director of the Division of Geriatric Medicine at Saint Louis University.

Validated: Acceptable cognitive test for PQRS measure #281 Dementia: Cognitive Assessment Measure

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://www.slu.edu/readstory/homepage/1294

* This tool is recommended by the Preparing MN for Alzheimer's 2020 Early Identification and Quality Health Care Leadership Group

Cognitive Assessment Tool Profile

Assessment Tool Name: The General Practitioner assessment of Cognition (GPCOG)

Description: The GPCOG is used for screening for dementia, specifically in a primary care setting. It takes less than 4 minutes to administer the patient assessment and 2 minutes to interview the caregiver, the GPCOG, performs at least as well as the standard screening tool, the Mini-Mental State Examination (MMSE) [2]. Recent reviews of dementia screening tools for the primary care setting recommend the use of the GPCOG. Another study indicates that the GPCOG score is not influenced by the cultural and linguistic background of a person making it an invaluable screening tool especially in multicultural patient settings.

Validated: In testing

Proprietary or Open Source: Open Source

Date accessed: 4/12/2012

Accessed from: http://www.gpcog.com.au/info.php

* This tool is recommended by the Preparing MN for Alzheimer's 2020 Early Identification and Quality Health Care Leadership Group

Cognitive Assessment Tool Profile

Assessment Tool Name: WebNeuro

Description: WebNeuro provides a standardized, objective assessment of Cognition & Emotion with a report sent to the referring clinician. The WebNeuro report primarily provides the raw scores and relative strengths and deficits (based upon validated, published and available scores in a large database, which are available to clinicians for interpretation).

Validated: Unknown

Proprietary or Open Source: Proprietary

Date accessed: 4/12/2012

Accessed from: http://www.brainresource.com/clinical-solutions/webneuro

National Dementia & Alzheimer's Strategies and Surveillance Systems

Surveillance System	Description
The Behavioral Risk Factor Surveillance System (BRFSS)- Cognitive Impairment Module	CDC's Healthy Aging Program used a comprehensive approach to develop a set of questions (Impact of Cognitive Impairment Module) for use in the Behavioral Risk Factor Surveillance System to assess and monitor the public's beliefs about the impact of cognitive impairment. In 2011, a total of 20 states added the Impact of Cognitive Impairment Module to their state-Overall added BRFSS questions. These data will lay the groundwork for advancing public health's understanding about the perceived impact of cognitive impairment among American adults by providing state-level data.
Canadian Study of Health and Aging (CSHA)	http://www.cdc.gov/aging/healthybrain/surveillance.htm CSHA is a large national study that provides a great deal of detailed data on dementia in Canada. The prevalence of dementia increases markedly with age for both sexes, approximately doubling every five years from ages 65 to 84, with a lower rate of increase at older ages. http://csha.ca/r_study_results.asp
United Kingdom: Department of Health	Living well with dementia: A National Dementia Strategy. This strategy provides a strategic framework within which local services can deliver quality improvements to dementia services and address health inequalities relating to dementia; provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services; and provide a guide to the content of high-quality services for dementia.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsP olicyAndGuidance/DH 094058

Appendix A: MN Statute 62U.15. Alzheimer's Disease: Prevalence and Screening Measures

Subdivision 1. **Data from providers.** (a) By July 1, 2012, the commissioner shall review currently available quality measures and make recommendations for future measurement aimed at improving assessment and care related to Alzheimer's disease and other dementia diagnoses, including improved rates and results of cognitive screening, rates of Alzheimer's and other dementia diagnoses, and prescribed care and treatment plans.

(b) The commissioner may contract with a private entity to complete the requirements in this subdivision. If the commissioner contracts with a private entity already under contract through section 62U.02, then the commissioner may use a sole source contract and is exempt from competitive procurement processes.

Subd. 2. Learning collaborative. By July 1, 2012, the commissioner shall develop a health care home learning collaborative curriculum that includes screening and education on best practices regarding identification and management of Alzheimer's and other dementia patients under section 256B.0751, subdivision 5, for providers, clinics, care coordinators, clinic administrators, patient partners and families, and community resources including public health.

Subd. 3. **Comparison data.** The commissioner, with the commissioner of human services, the Minnesota Board on Aging, and other appropriate state offices, shall jointly review existing and forthcoming literature in order to estimate differences in the outcomes and costs of current practices for caring for those with Alzheimer's disease and other dementias, compared to the outcomes and costs resulting from:

(1) earlier identification of Alzheimer's and other dementias;

- (2) improved support of family caregivers; and
- (3) improved collaboration between medical care management and community-based supports.

Subd.4. **Reporting.** By January 15, 2013, the commissioner must report to the legislature on progress toward establishment and collection of quality measures required under this section **History:** 1sp2011 c 9 art 2 s 4

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Appendix B: Proposed Alzheimer's Measurement Work Plan

- 1. Analyze current MN Community Measurement measure portfolio for gaps related to the National Priorities Partnership
- 2. If Alzheimer's/ Dementia meets a measurement gap; submit as a concept during the Call for Measure Concepts supported by the MN Department of Health and MN Community Measurement.
- 3. If accepted as a measure concept; follow established MNCM Measure Development Process
 - a. Impact Document to Measurement and Reporting Committee (MARC)
 - b. MARC approval for convening measure development workgroup/ input for charter
 - c. Recruit workgroup members and schedule 1st meeting
 - d. Five to seven meetings for measure development
 - i. Charter
 - ii. Population (denominator)
 - iii. Measure/s desired (numerator)
 - iv. Functional status tools if focus of measure
 - v. Exclusions (if any)
 - vi. If outcome measure, potential variables for risk adjustment
 - e. Draft measure specifications for public comment
 - i. Comments addressed, redesign or tweaking if needed
 - f. Draft measure specifications to MARC for approval proceed to pilot
- 4. If accepted for pilot; groups would need a significant amount of time to prepare for the implementation of a new tool/s that are currently not a part of standard practice nor contained within existing EMRs
- 5. Pilot data collection
 - a. Create mechanism for accepting pilot data
 - b. Work with groups to understand feasibility
 - i. Success with tool implementation
 - ii. Ability to collect data
 - c. Analyze pilot results/ recommendation for moving forward with full scale implementation based on qualities of a good measure (variability between practices and opportunity for improvement)
- 6. Present pilot results to MARC
- 7. Determine if measure should be recommended for inclusion in the Statewide Quality Reporting and Measurement System measure set

Appendix C: Proposed Alzheimer's Measurement Timeline

TASK		2012					2013								2014							2015													
		8	9 1	10	11	12	1	2	3	4	5	6	7	8	8	9	11	12	1	2	3	4	5	6	7	8	8	9	11	12	1	2	3	4	56
Commissioner to review existing Alzheimer's																																			Τ
and dementia quality measures																									_	_									
Health Care Home Learning Collaborative on																																			
Alzheimer's Early Detection and Screening																																			
for Dementia																																			
MDH Commissioner reports to legislature on																																			
progress of Alzheimer's measure																																			
development																																			
Submit Alzheimer's and dementia as a																																			
measure concept																																			
Develop impact document for MNCM's																																			
Measurement and Reporting Committee																																			
Receive MARC approval for measure																																			
development																																			
Recruit measure development workgroup																																			
Host measure development meetings																																			
Release draft specifications for public																																			
comment																																			
Allow time for clinics to implement technical																																			
and process changes																																			
Pilot the measure																																			
a) create mechanism for accepting data																																			
b) educate pilot groups																																			
c) analyze pilot results																																			
Present pilot results to MARC																										Ī									
Determine if measure should be included in						Ī	ľ				T							Ī																	
the SQRMS measure set																																			

Appendix 4: Preparing Minnesota For Alzheimer's 2020 and ACT on Alzheimer's

The Minnesota Legislature passed legislation related to Alzheimer's disease and related dementias in the 2009 and 2011 session. The 2011 legislation is the subject of this report. The 2009 legislation directed the Minnesota Board on Aging to establish the Alzheimer's Disease Working Group (ADWG) to study the status of Alzheimer's disease and related dementias in Minnesota to more fully understand and address the issues presented by the increase in the older population and the expected increase in the number of people with Alzheimer's disease and related dementias in Minnesota in coming years. The ADWG was directed to make recommendations to the Legislature for needed policy and program changes that will prepare the state for the future. The background documents generated by the working group and the final report can be accessed at http://alzworkinggroup.pbworks.com. In its priorities and recommendations, the Alzheimer's Disease Working Group's intent was to identify the greatest needs from the perspective of the person and family who are trying to deal with this disease and its effects. The working group's report, Preparing Minnesota for Alzheimer's: The Budgetary, Social and Personal Impacts, was released in January, 2011. The overarching vision of the report and its recommendations are that Minnesota must be prepared for the budgetary, social and personal impacts of Alzheimer's disease through a comprehensive, person-centered approach to the disease that is reinforced through transformation of the systems that touch the lives of persons with Alzheimer's disease and related dementias and their caregivers. The report makes seven broad recommendations:

- Identify Alzheimer's early
- Use "health care home" for Alzheimer's care
- Achieve quality and competence in dementia care
- Prepare our communities and the public
- Train medical providers in dementia care
- Pursue cost-saving policies
- Intensify research and surveillance. (1)

After the recommendations were delivered to the legislature, a subgroup of the Alzheimer's Disease Workgroup participants committed to assuring that the recommendations were implemented and established Prepare Minnesota for Alzheimer's 2020 (PMA). PMA is a statewide collaboration of more than 50 nonprofit, government and private organizations and 150 individuals. PMA identifies accomplishments in its first year progress report to include:

- Provider tools for identifying and managing cognitive impairment and making referrals to specialty care, <u>http://collectiveactionlab.com/content/provider-practice-algorithm-and-tool</u>
- On-line, interdisciplinary, dementia educational modules for infusion into undergraduate and graduate level courses throughout the Minnesota University System, http://collectiveactionlab.com/content/dementia-curriculum-modules
- A Dementia Capable Communities Toolkit for community leaders and influencers to guide communities through the process of developing community teams; assessing dementia capability within the community; synthesizing the assessment results; and planning and implementing needed changes. The toolkit is currently being piloted in five communities, <u>http://colectiveactionlab.com/content/community-tool-kit-documents</u> (2)

In November, 2012, Prepare Minnesota for Alzheimer's 2020 changed its name to ACT on Alzheimer's to better convey the need for action and community engagement. (3)

Endnotes

- 1. Preparing Minnesota for Alzheimer's: the Budgetary, Social and Personal Impacts, Report to the Minnesota Legislature by the Minnesota Board on Aging on behalf of The Alzheimer's Disease Working Group, January 15, 2011.
- 2. PMA One Year Progress Report, December, 2012.
- 3. ACT on Alzheimer's <u>http://collectiveactionlab.com/?q=node/61</u>

Appendix 5: Learning Collaborative Curriculum

Process and Partners for Development of HCH Learning Collaborative Curriculum:

Members of the PMA 2020 Early Identification Committee and the Health Care Home Team met to develop the initial draft of the health care home learning collaborative curriculum for patients with dementia. The team also developed an Alzheimer's Health Care Homes (HCH) Standards document with a cross walk between the HCH standards and the best practices treatment, care coordination and care giver supports. This tool will be used by HCH's to understand how to integrate care coordination of people with dementia into the systems of the HCH.

Team members developed the longitudinal high level curriculum adapted from the PMA 2020 Curriculum Outline. The goal is to address three main components in the first three learning collaborative sessions and re-evaluate.

<u>Session One Learning Collaborative:</u> Focus on baseline knowledge, care coordination with care givers, patient and family centered care and how the HCH works for dementia patients. Social Impact

- 1. The impact of Alzheimer's disease on patients, families and caregivers
- 2. The financial cost of Alzheimer's disease
- 3. The impact of Alzheimer's on the healthcare system

Demographics

- 1. Prevalence of Alzheimer's disease and other dementias
- 2. Statistical estimates of Alzheimer's disease
- 3. More women have Alzheimer's than men
- 4. Prevalence of Alzheimer's disease and other dementias by years of education
- 5. Older Hispanic and African-Americans are proportionally more likely to develop Alzheimer's than are older white people
- 6. Future trends in the prevalence and incidence of Alzheimer's

Disease Description

- 1. Normal aging
- 2. Description of dementia
- 3. Alzheimer's disease
 - a. Causes of Alzheimer's disease
 - b. Risk factors for Alzheimer's disease
 - **c.** Alzheimer's disease duration

Effective Interactions and Communications

- 1. Dementia care overview Year one only
- 2. Communication, Year one only
- 3. Physical interaction, Focus on in year two
- 4. Assessing behaviors, Focus on in year two

High level over view of cognitive assessment and value of early detection.

High level disease diagnosis

Session Two Learning Collaborative:

Disease Diagnosis

- 1. Diagnosis background
- 2. Current diagnosis efforts
- 3. Benefits of early diagnosis
- 4. Indicators that a person may be cognitively impaired
- 5. Provider barriers to diagnosis
- 6. Patient barriers to diagnosis
- 7. Diagnostic challenges
- 8. Provider Diagnosis Checklist following patient screening failure

Dementia as an Organizing Principle of Care

- 1. Care needs of individuals with dementia
 - a. Co-morbidities
 - b. Hospitalization
 - c. Self-care and compliance
 - d. Other complexities
- 2. Unique Role of Providers in Dementia Care
- 3. Approaches for Fulfilling Role
 - a. Early Assessment
 - b. Using Dementia Diagnosis as Organizing Principle of Care
 - c. Collaborative Team Approach
 - d. Elements of Effective Care Transitions

Quality Interventions

- 1. No treatment is available to slow or stop Alzheimer's disease
- 2. Pharmacological Interventions
 - a. Memory
 - b. Mood and behavior
 - c. Avoid or minimize the following medications
- 3. Non-Pharmacological Interventions
 - a. Diagnostic uncertainty & behavior management Refer to specialist as needed
 - b. Counseling, education, support & planning link to community resources
 - c. Stimulation / Activity / Maximizing Function
 - d. Legal/Financial, Driving, & Home Safety issues Provide or refer to:
 - e. Advanced care planning
 - f. Medication Management
 - g. Specific Interventions to Address Behavioral Issues
- 4. Active medical management
 - a. Appropriate use of available treatment options
 - b. Effective management of coexisting conditions

- c. Coordination of care among physicians, other health care professionals and lay caregivers
- d. Participation in activities and adult day care programs
- e. Taking part in support groups and supportive services such as counseling

Session Three:

Module V – Cognitive Assessment and the Value of Early Detection (In depth, assess audience knowledge)

- 1. Early detection and the critical role of providers as the gateway to interventions and support
- 2. Indicators that a person might need assistance with dementia
- 3. Rationale for early detection of dementia
- 4. Practice tips for early detection
- 5. The Medicare Wellness Visit
- 6. Initial considerations for cognitive assessment
- 7. General cognitive assessment tips
- 8. Actions to avoid during cognitive assessment:
- 9. List of cognitive assessment measures with pros and cons for each measure

Teaching Methods include focus on the following principles.

- Principles of adult learning using a framework of change and quality improvement. There is HCH team member engagement, clinician, care coordinator, and leadership participation in using experiential teaching methods.
- 2. Patients and families are involved in learning sessions and sharing feedback.
- 3. There is in-person face to face learning, supported by virtual learning that is founded on relationships in face to face meetings.
- 4. There is an evaluation process of learning and methods.
- 5. Baseline assessment is completed in order to measure team progress on HCH implementation in topic area and culture change.
- 6. Capitalize on the expertise of experienced team members and existing infrastructures. Inclusion of team based sharing best practices or emerging best practices and innovations.
- 7. There is oversight of the curriculum by the HCH learning collaborative advisory committee and the PMA 2020 Early ID Committee.

Learning Collaborative Sessions:

The first learning collaborative session was included in the Health Care Homes Learning Day, November 1, 2012. The objectives for this session, *Implementing the HCH for Patients with Alzheimer's: Early Identification, Care Coordination and Care Giver Support*, were:

- 1. Understand the importance of early diagnosis and identifying patients with dementia sucah as Alzheimer's in the HCH.
- 2. Identify key elements to effective management of Alzheimer's patients in the HCH.
- 3. Define care coordination structures that improve the quality of care for patients and families.
- 4. Understand the tools that support the work of the health care team in caring for Alzheimer's patients.

There were 167 HCH team members that participated in the session. Two physicians, a care coordinator, the Alzheimer association representative and a patient and her husband participated in the education session.

Evaluations from participants were very positive. The initial pre-assessment indicates that there is wide variation among HCH's as to the level of implementation of dementia related care coordination methods implemented in the health care home. Additional clinical guidelines and tools are in development for use at future learning collaborative sessions. The next face to face learning session is planned for May 1 and 2, 2013.

Additional information about Health Care Homes and their implementation in Minnesota can be found at <u>http://www.health.state.mn.us/healthreform/homes/index.html</u>.

Appendix 6: The National Plan to Address Alzheimer's Disease

National Alzheimer's Project Act

The National Alzheimer's Project Act (NAPA) was signed into law on January 4, 2011. (1) Passed unanimously in both the Senate and House of Representatives, NAPA called for a national strategic plan among federal agencies to address and overcome the challenges presented by the increasing prevalence of Alzheimer's disease and related dementias. Foundation for this initiative came from the Alzheimer's Study Group (ASG), a taskforce of national leaders from government, law, business, medicine and academia and co-chaired by former Speaker of the House Newt Gingrich and former US Senator Bob Kerrey that was established in July, 2007. The ASG was charged with creating a National Alzheimer's Strategic Plan. Their strategic plan was released in March, 2009 at a hearing of the Senate Special Committee on Aging and focused on four key areas:

- Support for research,
- Translating research breakthroughs into treatment,
- Ensuring quality care,
- Supporting families. (2)

The National Alzheimer's Project Act (NAPA) directs the Secretary of the U.S. Department of Health and Human Services (HHS) to:

- Create and maintain an integrated national plan to overcome Alzheimer's disease and related dementias.
- Coordinate Alzheimer's disease and related dementia research and services across all federal agencies.
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease and related dementias.
- Improve early diagnosis and coordination of care and treatment of Alzheimer's disease and related dementias.
- Improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease and related dementias.
- Coordinate with international bodies to fight Alzheimer's disease and related dementias globally.

National Plan to Address Alzheimer's

The law also established the Advisory Council on Alzheimer's Research, Care, and Services and required the Secretary of HHS, in collaboration with the Advisory Council, to create and maintain a national plan to overcome Alzheimer's disease and related dementias. The *National Plan to Address Alzheimer's* was released in May, 2012, and can be accessed at http://aspe.hhs.gov/daltcp/napa/natlplan.shtml.

Building on the preliminary work on the National Plan, in February, 2012, the Obama administration announced a \$156 million investment including immediately increasing Alzheimer's disease research funding, sustaining and growing the Alzheimer's disease research investment in fiscal year 2013, and providing funds to support the goals of the national plan including:

- Education and outreach to improve the public's understanding of Alzheimer's disease and related dementias.
- Outreach to enhance health care providers' knowledge of the disease.
- Expanded support for people with Alzheimer's disease and related dementias and caregivers in the community.
- Improved data collection and analysis to better understand the impact of Alzheimer's disease and related dementias on people with the diseases, families and the health and long-term care systems.

Additionally, a federal website, <u>www.alzheimers.gov</u>, was launched to provide information for those with Alzheimer's disease and related dementias and their caregivers. This site brings together information about Alzheimer's disease and related dementias, treatment options, Medicare and insurance issues, resources for assistance and the types of assistance that may be helpful and research that is underway.

The National Plan includes a detailed listing of current federal activities and initial recommendations for priority actions to expand, eliminate, coordinate or condense programs. The activities in the plan vary in scope and impact and include:

- Immediate actions that the federal government will take,
- Actions toward the goals that can be initiated by the federal government or its public and private partners in the near term, and
- Longer-range goals that will require numerous actions to achieve.

Achievement of the goals of the National Plan will require the active engagement of public and private sector stakeholders. Achievement of many of the long-range goals will be contingent on resources, scientific progress, and focused collaborations across many partners. The plan also recognizes a critical part of optimizing resources in ensuring coordination of the implementation of the National Plan with implementation of other HHS-wide plans and strategies including *Multiple Chronic Conditions: A Strategic Framework* (2010), the *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* (2011), *National Prevention Strategy* (2011), and *HHS Strategic Plan* (2010-2015). (1)

The National Plan is guided by three principles:

- 1. Optimize existing resources and improve and coordinate ongoing activities.
- 2. Support public-private partnerships.
- 3. Transform the way we approach Alzheimer's disease and related dementias.

The five foundation goals for the National Plan are:

- 1. Prevent and effectively treat Alzheimer's disease by 2025,
- 2. Optimize care quality and efficacy,
- 3. Expand supports for people with Alzheimer's disease and related dementias and their families,
- 4. Enhance public awareness and engagement, and
- 5. Track progress and drive improvement.

The National Plan includes the following goals and strategies:

Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025

Strategy 1.A: Identify Research Priorities and Milestones

Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease

Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease

- Strategy 1.D: Coordinate Research with International Public and Private Entities
- <u>Strategy 1.E</u>: Facilitate Translation of Findings into Medical Practice and Public Health Programs
- Goal 2: Enhance Care Quality and Efficiency
 - Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care

Strategy 2.B: Ensure Timely and Accurate Diagnosis

Strategy 2.C: Educate and Support People with AD and Their Families upon Diagnosis

Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings

Strategy 2.E: Explore the Effectiveness of New Models of Care for People with AD

<u>Strategy 2.F</u>: Ensure that People with AD Experience Safe and Effective Transitions between Care Settings and Systems

<u>Strategy 2.G</u>: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with AD

<u>Strategy 2.H</u>: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and for Populations Facing Care Challenges

Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families

<u>Strategy 3.A</u>: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials <u>Strategy 3.B</u>: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being

<u>Strategy 3.C</u>: Assist Families in Planning for Future Care Needs

Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease

Strategy 3.E: Assess and Address the Housing Needs of People with AD

Goal 4: Enhance Public Awareness and Engagement

<u>Strategy 4.A</u>: Educate the Public about Alzheimer's Disease <u>Strategy 4.B</u>: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease Awareness and Readiness across the Government <u>Strategy 4.C</u>: Coordinate U.S. Efforts with Those of the Global Community

Goal 5: Improve Data to Track Progress

<u>Strategy 5.A</u>: Enhance the Federal Government's Ability to Track Progress <u>Strategy 5.B</u>: Monitor Progress on the National Plan

Below is the information included in the National Plan that details the relationship with other key national strategic planning documents.

Crosswalk: National Plan to Address Alzheimer's Disease Goals and Objectives, and Related Strategies

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
Research				
Goal 1: Prevent and	Goal 4: Facilitate		Strategic Direction 4	Goal 2: Advance
Effectively Treat Alzheimer's	research to fill		Elimination of Health	Scientific Knowledge
Disease by 2025	knowledge gaps about,		Disparities	and Innovation
	and interventions and		4.4 Commont management	
<u>Strategy 1.A</u>: Identify	systems to benefit,		4.4 Support research	Objective A:
research priorities and	individuals with multiple		strategies to eliminate	Accelerate the process
milestones	chronic conditions.		health disparities	to improve patient
	Objective A: Increase			care
<u>Strategy 1.B</u> : Expand	the external validity of			cure
research aimed at preventing	trials			Objective B: Foster
and treating Aizneimer's				innovation to create
uisease	Objective B:			shared solutions
Strategy 1 C. Accelerate	Understand the			
efforts to identify early and	epidemiology of multiple			Objective D:
presymptomatic stages of	chronic conditions			Increase our
Alzheimer's disease	Objective C. Increase			understanding of what
	clinical community and			and human service
<u>Strategy 1.D</u> : Coordinate	patient-centered health			practice
research with international	research			Plactice
public and private entities				

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
<u>Strategy 1.E</u>: Facilitate translation of findings into medical practice and public health programs	Objective D: Address disparities in multiple chronic conditions populations			
Quality Workforce and Evidence	e-based Strategies	1	1	1
Goal 2: Enhance Care Quality and Efficiency	Goal 1: Foster health care and public health system changes to	<u>Goal 2</u> : Strengthen the Nation's Health and Human Services	Strategic Direction 4 Elimination of Health Disparities	Goal 2: Advance Scientific Knowledge and Innovation
<u>Strategy 2.A</u>: Build a workforce with the skills to provide high-quality care <u>Strategy 2.B</u> : Ensure timely and accurate diagnosis	improve the health of individuals with multiple chronic conditions. Objective A: Identify evidence-supported models for persons with	Infrastructure and Workforce <u>Strategy 2.A</u> : Increase the ability of all health professions and the health care	 4.2 Reduce disparities in access to quality health care 4.3 Increase the capacity of the prevention 	Objective D: Increase our understanding of what works in public health and human service practice
<u>Strategy 2.C</u> : Educate and support people with AD and their families upon diagnosis Strategy 2.D : Identify high-	multiple chronic conditions to improve care coordination <u>Goal 3</u> : Provide better	system to identify and address racial and ethnic disparities <u>Goal 3</u> : Advance the	workforce to identify and address disparities	Goal 3: Advance the Health, Safety, and Well-Being of the American People
quality dementia care guidelines and measures across care settings	tools and information to health care, public health, and social services workers who deliver care to	health, safety, and well- being of the American people Strategy 3.A:		Objective C: Improve the accessibility and quality of supportive
Strategy 2.E: Explore the effectiveness of new models of care for people with AD	individuals with multiple chronic conditions. Objective A: Identify	Reduce disparities in population health by increasing the availability and		services for people with disabilities and older adults
people with AD experience safe and effective transitions between care settings and systems	Objective B: Enhance health professionals training	effectiveness of community-based programs and policies		the National Health and Human Service Infrastructure and Workforce
<u>Strategy 2.G</u> : Advance coordinated and integrated health & long-term services and supports for individuals living with AD	Objective C: Address multiple chronic conditions in guidelines			Objective B: Ensure that the Nation's health care workforce can meet increased demands
<u>Strategy 2.H</u>: Improve care for populations disproportionally affected by AD and for populations facing care challenges				Objective C: Enhance the ability of the public health workforce to improve public health at home and abroad Objective D:
				Strengthen the Nation's human

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
				service workforce
Individual and Family Supports		1	1	
Goal 3 : Expand Supports for People with AD and Their Families Strategy 3.A : Ensure receipt of culturally sensitive education, training, and support materials Strategy 3.B : Enable	Goal 2: Maximize the use of proven self-care management and other services by individuals with multiple chronic conditions. Objective B: Facilitate home and community- based services.	Goal 1: Transform Health Care <u>Strategy 1.A</u> : Reduce disparities in health insurance coverage and access to care <u>Strategy 1.B</u> :	Strategic Direction 2 Clinical and Community Preventive Services 2.4 Support implementation of community-based preventive services and enhance linkages with clinical care	Goal 3: Advance the Health, Safety, and Well-Being of the American People Objective C: Improve the accessibility and quality of supportive services for people with disabilities and
family caregivers to continue to provide care while maintaining their own health and well-being		Reduce disparities in access to primary care services and care coordination	2.5 Reduce barriers to accessing clinical community preventive services, especially among populations at greatest risk	with disabilities and older adults <u>Goal 1</u> : Transform Health Care
Strategy 3.D: Maintain the		Reduce disparities in the quality of health care	Strategic Direction 1 Healthy and Safe Community Environments	Objective B: Improve health care quality and patient safety
dignity, safety and rights of people with Alzheimer's disease			1 Coordinate investments in transportation, housing, environmental protection,	Objective C: Emphasize primary & preventive care linked with community
<u>Strategy 3.E</u>: Assess and address housing needs of people with AD			and community infrastructure to promote sustainable and healthy communities	prevention services
Informed Stakeholders				
Goal 4: Enhance Public Awareness and Engagement			Strategic Direction 3 Empowered People	
Strategy 4.A: Educate the public about Alzheimer's disease			3.3 Engage and empower people and communities to plan and implement prevention policies and programs	
state and local governments to improve coordination and identify model initiatives to advance Alzheimer's disease awareness and readiness across the government			Priority 7 Mental and Emotional Well-being 7.3 Provide individuals and families with the support necessary	

National Alzheimer's Plan (2012)	Multiple Chronic Conditions: A Strategic Framework (2010)	HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011)	National Prevention Strategy (2011)	HHS Strategic Plan (2010-2015)
			to maintain positive mental well-being	
Quality Data				
Goal 5: Improve Data to Track Progress <u>Strategy 5.A</u> : Enhance the federal government's ability to track progress <u>Strategy 5.B</u> : Monitor progress on the National Plan		Goal 4: Advance Scientific Knowledge and Innovation <u>Strategy 4.A</u> : Increase the availability and quality of data collected and reported on racial and ethnic minority populations		Goal 4: Increase Efficiency, Transparency, and Accountability of HHS Programs Objective C: Use HHS data to improve the health and well- being of the American people

The Advisory Council Advisory Council on Alzheimer's Research, Care, and Services, consists of at least 22 members and meets quarterly to discuss the efficacy of government programs targeting the needs of individuals and caregivers coping with the consequences of ADRD. They oversee the implementation of the National Plan and achievement of the plan milestones. Information about the Advisory Council meetings and plan implementation can be accessed at http://aspe.hhs.gov/daltcp/napa/#Council

Endnotes

- 1. National Plan to Address Alzheimer's Disease. US Department of Health and Human Services. 2012. http://aspe.hhs.gov/daltcp/napa/natlplan.shtml
- 2. A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group. March, 2009. Accessed from <u>http://www.alz.org/documents/national/report_asg_alzplan.pdf</u>