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## Specialty Payment Model Opportunities and Design

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Environmental Scan for  
Neurology (Task 2): Final  
Version

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## 1. Introduction

The current primary payment model for health care in the United States is fee-for-service (FFS), in which providers are paid separately for each individual component of care. Stakeholders interviewed for this environmental scan suggested that this payment model can promote the overutilization of services that are amply reimbursed but that do not necessarily improve the quality of care. Additionally, stakeholders noted that services that are not currently reimbursed by Medicare but that improve the quality of care, such as patient education and care coordination, are often under-provided. In an attempt to correct these problems with the FFS payment model, efforts are underway across the country to move toward value-based payment models that reward the provision of high-quality care rather than the quantity of services provided. Alternative payment models (APMs) attempt to promote the delivery of high-quality care by linking provider payment to measures of quality rather than volume or intensity of services. APMs also move toward case- or person-level payments that enable providers to work together more effectively and to have more flexibility in delivering care based on each individual patient's needs. In this environmental scan, "care" constitutes any service that will help monitor, manage, or treat a patient's medical concerns regarding a specific symptom, diagnosis, or procedure. While implementing APMs is challenging, these types of models are becoming more prevalent in many areas of health care.

Considering APMs for Medicare beneficiaries with neurological conditions is a timely and important endeavor. Fragmented and poorly coordinated care under the current FFS model can diminish the efficiency and quality of neurological care, which often requires complex care management over long periods of time. Neurological care represents a large cost burden on the health care system as a whole.<sup>1</sup> In 2012, Medicare spent \$1.4 billion on Part B neurology services alone.<sup>2</sup> Moreover, by 2030, 19% of the U.S. population is projected to be over 65 years of age; a substantial part of this projected growth is among those over age 85—the demographic most vulnerable to many neurological conditions.<sup>3,4</sup> Despite the obvious need for payment reform within the field of neurology, the literature review and stakeholder interviews conducted for this environmental scan showed a lack of APMs focused on patients with complex chronic neurological conditions. However, the literature and stakeholders did identify alternative care models that exist within this space. Therefore, sustainable APMs could be developed to support these existing alternative care models for patients with these conditions.

Although care coordination is important for all complex chronic diseases, the cognitive deficits associated with many neurological conditions may preclude individuals with these conditions from effectively participating in their own care. This decline in cognitive and motor function frequently necessitates extensive involvement of caregivers and family members, adding another level of complexity to these patients' care. As a result, communication and coordination among providers is a vital part of caring for patients with complex chronic neurological conditions. In many cases, care for patients with neurological conditions requires coordination among primary care providers (PCPs), neurologists, geriatricians, nurses, emergency physicians, rehabilitation professionals, and social workers. Further, care frequently spans multiple sites-of-service, ranging from community settings to institutional care. Ideally, payments should be aligned to encourage providers' communication about various aspects of a patient's care—from proper disease diagnosis to care plan creation and execution. Stakeholders suggested that care coordination and support for patients with neurological conditions and

their caregivers should include discussions about disease expectations upon diagnosis, assistance with navigation of traditionally siloed services, training for caregivers to address problematic behaviors, and, where appropriate, guidance for caregiver stress management.

Care coordination and case management for complex chronic neurological patients are critical in transitions between care settings where continuity can be lacking. Some stakeholders noted that patients with complex chronic neurological conditions often require follow-up post-acute care services such as physical and occupational therapy, in addition to speech pathology. Individual physicians may not have sufficient time to address all the care transition needs of these complex patients since disease education and care coordination often occur outside of typical physician office visits. Additionally, coordination and management of follow-up appointments for these patients is inconsistent. This gap can lead to discontinuity in care, which may result in unnecessary hospitalization and/or readmissions. Although the field of neurology has a comparatively high success rate for follow-up appointments after an acute care episode, 27% of patients still fail to schedule their suggested follow-up appointments, with another 20% of patients failing to attend the appointments they scheduled.<sup>5</sup> Even when patients do attend their appointments, stakeholders noted that there is often poor communication and coordination between acute services and the community-based follow-up provider. Unfortunately, as emphasized by the stakeholders interviewed, the current FFS payments fail to cover the necessary time and energy it takes for providers to offer this type of coordinated care. Although at least one study shows that providers spend approximately five minutes a week per patient outside of typical office visits solely on patient care coordination (3.6 hours per week total), Medicare has not provided reliable reimbursement for coordination services to date.<sup>6</sup> While the Centers for Medicare & Medicaid Services (CMS) has released a proposed rule for a chronic care management code to begin in 2015 that could address some of these issues, only one provider associated with a beneficiary's care will be paid through the use of this code.<sup>7</sup> Therefore, APMs for these complex patients should address this gap in care and ensure that providers are adequately incentivized to coordinate with one another in order to help prevent unnecessary and costly services and procedures.

APMs that can support more evidence-based, coordinated care should help realign physician incentives to provide better neurological care at a lower cost. Specifically, key care elements such as timely and appropriate diagnosis, proper medication management, and patient education should be addressed when creating payment reforms for chronic neurological diseases. In addition, patients with complex chronic neurological conditions may also require the use of durable medical equipment (DME). Payments for DMEs, however, are subject to competitive bidding and, therefore, are outside the scope of possible APMs. Even so, those designing APMs for patients with complex chronic neurological conditions should consider including measures and incentives for more effective DME use. Lastly, while relevant to patients with complex chronic neurological conditions, these APMs should not solely focus on neurological patients as some reforms are population-based and, thus, may benefit other patients with complex chronic diseases.

## 1.1 Relevant Conditions

Stakeholder interviews and a literature review pointed to several complex chronic neurological conditions, including dementia, epilepsy, and multiple sclerosis (MS), as having potential for inclusion in APMs. Stroke was also identified by stakeholders as an important condition with promising potential for involvement in an APM. Stroke is the fourth leading cause of death in the U.S., if considered separately from other cardiovascular diseases.<sup>8</sup> In 2010—4%, approximately 1.24 million—of Medicare beneficiaries had a stroke.<sup>9</sup> Stroke is also a common comorbidity among Medicare beneficiaries; in 2010, for beneficiaries who had two or three comorbid conditions, four of the five most costly pairs and all of the five most costly triplets included stroke.<sup>9</sup> In the same year, direct medical costs of stroke in the United States were \$20.6 billion.<sup>8</sup> By 2030, this cost is projected to more than triple to \$184.1 billion, with most of the increased costs stemming from individuals between ages 65 and 79.<sup>10</sup> However, as requested by the Center for Medicare & Medicaid Innovation (CMMI), this environmental scan does not focus on stroke to avoid duplicating existing efforts by CMS such as the Bundled Payments for Care Improvement (BPCI) initiative.<sup>11</sup>

### 1.1.1 Dementia

Dementia is a condition characterized by significant impairment in two or more brain functions without loss of consciousness.<sup>12</sup> The condition refers to a group of diseases characterized by a progressive decline in mental ability that can affect a person's capacity to perform daily activities.<sup>3</sup> Different types of dementia include Alzheimer's disease (AD), vascular dementia, Parkinson's disease, and Lewy body dementia.<sup>12</sup> While these diseases contribute to the dementia category, Medicare does not currently distinguish between them within the claims data. This includes the current procedural terminology (CPT)/healthcare common procedure coding systems (HCPCS) codes, as well as the current international classification of diseases diagnosis (ICD)-9 codes. As such, this scan primarily groups these conditions under the single header of dementia, although some background statistics are provided for the individual diseases. Additionally, although stakeholders noted that Parkinson's disease has other manifestations apart from dementia, it is included in the dementia discussion since 50–80% of individuals with Parkinson's experience dementia at some point in their disease progression.<sup>13</sup>

Dementia is one of the leading causes of death in the United States.<sup>3</sup> Alzheimer's, responsible for the majority of dementia cases,<sup>3</sup> was the sixth most common cause of death in the country in 2010 and 2011.<sup>14, 15</sup> Parkinson's disease was the 14<sup>th</sup> most common cause of death in 2010 and 2011.<sup>14, 15</sup> Dementia places an especially high burden on Medicare since age is one of the major risk factors for the condition. Indeed, the Centers for Disease Control and Prevention (CDC) estimates that 4.7 million of the 5.4 million Americans currently diagnosed with AD are over age 65.<sup>16-18</sup> Dementia has a major impact on a patient's quality of life and is one of the most feared diseases as people age.<sup>19</sup> In addition, people with dementia have an increased risk of comorbid conditions and overall illness burden.<sup>20, 21</sup> Medicare beneficiaries with dementia have higher rates of service use and longer hospital stays, particularly those involving emergency department (ED) visits and hospitalizations.<sup>20-23</sup>

Across all payers in 2010, direct and indirect dementia costs in the United States were between \$159 and \$215 billion, \$109 billion of which were direct medical costs.<sup>24, 25</sup> After adjusting for coexisting

conditions and demographic characteristics, individuals with dementia had \$28,501 higher annual health care costs across all payers.<sup>25</sup> Based on these data, dementia is “the most costly disease in terms of actual spending in the United States.”<sup>25</sup> Direct cost projections specific to Alzheimer’s for all payers in 2014 are estimated to be \$214 billion, with Medicare expected to cover around 53% of these costs.<sup>3</sup> Additionally, when considering the full impact of dementia on the U.S. economy, indirect costs, such as those involving unpaid caregiving through family members, should be taken into account. Unpaid caregivers provide the majority of care for people with dementia, spending approximately 17.7 billion hours caring for individuals with dementia in 2013, according to the Alzheimer’s association.<sup>3</sup> Although there is not a standardized method of calculating the associated costs of this unpaid caregiving, the Alzheimer’s Association estimates that unpaid care amounts to \$220.2 billion of work.<sup>3, 24, 25</sup>

### **1.1.2 Epilepsy**

Epilepsy is a disease defined by the persistent tendency of the brain to cause epileptic seizures, which can result from a wide spectrum of conditions.<sup>26</sup> Approximately two million people in the United States are affected by the disease.<sup>26, 27</sup> Risk factors for epilepsy are more common in adults over 65 years old; thus, similar to dementia, epilepsy is of particular concern to Medicare as the elderly population is more vulnerable to the condition.<sup>27</sup> Additionally, people with epilepsy have higher rates of comorbid conditions than the general population.<sup>28</sup> Annually in the United States, indirect and direct epilepsy costs across all payers are approximately \$15.5 billion.<sup>27</sup>

### **1.1.3 Multiple Sclerosis**

Multiple Sclerosis (MS) is a complex neurological condition that has various clinical subtypes and is characterized by marked progressive functional decline necessitating assistance with daily living activities as the disease advances.<sup>29</sup> MS affects an estimated 400,000 individuals in the United States.<sup>30</sup> Similar to dementia, the substantial impact on quality of life for people with MS can cause immense fear among patients with the condition.<sup>31</sup> Although the disease generally affects a younger population, the prevalence of MS among Medicare beneficiaries is significant due to the under 65 disabled population. One study suggested that there is a 50% higher prevalence of MS among Medicare beneficiaries than among the privately insured.<sup>32</sup>

The cost of a Medicare beneficiary with MS is about two times greater than one without the disease.<sup>32</sup> In 2006, expenditures per Medicare beneficiary with MS were \$23,630 for those with prevalent progressive MS and \$5,887 for those with prevalent relapsing remitting MS (RRMS).<sup>33</sup> However, only a fraction of the total Medicare costs—19.1% for progressive MS and 25.5% for RRMS—were due to claims for beneficiaries with MS as the primary diagnosis.<sup>33</sup> These data suggest that the cost of care is greatly affected by the comorbid conditions associated with MS. Thus, it will be important for APMs to target care that is not solely specific to MS symptoms.

### **1.1.4 Other Conditions**

Other conditions, including traumatic brain injury (TBI) and complex headaches, are also an important part of chronic neurological care. TBI is responsible for 4.8% of all injuries seen in the ED and 15.1% of all hospitalizations and is a contributing factor in almost one-third of all injury-related deaths.<sup>34</sup> Each year, one-third of older adults fall, with a positive correlation between frequency of falls and age.<sup>35</sup> Between

2002 and 2006, falls contributed to 60% of ED visits, hospitalizations, and deaths due to TBI.<sup>34</sup> Finally, complex headaches such as migraines are a prevalent condition, with 20% of adults suffering from migraines.<sup>36</sup> While stakeholders did not primarily emphasize these two areas, they are important to consider when implementing APMs given their prevalence in the Medicare population.

## 1.2 Environmental Scan Overview

The purpose of this environmental scan was to identify existing APMs for patients with complex chronic neurological conditions and explore ways they can be used to efficiently improve the quality of care. While several alternative care models were identified through the literature review and stakeholder interviews, evidence for specific APMs in this area is lacking. Therefore, this environmental scan explores existing alternative care models related to complex chronic neurological care and works to identify potential APMs that may successfully support them. Section 2 describes the methodology of the literature review and stakeholder engagement. Section 3 outlines existing alternative care models, grouped by condition, and includes a limited discussion of how each alternative care model may fit within an APM. Section 4 expands on this discussion to fully describe how APMs could be applied to these alternative care models. Section 5 provides potential quality measures to pair with the APMs, and Section 6 summarizes the main conclusions of the scan.

While all of the identified APMs move away from the traditional FFS payment mechanism, they differ in the extent and manner with which they shift payments, as shown in Figure 1. APMs moving from left to right along the x-axis include increasingly comprehensive payments for services of an individual provider. APMs moving from bottom to top along the y-axis include more comprehensive payments for collaboration across providers. Traditional FFS, where each individual provider is paid for each individual

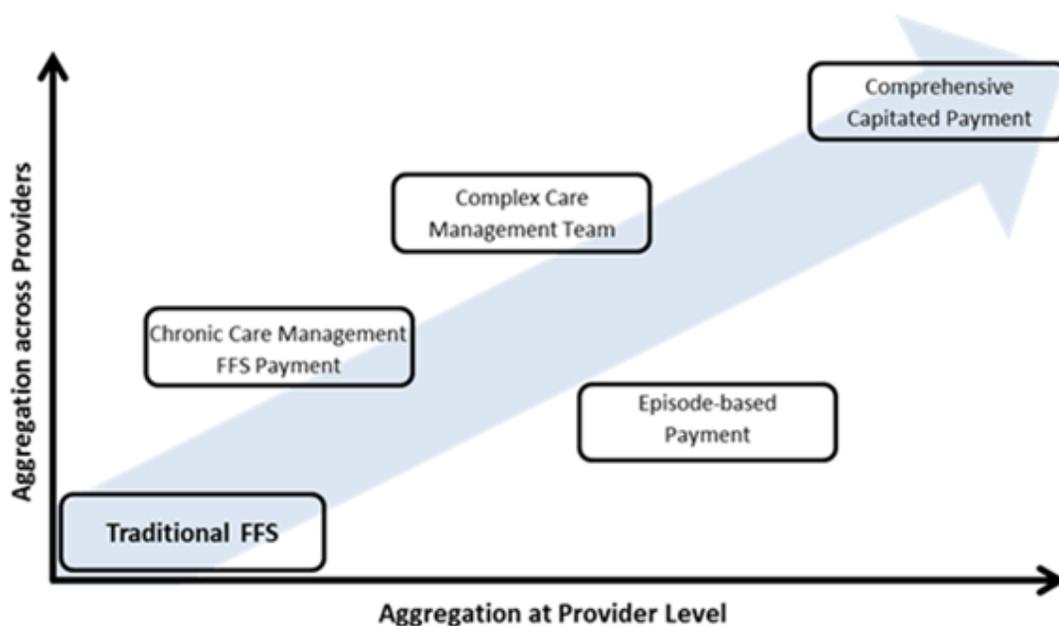


Figure 1. Direction and degree of shift away from the traditional fee-for-service payment for each alternative payment model. *Source: The Brookings Institution, 2014*

service, is located in the bottom left corner. In the top right corner is capitated payment, where a group of providers are given a single, global payment to cover all costs of care for a patient population. Other APMs, with their varying levels of comprehensive payments, are found between these two extremes.

### 1.2.1 Summary of Findings

The majority of alternative care models identified through the literature and stakeholder interviews focus on improving care through collaborative, case-based approaches such as **complex care management**. The Chronic Care Model, a primary care-focused general framework for chronic diseases, serves as the basis for these types of approaches.<sup>37-39</sup> The Chronic Care Model works to integrate the community, the specific provider organization, and the health care system as a whole by focusing on six main tenets of care: “community resources and policies, health care organization, self-management support, delivery system design, decision support, and clinical information systems.”<sup>37, 39</sup>

One payer interviewed described a complex care management program for patients with multiple chronic comorbid conditions, although this program was not specific to neurological care. In this general model, a group of physicians receives modified payments with specific criteria for managing these sicker, more complex patients (such as those with chronic conditions or multiple comorbidities), improving clinical results, and enhancing overall efficiency. The stakeholder explained that case managers are embedded in the provider group to help coordinate care between the various physicians, manage the patients’ comorbid conditions, and, when indicated, implement a compassionate care program for end-of-life care. In addition, the stakeholder noted that supplying data to the provider group is an essential component of their model, including immediately actionable data, summary data, and benchmark data that has been compared against mutually agreed upon goals.

The components included in this general complex care management model exemplify the type of care reform taking place within the field of neurology to date; Section 3 describes these models in detail for each neurological condition. Alternative care models examined in this scan focus on providing complex coordination and expanded support services to improve the quality of care. These alternative care models can reduce costs by preventing complications from suboptimal care and avoiding duplicative/unnecessary services through greater coordination and information sharing among the providers involved in care. The use of a care coordinator, for example, can help organize and manage all the divergent aspects of a patient’s care. In this role, the care coordinator can help ensure that all the patient’s needs are being met, appropriate services are performed, and duplicate efforts are avoided. In many alternative care models, a coordinator also works with patients to develop a care plan to ensure that the patient’s specific concerns are being addressed. Another important aspect of most alternative care models is expanded services such as caregiver support and education, social services, and emergency availability.

The general structures of alternative care models discussed in this environmental scan include:

- **Practice/health system-based models**, where all services are provided through the physician’s office.
- **Partnerships with community-based organization (CBO) models**, where providers actively educate and refer patients to CBOs that provide extended support services. Providers may also

have formal partnerships with these CBOs where the provider organization offers care coordination in addition to the education and referrals.

- **Transitional care models**, which focus specifically on enhancing care coordination during transitions of care.
- **Centers of excellence models**, which have a centralized location for disease-specific resources to support less-specialized providers in the community.
- **Self-management models**, which provide tools to help patients improve self-management of their condition.

Stakeholders interviewed for this environmental scan echoed themes found in the literature, noting that APMs are particularly relevant in the field of neurology due to the importance of coordinating care for complex chronic conditions. However, neither the stakeholders interviewed nor the literature review identified any existing neurology-specific APMs. The APMs discussed in this environmental scan, therefore, provide examples of how APMs could be used to support the existing alternative care models. These theoretical APMs can help address health care costs by promoting alternative care models that reduce costs and alter reimbursement for the same level of services. Stakeholders interviewed and the literature reviewed emphasized the importance of ensuring that cost savings are a result of higher-quality care rather than simply providing fewer services.

Several APMs could promote some or all components of the alternative care models:

- **A per-member, per-month (PMPM) payment**
  - As an **expanded chronic care management (CCM) payment** to support communication between providers, care coordination, and case management – This communication could include interactions not only between a neurologist and PCP, but also with providers in other care environments such as those in acute and post-acute settings. Rather than a bundled payment, this type of APM would be a specific coordination payment on top of current FFS payments.
  - To support a **complex care management team payment** – In this APM, the PMPM would support a multidisciplinary group of providers who work as a team to coordinate a beneficiary's care and provide expanded services. For complex chronic neurological conditions, a neurologist would be a vital part of the multidisciplinary team, either as the primary provider or as a consultant providing guidance and specialty care as needed. Potentially, the complex care management team payment could be supplemented with a value-based bonus or a shared savings arrangement.
- An **episode of care payment** to support discrete procedure- or time-defined care episodes.
- Partially or fully **capitated payments** could also support the services required for complex care management.

The feasibility of each APM depends on the required level of practice transformation and how comprehensive the shift is away from the traditional FFS payment model. The expanded CCM code would be most feasible since it requires very little practice transformation. However, it represents little actual payment reform since it is simply added into the existing FFS system. More comprehensive shifts away from FFS, such as a complex care management team payment or a capitated payment, represent

larger payment reform. However, they are less feasible since they require more practice transformation. For example, smaller practices or providers in rural communities may have trouble forming care teams with an adequate level of service expansion necessary to qualify for these types of APMs.

A private practice setting is most common for neurologists; however, like many specialists, neurologists often practice in multiple settings, including as consultants in EDs, inpatient clinicians in office-based settings, and treating physicians in ambulatory environments.<sup>40</sup> As with other specialties, FFS still remains the most common payment model within the neurology field, although neurologists are increasingly participating in APMs.<sup>40</sup> The alternative care models for dementia and other complex chronic neurological conditions illustrate that care coordination for patients with these conditions is lacking and often dispersed between caregivers, specialists, PCPs, and others.<sup>41-44</sup> Thus, when considering how to best manage these conditions and encourage coordinated, efficient care, it is worthwhile to consider how neurologists fit into the model and what type of quality/performance metrics could be used.

Quality measures are a critical component of APMs since they help ensure that beneficiaries are receiving high-quality, efficient care. Some APMs, such as shared savings and capitated payments, tend to incentivize under-utilization of services. Linking APMs with quality measures can avoid this perverse incentive by requiring the provision of certain high-quality practices for reimbursement. These quality measures can ensure that clinical practice standards are met and patient outcomes do not suffer as a result of the new APM. Quality measures have several different policy applications including public reporting, pay-for-performance (P4P), and pay-for-reporting. Some measures apply to complex chronic neurological care generally, while some are condition-specific.

## 2. Methodology

The project team conducted a comprehensive environmental scan that included (1) a literature review of the existing peer-reviewed and non-peer-reviewed literature as well as popular media, and (2) semi-structured interviews of 26 key stakeholders, some of whom were interviewed jointly. While the team made all attempts to ensure the environmental scan was comprehensive and representative of the neurology field, there is potential for selection bias due to the survey methods used and the particular stakeholders selected for interviews.

### 2.1 Literature Review

The project team conducted a semi-structured literature review using Medical Subject Headings search terminology to gain the maximum number of relevant citations compiled by PubMed and Google Scholar. Articles published in English since 2000 were included. Additionally, the team identified relevant articles from bibliographies of returned articles, including those published before 2000, and explored specialty information sources such as the American Academy of Neurology (AAN) and the CDC.

The team used the following search stems in the database research:

- 1.1.1. Neurology *or* multiple sclerosis *or* epilepsy *or* dementia *or* Alzheimer's *or* acquired brain injury *or* traumatic brain injury *or* TBI *or* stroke *or* Parkinson's *or* Amyotrophic lateral sclerosis *or* ALS *or* complex headache *or* migraine

- 1.1.2. 1.1.1 *and* payment *or* payment model *or* finance *or* compensation
- 1.1.3. 1.1.1 *and* prospective payment system *or* PPS
- 1.1.4. 1.1.1 *and* capitation *or* salary *or* per member per month *or* PMPM *or* full capitation *or* partial capitation
- 1.1.5. 1.1.1 *and* episode payment *or* episode-based payment *or* case payment *or* case-based payment
- 1.1.6. 1.1.1 *and* retrospective payment
- 1.1.7. 1.1.1 *and* bundle *or* bundled payment *or* aggregate payment
- 1.1.8. 1.1.1 *and* medical home *or* patient-centered medical home *or* medical neighborhood
- 1.1.9. 1.1.1 *and* accountable care organization *or* accountable care *or* care coordination *or* ACO
- 1.1.10. 1.1.1 *and* shared savings *or* risk sharing
- 1.1.11. 1.1.1 *and* fee-for-service *or* fee for service *or* FFS
- 1.1.12. 1.1.1 *and* value-based *or* value-based care *or* pay for performance *or* P4P
- 1.1.13. 1.1.1 *and* competitive bidding
- 1.1.14. 1.1.1 *and* pathways *or* clinical pathways *or* value-based pathways

## 2.2 Stakeholder Interviews

The project team identified a list of potential stakeholders and thought leaders spanning the neurology space (see Appendix A for a list of stakeholder organizations interviewed). From this list, the team conducted 23 one-hour, semi-structured, strategic interviews, three of which included multiple stakeholders. The group of selected stakeholders included patient advocates, providers, health service researchers, payers, and policy specialists. Following each recorded interview, one research team member transcribed comprehensive notes that were later summarized. Stakeholder responses were consolidated by stakeholder category and incorporated into a conceptual framework used to present each alternative care and payment model.

## 3. Alternative Care Models

This section describes the clinical needs associated with dementia, epilepsy, and MS and the existing alternative care models for each condition. Some discussion of how the alternative care models could fit within APMs is also included, although Section 4 covers the majority of the information on APMs. This section also includes a short discussion of how other neurological conditions, such as complex headache and TBI, may benefit from similar models of care. Although some alternative care models may be similar for the various neurological conditions, stakeholders emphasized the importance of discussing conditions separately due to their unique characteristics. Appendix B provides a table of the alternative care models described in this section, along with a brief description of each model.

Alternative care models for complex chronic neurological conditions aim to move the current fragmented health care system toward more proactive, coordinated, patient-centered care. Stakeholders interviewed for this environmental scan suggested that the current health care system is typically reactive, providing care only after some type of acute, and potentially preventable, exacerbation has taken place such as an adverse medication reaction or a fall. The stakeholders indicated that the lifestyle changes often necessary to manage these conditions, such as home modifications to avoid falls, are not adequately addressed or supported in the current health care

system. Several stakeholders stated that care should be more proactive, helping patients and caregivers avoid these unnecessary health complications by identifying timely interventions and support systems to best manage patients' conditions. To accomplish these goals, alternative care models use expanded tools and provide more comprehensive services for their patients. Support services, such as case management, help develop care plans and facilitate communication between providers involved in an individual's care. Alternative care models may also offer other support services, such as psychosocial care and extended emergency availability, to help manage health problems, including comorbidities, and provide timely interventions if/when required.

The alternative care components of each model covered in this scan are described in detail throughout this section. When available, outcome measures such as resource utilization, program costs, and associated savings are included along with the model description. Although the alternative care models identified through the stakeholder interviews and the literature review are not currently supported through APMs, some include suggested payment features or future plans for APM development. Where applicable, the team described these suggested APMs.

### 3.1 Dementia

Although individuals with mild cognitive impairment may successfully care for themselves, persons with more advanced forms of dementia will eventually require some type of caregiver support.<sup>45</sup> These caregivers help manage various aspects of care including medication adherence, physician visits, care instructions, and activities of daily living such as eating and bathing.<sup>45</sup> A large proportion of care for patients with dementia, which can be extremely challenging, is administered by unpaid caregivers such as family members, rather than through more formal relationships with registered nurses or home health aides.<sup>3,46</sup> The challenges associated with providing care for people with dementia often cause stress and can lead to caregiver depression.<sup>3</sup> Multiple stakeholders noted that this physical and emotional stress can result in increased utilization of health care services by the caregiver. The Alzheimer's Association reported that the decline in health associated with dementia caregiving added over \$9 billion in additional health costs in 2012 alone.<sup>3</sup> Stakeholders claimed that this health decline is particularly true of spousal caregivers, who are generally elderly, often physically frail themselves, and may have their own independent health concerns. Stakeholders suggested that interventions focused on providing caregiver education and support can reduce caregiver stress, improve caregiver knowledge of dementia, and extend the caregiver's network of support. The literature reinforces these stakeholder suggestions and highlights that caregiver interventions can reduce behavioral symptoms of people with dementia, which are reported to be some of the most stressful aspects of dementia care.<sup>47,48</sup> Multiple stakeholders recommended that any alternative care models for dementia include some type of caregiver education and support.

Between 60%–70% of people with dementia live in the community (e.g., at home) rather than in long-term institutional settings such as nursing homes.<sup>3</sup> Several stakeholders noted that this was the preference of many patients and their families. Although the majority of individuals with dementia live in the community, several stakeholders and the literature also noted that most people with dementia do spend time in a long-term care facility before their death.<sup>49</sup> In fact, half of all nursing home residents, as

well as over 40% of residents in assisted living, have dementia.<sup>50, 51</sup> Behavioral symptoms are common among dementia residents in these facilities and are often managed using antipsychotic medications.<sup>52</sup> Data show that the use of atypical antipsychotics to manage behavioral symptoms of dementia is associated with increased mortality.<sup>53</sup> In light of this challenge, and the common use of antipsychotics, CMS began an initiative in 2012 to reduce the prescription of these drugs in nursing homes.<sup>54</sup> Alternative care models for dementia could build on this initiative to encourage more effective medication use in all sites-of-service.

Research into non-pharmacological and psychosocial interventions has identified some successful techniques to improve care in long-term residential facilities without relying on antipsychotic medication. These effective techniques include providing patient-centered care for dementia residents through properly trained staff, increased frequency of disease assessments, and development of joint care plans with residents, family members, and staff.<sup>55</sup> However, the literature review and stakeholder interviews also suggested that few of these alternative care models could be supported through Medicare physician payment reform alone. Payment reform for skilled nursing facilities and Medicaid payment reform are much more applicable for achieving these care goals. Therefore, the remaining discussion focuses on opportunities for patients primarily living in the community.

### **3.1.1 Practice/Health System-Based Models**

The majority of alternative care models identified through the literature review and stakeholder interviews are comprehensive; the additional support services (such as caregiver counseling, patient-centered care plan development, and emergency telephone services) are offered within the practice or health system itself. Some of these models also helped connect patients with outside programs offering additional services, such as adult day care and legal services. Many of these programs are structured using complex care management teams, some of which exist within formal medical homes. The first three practice/health system-based models described here provide comprehensive case management, using extensive services and tools to address all aspects of dementia care, and include caregiver support, decision support tools, and care coordination. The last two practice/health system-based models, on the other hand, focus only on providing caregiver support.

Most, if not all, of the extended care services provided through these practice/health system-based models could be supported through some type of Medicare APM since they are provided directly through the health system or physician practice. One option for an APM could be the use of a PMPM payment on top of the current FFS schedule to support the necessary extended services required to provide adequate dementia care management. These additional services should increase the quality of care by improving the coordination of services between providers and sites of services, while also bolstering the education and support of caregivers. The additional services should simultaneously assist in preventing avoidable complications and exacerbations, such as hospitalizations, which should lower long-term costs. A shared savings component could be included in addition to a PMPM to capture the long-term benefits that can result from this type of practice/health system-based model. These benefits could include a reduction in resource utilization, delayed institutionalization, and/or more proactive disease management.<sup>56-58</sup> Alternatively, this type of practice/health system-based model could be

supported through a shift from FFS toward a capitated payment, giving providers stronger incentives to shift services away from traditional approaches to care.

### **Aging Brain Care Model**

Granted a CMMI Health Care Innovation Award in 2012, the Aging Brain Care (ABC) model integrates a medical home with an ABC center to provide multidisciplinary, comprehensive care to patients with dementia.<sup>59</sup> This program is designed to support PCPs, who continue to provide the majority of patient care in this model.<sup>60</sup> The ABC center is a clinic specific for neurological conditions that complements the medical home by providing specialist services as needed.<sup>59</sup> An ABC center physician—either a neurologist or related specialist—works half-time as a medical director, serving as a bridge between the ABC center and the PCP.<sup>60</sup> Other members of the ABC multidisciplinary complex care management team include an advanced practice nurse or nurse practitioner who serves as a care coordinator, a social worker, and a medical assistant. The care coordinator conducts patient assessments, manages patient care between PCP visits, and provides counseling to both patients and caregivers.<sup>60</sup> In addition, the care coordinator provides case management by connecting patients to community and home resources, overseeing medication adherence, and delivering post-visit and follow-up care.<sup>60</sup> The social worker supports care coordination, oversees medication adherence, manages patient transitions, connects patients with local resources, and provides problem-solving therapies when needed.<sup>60</sup> Lastly, a medical assistant works with the care coordinator to manage patient scheduling and input patient data.<sup>60</sup>

The ABC is a mobile model, providing care for patients in a variety of settings including primary care clinics, specialty clinics, local hospitals, patient homes, and other locations within the community.<sup>60, 61</sup> Importantly, the ABC medical home provides a robust set of support tools for physicians and patients to improve care.<sup>62</sup> One such tool for physicians and caregivers helps guide patient screening, diagnosis, and symptom management.<sup>63</sup> ABC also uses a specialty electronic medical record (EMR), eMR-ABC, designed to capture patient and caregiver demographics, medication adherence and management, and ED visits or hospital admissions, and also to track depression and cognition.<sup>62</sup> The inclusion of caregiver demographics in the EMR is particularly interesting since several stakeholders noted that, although the attribution of caregivers is essential to APMs supporting dementia care reform, capturing this information using Medicare claims data is currently impossible. The ABC utilizes care protocols such as clinical guidelines, care timing and triggers, medications, referrals, and advanced diagnoses.<sup>64</sup> It also uses non-pharmacological guidelines for communication, stress, exercise, and coping strategies.<sup>64</sup>

A pilot version of the ABC model, the Healthy Aging Brain Center (HABC), was implemented through a safety net health care system in Indiana.<sup>65</sup> The HABC used a two-phase program that included an “initial assessment phase” and a “follow-up phase.”<sup>65</sup> The initial assessment phase consisted of a structured needs assessment, full diagnostic exam, and introduction of a personalized care plan.<sup>65</sup> The follow-up phase included telephone and in-person contacts to discuss the individual care plan and make adjustments as needed.<sup>65</sup> Analyses showed that the HABC intervention successfully reduced utilization of acute services, decreasing ED usage by 45%, length of hospital stays by 28%, and readmission rates by 45%.<sup>56</sup> In addition, the HABC program improved the overall quality of care provided by the PCPs.<sup>65</sup> To cover the necessary operational costs (e.g., required staffing hours), the cost per patient of providing the HABC intervention in 2012 was \$618.<sup>66</sup> The intervention generated net savings ranging from \$980 to

\$2,856 annually for each patient, with overall savings to the health system of 30%.<sup>56,66</sup> The majority of these savings resulted from the reduction in inpatient expenditures, with the remaining savings due to reductions in ED visits and outpatient care.<sup>66</sup>

### **Dementia Care Ecosystem Model**

The Dementia Care Ecosystem model, which was granted a CMMI Health Care Innovation Award starting in September 2014, is a program that will focus on providing proactive care for patients with dementia in San Francisco and rural Nebraska.<sup>67</sup> The model was developed and will be implemented through a partnership between the University of California, San Francisco and the University of Nebraska Medical Center.<sup>67</sup> A stakeholder associated with this work noted that the Dementia Care Ecosystem was developed to provide personal, continuous care focused on prevention, rather than the reactive care patients currently receive. In this model, a care team navigator (CTN), with the aid of a computer-based dashboard, will serve as the connection point between the patient-caregiver dyad and the care team.<sup>67</sup> Unlike many other alternative care models, CTNs in the Dementia Care Ecosystem will have relatively little prior specialized education, generally only holding a bachelor's degree, although they will receive specific training through the program.<sup>67</sup> The stakeholder noted that this should reduce program costs and increase the project's scalability if it were to be applied nationally. It is expected that each CTN will be in charge of 70–80 patients and will be available 24/7.<sup>67</sup> The CTN will determine necessary members of the care team and help coordinate between the various team members, which may include geriatricians, pharmacists, nurses, neurologists, and psychologists.<sup>67</sup>

After an initial diagnostic evaluation, a patient care plan will be implemented and integrated into the dashboard.<sup>67</sup> The dashboard, which will have separate care team and patient/caregiver portals, will be embeddable in the current EMR system so that any new information added to the EMR or dashboard will be automatically populated in the other.<sup>67</sup> For the patient-caregiver dyad, the dashboard will provide educational information, links to community resources, and online support groups.<sup>67</sup> The CTN will help direct the patient-caregiver dyad to resources that could be particularly useful to them.<sup>67</sup> When implemented, this model will have four main modules that will focus on collaborative care management: (1) the Caregiver Module, which will focus on improving caregiver quality of life, (2) the Decision-Making Module, which will help with advanced care and financial planning, (3) the Medication Module, which will assist patients with medication management, and (4) the Functional Monitoring Module, which will track the patient's functional status.<sup>67</sup> The stakeholder familiar with this work explained that the program will also provide smartphones to monitor patients who are considered high-risk due to advanced stage dementia or existence of comorbid conditions, social issues, and/or environmental concerns. The smartphone technology will track activity in the home and community, securely transmitting information to the dashboard at set intervals throughout the day. The stakeholder believes that this tracking will allow care providers to identify changes in health status through decreases in activity levels and to intervene in a more opportune manner.

The Dementia Care Ecosystems model is projected to delay entry into long-term care facilities by 180 days as well as reduce ED visits, ambulatory costs, hospitalizations, and drug costs by 50%, 30%, 30%, and 15%, respectively.<sup>67</sup> The model is expected to cost \$131 per patient for each month, which should result in an annual net savings of \$4.6 million for every 1,000 patients enrolled.<sup>67</sup> Unlike most other

alternative care models identified in this scan, the Dementia Care Ecosystem has proposed a specific APM that could be used to sustain the alternative care model independent from philanthropic and grant-based support. This proposed system would use an add-on payment in the form of a sliding scale monthly enrollment fee, shared by the patient and the payer, with a bi-annual, tiered, pay-for-performance (P4P) bonus component based on providers meeting Physician Quality Reporting System (PQRS) measures for dementia.<sup>67</sup> The bonus payment, a value-based modifier of a Current Procedural Terminology (CPT) code, will be 0.5% of the Medicare payments associated with beneficiaries for which all measures are met.<sup>67</sup> The associated stakeholder noted that multiple private insurance companies have indicated interest in enrolling patients in the program after the first year, provided the projected cost savings prove realistic.

#### **University of California, Los Angeles Alzheimer's and Dementia Care Program Model**

Supported through a 2012 CMMI Health Care Innovation Award, the University of California, Los Angeles' (UCLA) Alzheimer's and Dementia Care (ADC) program works to improve caregiver support, provide coordination during transitions in care, and help patients access CBOs.<sup>68</sup> Each patient in UCLA's ADC is assigned a geriatric nurse practitioner who serves as the dementia care manager (DCM) and completes an initial assessment of the dementia patient and caregiver.<sup>68</sup> The DCM then develops a patient-centered care plan, independently addressing social and behavioral issues while receiving approval/modification(s) for the medical portion of the plan from the PCP.<sup>69</sup> The goal of this process is to improve PCP buy-in to the program by including them earlier on in the decision-making process.<sup>69</sup>

Once approved, the care plan is discussed in detail with the patient-caregiver dyad.<sup>69</sup> The DCM adjusts the care plan as needed and instructs caregivers to contact them if any concerns arise.<sup>68</sup> In this framework, a DCM is able to provide support for around 250 patient-caregiver dyads.<sup>69</sup>

Caregivers are trained via text, web, or in-person on dementia basics, including communication techniques and practical skills, to help avoid and cope with problematic patient behaviors.<sup>68</sup> A 24-hour telephone advice line is also available to caregivers.<sup>68</sup> The DCM is automatically notified if patients utilize UCLA's acute care system, and caregivers are instructed to notify the DCM of any acute care interactions that occur outside the UCLA system.<sup>68</sup> In addition, this program provides referrals to government and community-based services, including the local Alzheimer's Association chapter, that may benefit the patient-caregiver dyad but are not directly available within the program.<sup>68</sup> This type of care may include care support, counseling, and financial and/or legal services.<sup>68</sup> To improve access, the ADC program partially subsidizes these services using CMS funds that support access to community services for patients who cannot afford them.<sup>68</sup>

Although full results from this program are not yet available, initial surveys indicate high patient and provider satisfaction.<sup>68</sup> However, the program as it is constructed is not financially sustainable in the current FFS system; in-person visits with the DCM are charged, but the costs of all other components of the program are borne by UCLA through the CMMI grant.<sup>69</sup> If successful in reducing utilization of acute services, a PMPM case management fee coupled with some type of shared savings could potentially finance the program.<sup>69</sup>

### **New York University Caregiver Intervention Model**

The New York University Caregiver Intervention (NYUCI) began as a research study in 1987 to examine the effects of supporting spousal caregivers through six scheduled counseling sessions tailored to their specific needs.<sup>58</sup> Although the intervention did not directly connect caregivers with a support group, telephone counseling was made available as needed, with additional encouragement to join an outside system of support.<sup>58</sup> The caregiver support given in this intervention could be provided through case managers embedded in a provider group. Results from the NYUCI model showed delays of over a year for placement of individuals with dementia into long-term care facilities.<sup>58</sup> Stakeholders and literature indicated that this delay is likely due to increased caregiver well-being.<sup>70, 71</sup> Since long-term care is one of the primary cost drivers for dementia, delaying institutionalization should lead to significant cost savings.<sup>72</sup>

Due to its success, the NYUCI research model has been translated into other care reform interventions in multiple locations throughout the country. One example, the Minnesota Family Memory Care (FMC) program, is grant-funded with additional support from the state and has been integrated into the state's "network of caregiver consultation services" to help achieve sustainability.<sup>73</sup> In 2010, the FMC program used trained counselors to implement the intervention at existing caregiver support sites around the state. Although FMC offered the six NYUCI-prescribed counseling sessions, caregivers were considered to have completed the program if they attended at least four sessions.<sup>73</sup> Even so, close to a fourth of the enrollees did not complete the program, with just under half attending all six sessions.<sup>73</sup> Regardless, after eight months of the intervention, there was a significant reduction in caregiver depression and reaction to problematic patient behaviors as well as significant improvement in caregiver satisfaction.<sup>73</sup> After a year, satisfaction with support structures remained significantly increased, and reactions to problematic behaviors remained in decline.<sup>73</sup> This real-world translation of the NYUCI study also found delays in institutionalization when caregivers completed all six counseling sessions.<sup>73</sup> Mathematical modeling of potential cost savings found that population-level cumulative cost savings from the FMC program will increase from \$289 to \$996 million over time.<sup>57</sup> One stakeholder suggested that even with more conservative estimates of uptake and long-term placement delays, potential savings are still substantial. Fewer required in-person sessions for completion enhances sustainability of this program.

The North Dakota Dementia Care Services Program, funded by the state, is another translational intervention based on the NYUCI model that was created with goal of reducing utilization of acute services, increasing caregiver empowerment, and delaying long-term patient placement.<sup>74</sup> Compared to the NYUCI model, this program provided fewer in-person counseling sessions over a longer time-frame.<sup>74</sup> However, this model did offer unlimited phone consultations to help account for accessibility difficulties in rural areas.<sup>74</sup> The program provided services to 951 persons with dementia and 1,750 associated caregivers over the first 42 months of implementation.<sup>74</sup> The reported cost of the program was \$1.2 million over two years.<sup>74</sup> Upon conclusion of the program, caregivers reported improved feelings of empowerment that reduced the likelihood of placing the patient in long-term, institutionalized care.<sup>74</sup> Estimations of these results indicated possible delays in long-term care placement by over seven years per dementia patient, potentially saving almost \$23 million every two years.<sup>74</sup> Additionally, this intervention significantly reduced utilization of acute services, with potential

savings of \$833,516 over an 18-month period.<sup>74</sup> Again, fewer in-person sessions makes this model applicable to a broader population. Substantial cost savings suggest that this model could be implemented sustainably.

### **Resources for Enhancing Alzheimer's Caregiver Health Model**

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) was a two-part, multi-site research program funded by the National Institutes of Health (NIH) and the National Institute of Nursing Research (NINR). The purpose of this program was to determine the effect of psychosocial interventions on caregivers for people with dementia.<sup>75</sup> REACH I, the first phase of the study, tested numerous caregiving interventions to determine which was most effective in reducing caregiver stress and burden.<sup>76</sup> Results showed that active interventions and skills training were the most successful in meeting these goals.<sup>77,78</sup> Additionally, the active intervention components of REACH I reduced caregivers' grief when faced with the loss of a person with dementia.<sup>79</sup>

The second phase of the study, REACH II, used successful intervention components of REACH I to target problem areas in caregiver quality of life, including caregiver education, skills to manage problem behaviors, social support, and stress management skills.<sup>75</sup> The REACH II intervention consisted of nine in-home sessions, three telephone sessions, and five structured support group sessions through a computer-integrated telephone system. Results from REACH II showed significant improvements in quality of life for most caregivers, including a reduction in depression and problem behaviors as well as an improvement in social support, self-care, and self-rated health.<sup>75,80</sup> The program cost \$1,214 per caregiver over the six-month intervention period, with an incremental cost-effectiveness ratio of \$4.96 for an extra hour of non-caregiving time per day.<sup>81</sup>

The Family Caregiver Program (FCP), provided through the nonprofit integrated health care system Scott & White Healthcare in Texas, utilizes a published manual, the Caregiver Notebook, to implement the REACH II program.<sup>82</sup> The FCP is specifically integrated into the health care system to help identify caregivers of people with dementia—a task which stakeholders suggested can be a major difficulty.<sup>82</sup> The FCP categorizes patient-caregiver dyads by level of risk, delivering four phone calls to low-risk dyads, four phone calls and an in-person visit to medium-risk dyads, and five phone calls with two in-person visits to high-risk dyads.<sup>82</sup> In addition to REACH II components, the FCP provides support for local resources and a family profile, which integrates specifics of the caregiving family into the care plan to address any individual issues.<sup>82</sup> Even with reduced contact, caregivers reported satisfaction with the intervention, and the program has been recently expanded to allow for more robust analysis.<sup>82</sup>

The Veterans Health Administration (VHA) also incorporated the REACH II intervention for caregivers into their Home-Based Primary Care programs (REACH VA).<sup>83</sup> REACH VA aimed to promote caregiver problem solving, develop action-based strategies for caregivers to address patient behavioral issues, and teach caregiving stress reduction techniques.<sup>83</sup> The intervention attempted to address these goals through caregiver-specific meetings over the period of six months, nine of which were home-based and three of which were by telephone, with an additional five telephone-based support sessions.<sup>83</sup> However, REACH VA did not provide computer-assisted screen telephones due to their cost.<sup>83</sup> A caregiver notebook, written at a fifth grade reading level, included educational information and strategies for

addressing stress and problem behaviors.<sup>83</sup> Including descriptions of behavioral strategies acted to reduce the time between identification of problems and care plan development.<sup>83</sup> Additionally, REACH VA used a 21-item shortened risk appraisal measure, which was reduced from the original 51-item risk-appraisal measure used in REACH II.<sup>83</sup> The translated program successfully reduced caregiver burden, depression, and frustration.<sup>83</sup> The protocol and materials developed for REACH VA have also been used in two other REACH translational programs.<sup>83</sup> More analysis is needed to determine the cost implications of this model to ensure that this type of program can be implemented sustainably.

### **3.1.2 Partnerships with Community-Based Organizations Models**

Several stakeholders stated that many physicians do not have sufficient time or resources to provide the expanded support services needed by patients and caregivers. CBOs, on the other hand, currently offer a variety of services that can help offer such support. The Alzheimer's Association, for example, is a nationwide organization with local community chapters that provides support services such as a 24-hour help line, educational resources and programs, and support groups.<sup>84</sup> These support services can be used to help augment the medical services provided at a physician's office. Unfortunately, many physicians are not properly informed about CBOs and therefore do not take advantage of the services they provide.<sup>85</sup> To address these issues, some alternative care models focus on linking physician and community services.

One way to encourage collaboration between physician/health system-based programs and CBOs is to provide financial incentives for providers to educate patients about the services CBOs offer. Providing greater support for these community services in the traditional Part B system would be very difficult since Medicare does not currently pay for services provided by CBOs. However, it may be feasible within Medicare to incentivize physicians to encourage beneficiaries to use existing CBO services. A PMPM could be used to support educating patients on available programs and their services. While referrals would not be directly incentivized, patient education could potentially increase the rate at which the CBOs are utilized. Other public programs such as Medicaid could work in conjunction with Medicare reform efforts to ensure that patients receive these necessary services.

A more robust approach would be for provider groups to develop formal partnerships with CBOs where the provider groups offer care coordination but not the expanded care services. In this type of alternative care model, a care manager at a provider group would work to coordinate with a CBO providing extended care services. Using this approach, a patient would still receive complex care management, but the services would be split between provider groups and CBOs. Appropriate technology would be particularly critical for this type of alternative care model to efficiently facilitate the exchange of information between the CBOs and providers.

The care managers could be supported through a specific Medicare APM since they would be embedded within the health system or practice. However, unlike the comprehensive complex care management models described above, supporting the expanded care services would require more substantial reform in Medicare payments and existing payments for community services since they are provided by CBOs. A PMPM fee could be used on top of the FFS schedule to support the use of a care manager. Since this payment would not support the actual extended care services, it could be smaller than a PMPM for the

practice/health system-based alternative care models described in the previous section. An additional shared savings component could further incentivize providers to collaborate with CBOs, given that their services could help reduce overall costs. Lastly, a shift to a partially or fully capitated payment model could provide similar incentives and support for physicians to engage in this type of alternative care model. In fact, a provider group may choose to use some of a capitated payment to pay for services at CBOs since their services may reduce the overall cost of care.

Little research exists that is directly relevant to determining the appropriate payment amount and quality metrics that could reliably lead to improvements in costs and outcomes for patients with dementia. One telephone-based program, Partners in Dementia Care (PDC), suggested that a PMPM of \$60–\$80 would sufficiently cover all costs of the program, including the CBO-based caregiver.<sup>86</sup> Further research to fill this gap at the intersection of delivery and payment reform for dementia is needed.

### **Assessing Care of Vulnerable Elders – Alzheimer’s Disease**

Assessing Care of Vulnerable Elders – Alzheimer’s Disease (ACOVE AD) implements features of the collaborative care management model including data collection, EMR workflow prompts, patient and physician education, and decision support for physicians.<sup>43,85</sup> Additionally, the program includes a quality improvement component as well as referrals to local Alzheimer’s Association chapters for enhanced patient education and training.<sup>43</sup> Research indicates that using this alternative care model, physicians were more successful in connecting patients to local Alzheimer’s Associations, helping to improve the overall quality of care scores and caregiver counseling rates.<sup>43</sup> Importantly, ACOVE AD found that physicians must proactively refer patients to Alzheimer’s Associations chapters or other similar community-based services while also educating the patient-caregiver dyads about the services available.<sup>43</sup> This additional education not only helps patients and caregivers understand the purpose of the referral, but also brings light to some of the long-term benefits that CBO services can provide as the condition progresses, such as end-of-life planning. This component of offering education before the referral could be incentivized using a FFS payment, but again, little evidence exists on whether such a payment would significantly improve care and reduce other costs.

### **Partners in Dementia Care Model**

The Partners in Dementia Care (PDC) model, developed through the Department of Veterans Affairs (VA), formally links VA medical centers with Alzheimer’s Associations.<sup>44</sup> PDC provides telephone-based care focused on education and emotional support linking patient-caregiver dyads to useful resources and enhancing support networks.<sup>44</sup> In the PDC model, the VA and the Alzheimer’s Association each have part-time care managers who jointly work with patient-caregiver dyads through weekly in-person or telephone meetings to discuss cases.<sup>44,86</sup> These care managers support 75–125 families.<sup>86</sup> Within the Medicare system, the provider-based care manager can be supported through an APM, but the CBO-based care manager cannot. The PDC uses a Microsoft Excel-based clinical information system to promote communication between the two care managers.<sup>44</sup> To properly manage all aspects of patient care, the VA and Alzheimer’s Association-based care managers are responsible for different care needs: the VA-based care managers focus on the medical needs and help patients navigate the VA system, and the Alzheimer’s Association-based care managers concentrate on caregiver support.<sup>44,86</sup>

Depending on the primary needs of the patient-caregiver dyad, either the VA- or the Alzheimer's Association-based case manager is established as the primary case manager to develop the patient's care plan. Action steps are built into the care plan and monitored through biweekly, and later monthly, telephone calls by either care manager.<sup>44, 87</sup> These action items are added continuously, and copies of the action plan are regularly mailed to patient-caregiver dyads.<sup>87</sup> Results from the PDC program showed a reduction in adverse outcomes and improvement in positive outcomes after six months, although some effects diminished at 12 months.<sup>86, 87</sup> A PMPM of \$60–\$80 would cover all expenses of a PDC-like program including salaries and benefits, training, equipment, software, supervision, and administrative overhead.<sup>86</sup> Since Medicare only covers the care and services provided through the physician's office and not the CBO, complementary reforms in other payment systems, such as Medicaid, would likely be required in conjunction with the addition or shift to a PMPM payment for physicians.

### **Other CBO-Partnership Models**

In other CBO-partnership models, providers' offices work directly with CBOs to avoid duplicating efforts between the two organizations while making sure key aspects of the collaborative care management model are provided.<sup>88, 89</sup> In one example, a case manager from either the health care organization or the CBO works with patient-caregiver dyads to conduct home assessments and develop a care plan emphasizing improvement in patient-specific problem areas.<sup>89</sup> The care manager helps facilitate referrals to CBOs through an electronic system, allowing the CBOs to access the assessment and care plan.<sup>89</sup> This version of the disease management model improved the health-related quality of life for dementia patients and almost doubled the rate of adherence to dementia care guidelines.<sup>89</sup>

Another example linked the local Alzheimer's Association chapter with the PCP using a care manager at the CBO.<sup>88</sup> In this framework, the care manager provides caregiver support through telephone calls occurring biweekly, monthly, or every three months, which address specific patient problem areas.<sup>88</sup> These calls are also used to develop a patient-centric care plan, which is then faxed to the PCP upon completion.<sup>88</sup> Implementation of this alternative care model led to improvements in caregiver satisfaction and delays in long-term care placement.<sup>88</sup> In this alternative care model design, Medicare payments tied to appropriate quality metrics could provide incentives and support for the PCP to collaborate with the CBO-based care manager.

### **3.1.3 Transitional Care Models**

People with dementia are particularly vulnerable during transitions between care settings due to the progressive nature of their cognitive decline. For example, they may not be able to recall or carry out treatment plans or instructions following discharge from an inpatient setting. Alternative care models focused on transitional care aim to address these issues by ensuring safe movement from one care environment to another. This transition could include a patient's movement from their home to the hospital and back, their home to residential care, residential care to hospital, and/or the transition to end-of-life or palliative care.<sup>90-92</sup> The Transitional Care Model (TCM) was developed to focus on adults with complex chronic conditions and risk factors such as recent hospitalizations or comorbid conditions. While not explicitly developed for dementia patients, this alternative care model has been shown to be effective for patients with cognitive impairments.<sup>91</sup> A PMPM payment could support the additional

services provided in the TCM. A time-limited episode of care payment could also support this type of alternative care model or, alternatively, a capitated payment model could be used.

### **Transitional Care Model for Cognitively Impaired Elders Model**

In the TCM for Cognitively Impaired Elders, transitional care nurses (TCNs), who are available 12 hours a day, seven days a week, serve as care coordinators to help patients with caregivers transition after an acute episode has taken place.<sup>90, 91</sup> These nurses begin their care coordination when the patient is still in the hospital, meeting daily to assess the patient's health, analyze the goals of the patient-caregiver dyad and the treatment team, and coordinate discharge plans when needed.<sup>90</sup> TCNs also visit patients within 24 hours of hospital discharge to help develop an emergency plan in the event the TCN is unavailable.<sup>90</sup> As part of this program, TCNs work with the patient-caregiver dyad to develop a set of questions for their post-hospital PCP or specialty physician visits.<sup>90</sup> They also participate either in-person or over the phone during the initial visit to help with continuity of care.<sup>90</sup>

Throughout the patient's participation in the program, TCNs visit the home or specialty nursing facility once a week for the first month and bimonthly thereafter to help develop goals and identify areas of need.<sup>90</sup> TCNs are also available by telephone and contact patients at least once a week when in-person visits have not been scheduled.<sup>90</sup> Additionally, TCNs work with members of the specialty care team including specialty nurses, nutritionists, pharmacologists, and neurologists on an as-needed basis.<sup>90</sup> Using this TCM has improved quality and cost outcomes including reducing preventable hospital readmissions, improving health outcomes and patient satisfaction, and reducing the total costs of these patients in the health care system.<sup>91</sup> Currently, the Aetna Corporation and Independence Blue Cross are offering the TCM for Cognitively Impaired Elders model to enrollees.<sup>91</sup> However, results of these initiatives are unknown at this time.

### **Amedisys Care Transitions Initiative Model**

Amedisys—a private, for-profit company focused on home health and hospice care that patients can access via Medicare or private insurance plans—offers the TCM nationwide under their Care Transitions Initiative.<sup>93</sup> They have registered nurses who serve as care transition coordinators (CTCs) in the acute care facilities that the company supports.<sup>93, 94</sup> The CTC meets with patients in the hospital to begin planning the transition from the acute care facility, including facilitating an initial visit with the patient's PCP and an initial home visit by a home health nurse.<sup>93, 94</sup> The CTC uses a notebook tool entitled "Bridges to Healthy Living" to write down the patient's diagnosis and the CTC's name and contact information as well as to help schedule the first PCP appointment and first home visit.<sup>93, 94</sup> During home visits, the home health nurse helps patients manage their medication and care plan.<sup>93</sup> The Amedisys program has seen a reduction in the average readmission rate, in addition to an increase in patient and physician satisfaction.<sup>93</sup> Using this type of framework, the Amedisys model has the ability to work with all providers across different sites of service to help coordinate care, particularly in relation to care transitions.<sup>93</sup> Under home health coverage in traditional Medicare, Amedisys is given episode-based payments to provide all aspects of the time-limited care, including the care transitions initiative.<sup>95</sup>

## 3.2 Epilepsy

Several stakeholders mentioned that the majority of people with epilepsy currently see a PCP for the longitudinal management of their symptoms. However, these stakeholders emphasized neurologists play an important role in the initial diagnosis of the condition. They also suggested that a neurologist may need to take over the primary management of the patient if symptoms remain uncontrolled or worsen. Patients with epilepsy, depending on their medication regimen, also require therapeutic drug monitoring, occasional imaging, and functional evaluations to assess their ability to drive and need for further therapy, among other issues. These services can be conducted by several different types of specialists/clinicians. A neurologist working together with an internist or geriatrician, as well as a radiologist, can better coordinate frequency of labs, imaging, and clinical visits. In addition, elderly patients with epilepsy often require other specialists who manage other comorbidities such as heart disease. Coordinated care can better ensure that medication adherence and therapeutic goals are met while also hopefully improving the patient's experience and satisfaction with their care. Alternative care models in epilepsy work to support these coordination needs and encourage improved self-management.

### 3.2.1 Centers of Excellence Models

As with some other complex chronic neurological conditions, the collaborative care management model can be used to help improve care for people with epilepsy.<sup>96</sup> One complex care management model developed by the VA, Epilepsy Centers of Excellence (ECOE), acts as a hub to provide specialized diagnostics and care for local VA facilities.<sup>42</sup> ECOE focus on effective information flow between facilities and proper coordination of care.<sup>42</sup> Research is currently underway on the effectiveness of the ECOE model.<sup>42</sup> These types of management services and coordination of care could be supported using a PMPM payment either through an expanded chronic care management FFS code or a complex care management team. Alternatively, a partial or fully capitated payment could also be used to support this alternative care model.

### 3.2.2 Self-Management Models

Another alternative care model for patients with epilepsy uses a web-based intervention to improve self-management of the disease.<sup>97</sup> The Web Epilepsy Awareness Support and Education (WebEase) program includes three modules: medication, stress, and sleep management.<sup>97</sup> These modules all have five sub-modules, each of which contains an introductory assessment, a section focused on current behavior, and a goals and planning segment.<sup>97</sup> The information in the second sub-module sections differs depending on which program stage the person is in.<sup>97</sup> The WebEase program also uses a daily information log, MyLog, where patients can enter information about medications, seizures, stress, and sleep to view a text and graphic summary.<sup>97</sup> MyLog also helps integrate the information into the modules.<sup>97</sup> The program provides online discussion boards, fact sheets, quizzes, and online resources.<sup>97</sup> Analysis on WebEase found that patients felt it was a useful educational tool.<sup>98</sup> With WebEase, 59% of patients reported improvement in sleep quality, 41% reported better medication adherence, and 25% reported more effective stress management.<sup>98</sup> Overall, WebEase has been shown to help improve epilepsy self-management, adherence, sleep quality, and social support.<sup>98,99</sup> A self-management model could be sustained through a small PMPM payment to support education and provision of these tools.

### 3.3 Multiple Sclerosis

Due to the complex, progressive nature of MS, individuals with this disease may need assistance with care coordination. Therefore, alternative care models that support complex care management, including educating patients and caregivers about the disease and providing active tools to address problems, are particularly valuable. Additionally, one stakeholder noted that because MS care is constantly evolving, a neurologist or MS specialist should be the principal care provider rather than a PCP. This is different from the other conditions highlighted in this scan but similar to other illnesses in which a specialist serves as the primary coordinating physician for a patient (e.g., oncologists for patients undergoing new cancer treatment, gastroenterologists for patients with inflammatory bowel disease, and nephrologists for patients with renal failure).

#### 3.3.1 Centers of Excellence Models

One alternative care model for MS is the VA's MS Centers of Excellence (MSCoE). MSCoE works to provide integrated care for people with MS and serves as a hub for MS care, providing standards of care to regional VA sites.<sup>100</sup> The VA developed an MS Handbook, VHA handbook 1011.06, describing services required to care for people with MS and outlining a comprehensive care plan.<sup>100</sup> These services include "primary care, MS specialty care, rehabilitation, palliative care, respite care, home care, long-term care, mental healthcare, social work services, telehealth services, and access to disease-modifying and symptomatic pharmacological therapies."<sup>100</sup> In addition, the handbook suggests annual review of the current MS care plan.<sup>100</sup> As with the centers of excellence discussed for epilepsy, an MSCoE could be supported through some type of PMPM payment or through a capitated payment.

#### 3.3.2 Self-Management Models

Stakeholders suggested that one of the primary care challenges in MS stems from the complicated drug regimen that may be required to manage the disease effectively. Therefore, alternative care models that provide decision support tools for physicians to determine the optimum drug regimen while avoiding unnecessary costs are useful. Some disease therapy management programs help to address this issue by combining symptom management and healthy lifestyle promotion with drug management.<sup>101</sup> In one program, a clinician-developed care plan—which included medication specifics and MS management skills—was made available to both the provider and the patient. Patients also were given telephone consultations followed up by mailed care plans and educational materials.<sup>101</sup> The frequency of telephone consultations depended on patient need, which was determined through a biopsychosocial assessment.<sup>101</sup> Emphasizing patient education and medication management led to overall improvements in medication adherence.<sup>101, 102</sup> Other care management programs have also shown improvement in medication adherence as well as a reduction in hospitalizations and overall health costs due to MS.<sup>103</sup> Self-management models could be supported through a PMPM payment.

#### 3.3.3 Telemedicine Models

Lastly, telemedicine can be used in these integrated care models to help screen for symptoms, educate patients about the disease, and monitor patients' fitness level.<sup>104</sup> In one telemedicine model, an automated program running through a personal computer inquired about the patient's condition and provided detailed exercise instructions.<sup>104</sup> This program also quizzed the patient about his or her MS knowledge.<sup>104</sup> This telemedicine system provided a phone-based safety net for patients to call for MS-

related questions and emergencies.<sup>105</sup> The program was associated with a decrease in symptom severity and a one-third reduction in medical costs in 67% of patients.<sup>105</sup> Additionally, patients reported satisfaction with the telemedicine services that provided extra support.<sup>105</sup> This type of intervention could be sustained through a PMPM tied to shared savings or through capitated payments.

### 3.4 Other Neurological Conditions

In addition to dementia, MS, and epilepsy, other complex chronic neurological conditions may lend themselves to some alternative care models described above. Stakeholders suggested that TBI may have some potential for alternative care models that promote effective chronic care management. However, few TBI alternative care models exist that are explicitly relevant for the Medicare population. One research study did show that using a goal-oriented approach can improve treatment by providing structure and helping patients overcome barriers such as motivation reduction and impaired self-awareness.<sup>106</sup>

Chronic complex headache was another condition the stakeholders suggested as a candidate for alternative care models. Unfortunately, few such models exist in the U.S. for this specific neurological condition, although some sources suggest using the collaborative case management model to improve care.<sup>107</sup> While not based in the U.S., the Multidisciplinary Day Clinic Treatment (MPT) program, through the West German Headache Center, has shown promising results in reducing the frequency of headaches.<sup>41</sup> Through the MPT, patients receive care from a multidisciplinary team that includes “neurologists, behavioral psychologists, physical and sports therapists, headache nurses and consultants from psychosomatic medicine, psychiatry and dentistry if needed.”<sup>41</sup> The MPT program focuses on providing education about headache symptoms, etiology, and the pathophysiology, efficacy, and potential adverse effects of treatments.<sup>41</sup> Further, research suggests that tools that assess migraines can improve physician-patient communication and improve understanding of the condition.<sup>107, 108</sup> This type of collaborative case management could be provided through a practice/health system-based model where the collaborative case management team is supported through a PMPM payment or a partially or fully capitated payment.

## 4. Promising and Potential Payment Models

Many stakeholders view the current FFS payment model as a barrier to effective care management for the complexities of chronic neurological conditions.<sup>109</sup> Several important components of the complex care management models described in Section 3, such as the use of care managers, are not reimbursed in the current FFS system. Further, many services provided by these complex care management models are not easily broken down into discrete services that could be individually billed to FFS, and even when the services are separated out, they are often not reimbursable under the current FFS policies.<sup>109</sup> APMs aim to address this issue by supporting care reforms that promote coordinated care and appropriate access to an expanded range of services; together, these changes in care can potentially improve patient outcomes and reduce medical costs.

While there is considerable evidence that such comprehensive approaches to care can achieve better results for patients with complex chronic neurological conditions, neither stakeholder interviews nor the

literature review uncovered past or present neurology-specific APMs. One stakeholder noted that much of the foundational research for current alternative care models focused on demonstrating improved care rather than economic sustainability. Consequently, most current alternative care models rely on philanthropy and/or time-limited grants, including several CMMI Health Care Innovation Awards. This approach fails to address the long-term sustainability and widespread application of these alternative care models.

Some alternative care models supported through CMMI awards could be supported through APMs, such as a PMPM payment with an annual, tiered bonus tied to quality performance measures.<sup>67</sup> However, such APMs have yet to be implemented. The reforms implemented to date with research or other funding could provide needed evidence on the potential implementation costs and net savings of alternative care models related to the field of neurology, and how they may fit into current and future APMs. To ensure long-term sustainability, and ultimately savings for Medicare, these APMs are likely to require a significant shift to more case or episode-based payments.

While no current neurology-specific examples have been put into practice, alternative care models for other complex conditions have been supported through APMs, including those for patients with chronic conditions and multiple comorbidities. For example, one stakeholder described a Medicare Advantage program for beneficiaries with diabetes. Another example, the Vermont Blueprint for Health, utilizes a PMPM payment and was originally designed for patients with chronic conditions, although it has since been expanded.<sup>110</sup> The Blue Cross Blue Shield of Michigan's Physician Group Incentive Program gives physicians associated with designated medical homes a 10% increase in their FFS payments, along with a bonus based on quality measures.<sup>111</sup> The Program of All-Inclusive Care for the Elderly (PACE), supported through comprehensive capitated payments, is yet another example.<sup>112</sup>

APMs similar to these could be applied to support improved care for the complex chronic neurological conditions discussed in this scan. However, some specific features of neurological conditions should be addressed. For example, alternative care models for dementia have shown that providing education and support to patients *and* their caregivers is effective in improving the overall quality and health of patients. However, stakeholders repeatedly emphasized the difficulty in supporting caregivers within Medicare's existing FFS system. In addition, some stakeholders pointed out that patients with neurological conditions often require other services such as physical and occupational therapy, speech language pathology, and vocational rehabilitation. Although few of the alternative care models addressed these additional needs, they are important aspects of complex chronic neurological care and should be addressed in an APM.

Despite these challenges, APMs that have been applied for other complex populations could potentially be adapted for Medicare beneficiaries with complex chronic neurological conditions. In these APMs, neurologists would work together with other providers to improve care of beneficiaries with these conditions. Therefore, APMs need to address this collaborative effort. The following potential APMs—PMPM payment, episode-based payment, and capitated payment—illustrate some of these opportunities and challenges. While not currently in place, these payment models could be used to support the types of alternative care models discussed in Section 3. As some of these APMs are

population-based (e.g., patient-centered medical homes), they should refrain from exclusively focusing on beneficiaries with only complex chronic neurological conditions, since other comorbid conditions common in these beneficiaries could also benefit from these reforms.

## **4.1 Per-Member, Per-Month Payment**

A PMPM payment is a flat payment given each month to a provider or group of providers to cover a set range of services offered to beneficiaries. A PMPM payment could be given as part of an expanded chronic care management (CCM) code or to support a complex care management team. The expanded CCM code would be given directly to providers who participate in a beneficiary's chronic care management. Alternatively, the PMPM to support the complex care management team would be given to a multidisciplinary group of providers who offer expanded services to beneficiaries with complex chronic neurological conditions.

### **4.1.1 Chronic Care Management Fee-for-Service Payment**

Improving care management, including communication and coordination between providers, is one of the primary needs in reforming care for complex chronic neurological conditions. Due to the wide range of services required for these conditions, patients may receive care from several providers including neurologists, PCPs, radiologists, acute care physicians, and post-acute care providers. One potential payment mechanism to improve case management and communication/coordination between these providers is a new or modified code. CMS already developed a code that will go into effect in 2015, aimed at "primary care and chronic care management" for the care of beneficiaries who have two or more chronic conditions.<sup>113</sup> This code will have a payment amount of \$41.92 and can be billed each month by the provider managing the beneficiary's care to support care plan development, medication management, and coordination between providers.<sup>113</sup> However, only one provider can be reimbursed for each beneficiary, even though effective care coordination will require reciprocal activities by a patient's other providers.

The CCM code could be expanded to include additional key providers, rather than only a single provider, participating in the enhanced management of these complex beneficiaries. The services covered by the expanded CCM code could remain the same as the code set to go into effect in 2015, but the providers could each receive reinforcing payments. In addition, stakeholders, including those who represent patients, continually emphasized the need for better communication with patient caregivers, yet noted that no mechanism exists within Medicare billing to attribute or acknowledge these caregivers in the care process. To address this, a monthly, flat payment through the expanded CCM code could have the explicit expectation of such communication and potentially include a mechanism to identify, and thus attribute, caregivers. Including this component would also provide data about the level of caregiver involvement and their effects on patient/beneficiary-centered outcomes. Finally, a CCM code could be considered to cover care for beneficiaries with only one complex chronic condition, such as one of the neurological conditions identified in this scan. Although comorbid conditions are common among complex chronic neurological patients, beneficiaries with only a single neurological condition could still benefit from enhanced chronic care management.<sup>9</sup>

As discussed briefly in Section 3, an elderly patient with epilepsy is one example of when an expanded CCM code could be useful. An expanded CCM code could support improved coordination among the multiple providers involved in the care of an epileptic beneficiary. The hope is that by providing incentives for care management and coordination between providers, beneficiary experience and satisfaction with care will improve, and in turn, the improved coordination and outcomes will reduce costs through fewer unnecessary or duplicative services and preventable complications.

This type of expanded CCM code could also be particularly useful when patients experience transitions in care, either in site of service or among providers. Although PCPs are often the long-term providers for these patients, neurologists and other specialty care physicians play an important role in the initial diagnosis and overall care management of these conditions, particularly when the severity of the condition worsens. For example, one stakeholder explained that beneficiaries should be referred to a neurologist if/when they experience a re-emergence of seizures or medication complication. If the neurologist can adequately address the issue(s), the patient can subsequently be referred back to the PCP for long-term management. The stakeholder noted that communication between physicians is critical, but often lacking, during these transitions in care. An expanded CCM code that reimburses both the PCP and the neurologist would help incentivize both providers to be adequately involved in this critical component of care. This type of payment may also be relevant for post-acute care to promote better communication and care coordination for beneficiaries receiving services over time, from several types of health professionals, across multiple sites of service.

One major benefit of an expanded CCM code is that it is both administratively straightforward and could be used by providers that have undertaken very little practice transformation, so it is highly feasible for all practice types, large and small. However, while easier to implement, adding/expanding the CCM code does not represent a significant shift away from the FFS system. In addition, although this code would help support more coordinated care, it does not provide strong pressure or financial support for the more fundamental care transformations included in many promising alternative care models for patients with complex chronic neurological conditions described in Section 3. Thus, this APM may not adequately support the intricacies of care required by many beneficiaries with these conditions, and it may result in higher overall costs for the Medicare program without commensurate improvements in outcomes for complex neurological patients.

#### **4.1.2 Complex Care Management Team Payment**

Many alternative care models identified through the literature review and stakeholder interviews utilize complex care management teams that could be supported through a PMPM payment. These teams could include a variety of providers such as PCPs, neurologists, pharmacists, social workers, and care managers, as well as other health professionals and support staff. In this APM, the monthly payment would support the care team, who would work together to offer comprehensive care to a designated population of individuals. The PMPM could be an add-on to traditional FFS payments or could replace some portion of the current FFS schedule. The latter approach would be more likely to avoid higher overall costs up front, but would likely make it more difficult for providers to make the investments needed to set up effective care teams. An alternative is to transition from an add-on payment by

replacing some or all of the FFS payments or rate increases. In any of these APMs, the PMPM would be used to support the expanded services described in Section 3, as well as the associated staffing.

The flat monthly fee would be given to a group of eligible Medicare providers who have formed a comprehensive complex care management team. This APM would be a significant step beyond the expanded CCM code as it would require a more substantial complex care management approach as well as an expanded set of services, both of which should improve beneficiary care. One stakeholder stressed that the specific team members participating in each beneficiary's care should not be predetermined by the payment model since the number and types of providers required may differ depending on the beneficiary's needs. Instead, payments could be tied to specific key features of an effective complex care management program, which may include regular patient contact, implementation of a joint care plan, medication management, caregiver education and support, availability of emergency appointments, and 24-hour telephone assistance. Additionally, the PMPM payment should be tied to quality outcome measures, like complication rates, in addition to patient and caregiver experience. More research is required to determine how to best incorporate patient and/or caregiver-level measures into an APM since such measures can be exceedingly complicated to track.

Many expanded services provided in the care management models, such as care coordination, decision support tools, and caregiver support, could be integrated into the complex care management team model. The primary counseling and education components of the caregiver interventions could be delivered when beneficiaries are introduced to the program. The follow-up services, such as telephone support and regular check-ins, properly align with the core components of this APM. Although a CMMI grant will initially support the Care Ecosystems model, the grant application suggestion of the future use of a \$131 PMPM to cover the program costs is a good illustration of this type of payment structure. Alternatively, the less robust PDC model suggests that a smaller PMPM fee of \$60–\$80 could cover all program costs.

A patient-centered medical home (PCMH) is one example of an intensive, comprehensive complex care management team. To be awarded full PCMH status for complex patients, the complex care management team must provide a specific set of expanded services including extended clinic hours, availability of emergency appointments, and on-call staff as well as other traditionally non-billable services.<sup>114</sup> PCMHs have already been developed for patients treated by PCPs without complex conditions, and the model has been suggested for neurological care.<sup>115</sup> To properly manage a complex chronic neurological condition, the PCMH would require a multidisciplinary team that includes a neurologist, either as a principal physician or as a well-integrated specialist resource for shared patient management or consultation.<sup>115</sup> Less intensive complex care management teams without official PCMH designation may offer some, but not all, of the expanded services found in a PCMH. One stakeholder explained that a more comprehensive, official PCMH (presumably with a larger PMPM payment) could be appropriate for patients who require a particularly high level of complex care management, such as those with diminished cognitive and/or functional capacity and those with multiple comorbidities. On the other hand, patients who need less intensive care could be managed by a less robust complex care management team, which could include just a PCP and a neurologist.

Although not specific to neurological care, this type of APM has been successfully used to support alternative care models for high-cost, complex, chronic conditions. The Health Buddy Consortium's (HBC) Care Management for High Cost Beneficiaries (CMHCB), one of Medicare's six demonstration projects, provided care management to the highest-cost Medicare beneficiaries with an associated PMPM between \$120 and \$130.<sup>116, 117</sup> Using a Health Buddy device or telephone calls, beneficiaries in the HBC CMHCB routinely relayed information to program staff about vital signs, symptoms, health-related behaviors, and disease knowledge.<sup>117</sup> They were also given corresponding education on how these areas applied to their condition(s).<sup>117</sup> Results from this study showed improved medication compliance and a potential reduction in hospital admissions.<sup>116, 117</sup> Different cost analyses of the program have produced different results, although all show large enough cost decreases to meet the set program threshold of a 5% reduction.<sup>116-118</sup> Although not statistically significant, CMS's evaluation shows a reduction in costs between 6.0%–8.1%, with potential savings of \$0.12–\$0.20 for every dollar that Medicare spends.<sup>117</sup> In addition, an independent analysis found a statistically significant 7.7%–13.3% decrease in spending from the program over two years.<sup>118</sup>

The Vermont Blueprint for Health is another relevant example of this type of APM. The program is a public-private initiative that includes all major commercial insurers, Medicaid, and Medicare.<sup>119</sup> The APM was initially developed to address chronic care for conditions like congestive heart failure, coronary artery disease, chronic obstructive pulmonary disease, and diabetes but now has been expanded statewide to support the general population.<sup>110, 119</sup> In this APM, advanced primary care practices act as PCMHs and are connected to the public through community health teams, which provide many of the expanded services described in Section 3.<sup>110</sup> Health information technology also supports the program by facilitating information sharing between providers.<sup>110</sup> Importantly, by providing a regional approach for these services, the Blueprint for Health demonstrates how small and rural provider practices can fit into this type of APM.<sup>109</sup> In addition to the FFS schedule, the medical homes receive a PMPM ranging from \$1.20–\$2.39, depending on the score the medical home achieves on the National Committee for Quality Assurance (NCQA) PCMH criteria.<sup>110, 119</sup> Results from the pilot version of the Blueprint program showed significant reductions in hospital admissions and ED visits, with a corresponding respective reduction in costs per person per month of 36% and 11.6%.<sup>110</sup> In 2012, medical homes and community health teams received an average PMPM of \$2.00 and \$1.50, respectively.<sup>119</sup> These costs were more than offset by the one-year savings generated through the program, with a gain to cost ratio (total saved divided by total invested) of 8.2 for Medicaid (excluding Special Medicaid Services) and 15.8 commercial insurers.<sup>119</sup>

Other types of payment structures could be combined with the PMPM fee to further incentivize high-quality, coordinated care. A pay-for-performance (P4P) bonus payment could be used to reward high performance standards or the adoption of certain expanded services. A P4P component is very data-intensive and requires valid measures to assess performance level. Additionally, or as an alternative to P4P payments, savings garnered from improved care could be shared with the complex care management team. Results for alternative care models have demonstrated that overall health costs can indeed be reduced. This dynamic could involve one-sided or two-sided risk: one-sided risk models allow provider groups to share in savings without consequence if costs increase beyond the targeted

threshold; two-sided risk models similarly allow providers to share in savings if costs decrease, but also hold them financially responsible if costs increase beyond the threshold. The overall health costs for patients participating in these types of programs would be expected to decrease since aspects of care provided through the complex care management team model are expected to reduce use of acute health services, prevent exacerbation of health issues, and potentially delay placement in long-term care facilities. Importantly, a robust quality monitoring program would need to be implemented to ensure that any savings are the result of improved care and not simply fewer, or lower-quality, services.<sup>109, 110,</sup>  
<sup>120</sup> Involving more than one specialty in an explicit APM and aligning quality measures that depend on better coordination among specialists creates a greater opportunity for aligning the needs of beneficiaries and their families. Such models of increasing accountability for quality and costs could also be phased in over time.

While potentially effective, an APM used to support a complex care management approach could face a number of implementation challenges. To start, a high level of practice transformation may be required to provide the expanded services necessary to qualify for the additional payment. Consequently, this APM is likely to be less feasible for many practices, particularly those that serve a small patient population or are located in a rural setting. However, as demonstrated in the Vermont Blueprint for Health, small practices can pool resources and work as partners to jointly provide the required expanded services of the APM. Rural practices could also expand the variety of telephone-based patient interactions that are already a part of many alternative care models for complex chronic neurological conditions. Another challenge is that the level of care required for beneficiaries with these neurologic conditions may require an APM that is too high to be offset by savings from more effective care. However, this type of APM has been successfully used for other chronic conditions requiring a similar level of care.<sup>110, 117</sup> Moreover, it could be implemented with a transition away from FFS payments through a shared savings or a reduction/freeze in the FFS payment rates. Overall, a PMPM payment supporting a complex care management team would help shift away from the traditional FFS payment model to encourage the provision of necessary services and high-quality care that these complex chronic beneficiaries require.

### 4.3 Episode of Care Payment

CMMI recently initiated the Bundled Payments for Care Improvement Initiative (BPCI), piloting inpatient bundled payments for 48 different episodes of care, including stroke.<sup>11</sup> An episode-based APM could also be used outside of the inpatient setting for other complex chronic neurological conditions, including specific interventions in MS and epilepsy. In this type of payment, specified services are provided during a defined episode of care, either time- or procedure-based, and are reimbursed through a lump-sum, global payment. For the chronic management of complex neurologic patients, such bundled payments could begin to replace some or all types of PMPM payments directed at multidisciplinary care teams described in Section 4.1.2. While the same challenges would apply, such a long-term bundled payment approach would have the advantage of encouraging broader care coordination, and would be even closer to the capitated payment reform described in Section 4.4.

Several stakeholders suggested that major acute intervention is the most feasible area of care for which to begin implementing procedure-based bundled payments for patients with certain chronic neurologic conditions. In particular, stakeholders explained that a procedure-based bundled payment could be useful for surgical epilepsy interventions, which have a defined trigger- and end-point of care. This payment would cover all services included in the pre-procedure appointments and during the procedure and post-procedure visits, including post-acute care. Alternatively, some stakeholders described an episode-based payment centered on the initial diagnosis and treatment of these complex chronic neurological conditions. The episode of care could include any tests required for the initial diagnosis and the first round of treatments, including some or all necessary drugs and other therapies. Finally, an episode of care payment could be used to cover all the services needed to address a relapse episode for beneficiaries with Relapsing Remitting MS.

An episode-based payment succeeds in shifting away from the current FFS system, providing significantly more support for coordination and stronger incentives for efficient, team-based care. Unfortunately, many complex neurological conditions do not contain discrete interventions or care treatments that could be easily separated out into a procedure-based episode of care. The chronic nature of these conditions also makes time-based episodes difficult to define. Moreover, tying large payments to procedures may encourage more volume rather than focusing on the prevention of the complications that lead to these procedures. Therefore, although this model may be useful for some smaller, easily defined episodes, it is likely not applicable to a large proportion of the care needed for beneficiaries with complex chronic neurological conditions.

#### 4.4 Capitated Payment Model

Lastly, a capitated payment model is a more intensive version of an episode-based payment that works to provide and coordinate *all* aspects of care for a patient population. In this APM, providers are given a global, lump-sum payment to cover the entirety of a patient's care over a given time period (e.g., one year). Due to the comprehensive nature of a capitated payment, this APM allows providers more freedom to incorporate the alternative services described in Section 3 to improve outcomes and reduce their total cost of care. Similar to other APMs, robust quality measures would need to be paired with a capitated payment to ensure that adequate care was being provided to beneficiaries.

Accountable Care Organizations (ACOs) are one form of this type of payment structure. In an ACO, a provider group takes on some responsibility for the health of a defined patient population, which may include beneficiaries with complex chronic neurological conditions. Around 24% of neurologists presently report that they are associated with an ACO.<sup>40</sup> Many care management models discussed in this scan could be integrated into existing ACO programs. In fact, many ACOs currently use complex care management to help improve care and reduce the cost of their patients with complex chronic conditions.<sup>120</sup>

Today, most ACOs rely on shared savings or limited forms of partial capitation. More complete capitation APMs exist in Medicare Advantage (MA) contracts (including MA Special Needs Plans that target beneficiaries with complex conditions), Medicaid managed care plans, and programs such as PACE. Such plans may be formed around integrated health systems such as Kaiser Permanente or they

may be managed by private payers. Several stakeholders indicated that MA plans are effective in providing complex chronic care. Through MA, Medicare pays private insurance companies a flat fee to provide, at minimum, the services a beneficiary would receive under original Medicare.<sup>121</sup> This flat fee allows private organizations to invest in expanded services, such as those described in Section 3, to reduce long-term health costs. For example, CareMore, an MA organization, provides care managers and specialist intensive services to frail and chronically ill beneficiaries. One stakeholder associated with CareMore described their Brain Health Dementia Program, which provides complex care management that includes after-hours care, robust palliative care, and, depending on the severity of the condition, enhanced home-based care. The stakeholder explained that the extra up-front costs of providing these services are recouped through the improved long-term health of the patient population, making capitation a sustainable payment model for supporting well-coordinated care.

Blue Cross Blue Shield of Massachusetts (BCBSMA) also provides an example of a capitated model. Although not specifically for neurological conditions, the BCBSMA model has implemented the Alternative Quality Contract (AQC) for provider organizations in their network. These providers receive an annual global payment from BCBSMA to cover all costs and services of treating their BCBSMA-attributed patients.<sup>122</sup> Additionally, providers can receive a 10% performance-based bonus by meeting certain specified quality measures.<sup>122</sup> This type of APM structure, with associated quality measures to address specific needs of this population, could be used for patients with complex chronic neurological conditions.

A capitated payment model is the most comprehensive shift away from the current FFS payment model. This type of APM could be beneficial for complex chronic neurological patients because it encourages providers to improve care coordination and offer the expanded services that improve patient outcomes and control overall costs. By placing the responsibility and financial risk of providing all care for a patient population on a group of providers, a capitated payment model creates strong incentives for the care services described in Section 3, which have been shown to lower resource utilization and corresponding costs. One payer for an MA program noted that the collaborative care management programs they provide for complex chronic conditions had drastically reduced costs with high levels of patient satisfaction. As with the other APMs, integrating relevant quality metrics into a capitated system is vital to ensure that lower costs are not being achieved through lower-quality care. Many stakeholders noted that this type of comprehensive, capitated payment model best allows providers to implement the services required for complex chronic neurological care. However, capitation's high level of migration away from the current FFS payment system makes such a model difficult to implement.

## 5. Quality Measures

Although quality measures are not a required component of any payment system design, they are useful in payment models for ensuring that alternative care models provide high-quality, efficient care. This is especially true when aspects of the APM could incentivize under-utilization or “scrimping” of services, such as with shared savings or capitated models. Quality measures have several different policy applications including public reporting, P4P, and pay-for-reporting. Some measures, such as those associated with patient experience and care transitions, cut across all conditions addressed in this scan.

Table 1 outlines measures relevant to all neurological conditions including patient satisfaction measures, care coordination measures, and functional outcome measures. National Quality Forum (NQF) measures are included where relevant.

**Table 1. Quality Measures Relevant to All Neurological Conditions**

#	Measure Title	Measure Description
<b>Patient Satisfaction Measures</b>		
1	Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Clinician/ Group Surveys – (Adult Primary Care, Pediatric Care, and Specialist Care Surveys) (NQF #0005)	A specialist care survey with 37 core and 20 supplemental questions of adult outpatient specialist care patients. The level of analysis for each of the three surveys covers group practices, sites of care, and/or individual clinicians.
2	CAHPS® Home Health Care Survey, also referred as the “CAHPS Home Health Care Survey” or “Home Health CAHPS”(NQF #0517)	A standardized survey instrument and data collection methodology for measuring home health patients’ perspectives on their home health care in Medicare-certified home health care agencies. The survey was developed to measure the experiences of those receiving home health care with these three goals in mind: (1) to produce comparable data on patients’ perspectives on care that allow objective and meaningful comparisons between home health agencies on domains that are important to consumers, (2) to create incentives for agencies to improve their quality of care through public reporting of survey results, and (3) to enhance public accountability in health care by increasing the transparency of the quality of care provided in return for public investment.
3	CAHPS® Nursing Home Survey: Family Member Instrument (NQF #0693)	A mail survey instrument to gather information on the experiences of family members of long-stay (greater than 100 days) residents currently in nursing homes. CMS requested development of this questionnaire, which is intended to complement the CAHPS Nursing Home Survey: Long-Stay Resident Instrument and the Discharged Resident Instrument. The Family Member Instrument asks respondents to report on their own experiences (not the resident’s) with the nursing home and their perceptions of the quality of care provided to a family member living in a nursing home. The survey instrument provides nursing home scores on four topics valued by patients and families: (1) Meeting Basic Needs: Help with Eating, Drinking, and Toileting, (2) Nurses/Aides’ Kindness/ Respect Towards Resident, (3) Nursing Home Provides Information/Encourages Respondent Involvement, and (4) Nursing Home Staffing, Care of Belongings, and Cleanliness. In addition, the survey provides nursing home scores on three global items including an overall Rating of Care.
4	CAHPS® Nursing Home Survey: Long-Stay Resident Instrument (NQF #0692)	An in-person survey instrument to gather information on the experience of long-stay (greater than 100 days) residents currently in nursing homes. The survey instrument provides nursing home scores on five topics valued by residents: (1) Environment, (2) Care, (3) Communication & Respect, (4) Autonomy, and (5) Activities. In addition, the survey provides nursing home-level scores on three global items.

#	Measure Title	Measure Description
<b>Care Coordination Measures</b>		
1	Risk-standardized All Condition Readmission (NQF #1789)	Estimate of the hospital-level, risk-standardized readmission rate (RSRR) of unplanned, all-cause readmission after admission for any eligible condition within 30 days of hospital discharge for patients age 18 and older. The measure reports a single summary RSRR derived from the volume-weighted results of five different models, one for each of the following specialty cohorts (groups of discharge condition categories or procedure categories): surgery/gynecology, general medicine, cardiorespiratory, cardiovascular, and neurology. The measure also indicates the hospital standardized risk ratios (SRR) for each of these five specialty cohorts.
2	Percent of Primary Care Physicians Who Successfully Qualify for an Electronic Health Record (EHR) Program Incentive Payment	Percentage of PCPs who successfully qualify for either a Medicare or EHR Program incentive payment
3	Medication Reconciliation (NQF #0097)	Percentage of patients age 18 years and older discharged from any inpatient facility (e.g., hospital, skilled nursing facility, or rehabilitation facility) and seen within 30 days of discharge in the office by the physician, prescribing practitioner, registered nurse, or clinical pharmacist who had reconciliation of the discharge medications with the current medication list in the outpatient medical record documented. This measure is reported as two rates stratified by age group: 18–64 and 65+.
4	Falls: Screening for Future Fall Risk (NQF #0101)	This is a clinical process measure that assesses fall prevention in older adults. The measure has three rates:  Screening for Future Fall Risk: Percentage of patients age 65 years and older who were screened for future fall risk at least once within 12 months  Falls: Risk Assessment: Percentage of patients age 65 years and older with a history of falls who had a risk assessment for falls completed within 12 months  Plan of Care for Falls: Percentage of patients age 65 years and older with a history of falls who had a plan of care for falls documented within 12 months
<b>Functional Outcome Measures</b>		
1	Change in Basic Mobility as Measured by the Activity Measure for Post-Acute Care (AM-PAC) (NQF #0429)	The proportion of a clinician's patients in a particular risk-adjusted diagnostic category who meet a target threshold of improvement in basic mobility functioning compared to all patients in a risk-adjusted diagnostic category with a mobility goal for an episode of care. Cases to be included in the denominator could be identified based on ICD-9 codes or alternatively, based on CPT codes relevant to treatment goals focused on basic mobility function.
2	Change in Daily Activity Function as Measured by the AM-PAC (NQF #0430)	The proportion of a clinician's patients in a particular risk-adjusted diagnostic category who meet a target threshold of improvement in daily activity (i.e., Activities of Daily Living (ADL) and Instrumental ADL) functioning compared to all patients in a risk-adjusted diagnostic category with a daily activity goal for an episode of care. Cases to be included in the denominator could be identified based on ICD-9 codes or alternatively, based on CPT codes relevant to treatment goals focused on daily activity function.
3	Depression Remission at Six Months (NQF #0711)	Adult patients age 18 and older with major depression or dysthymia and an initial Patient Health Questionnaire (PHQ)-9 score > 9 who demonstrate remission at six months defined as a PHQ-9 score less than 5. This measure applies to both patients with newly diagnosed and existing depression whose current PHQ-9 score indicates a need for treatment.

#	Measure Title	Measure Description
4	Depression Remission at Twelve Months (NQF #0710)	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate remission at twelve months defined as a PHQ-9 score less than 5. This measure applies to both patients with newly diagnosed and existing depression whose current PHQ-9 score indicates a need for treatment.
5	Depression Response at Six Months – Progress Towards Remission (NQF #1884)	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate a response to treatment at six months defined as a PHQ-9 score that is reduced by 50% or greater from the initial PHQ-9 score. This measure applies to both patients with newly diagnosed and existing depression identified during the defined measurement period whose current PHQ-9 score indicates a need for treatment.
6	Depression Response at Twelve Months – Progress Towards Remission (NQF #1885)	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate a response to treatment at twelve months defined as a PHQ-9 score that is reduced by 50% or greater from the initial PHQ-9 score. This measure applies to both patients with newly diagnosed and existing depression identified during the defined measurement period whose current PHQ-9 score indicates a need for treatment.
7	Hip Fracture Mortality Rate (IQI 19) (NQF #0354)	In-hospital deaths per 1,000 hospital discharges with hip fracture as a principal diagnosis for patients age 65 years and older. Excludes periprosthetic fracture discharges, obstetric discharges, and transfers to another hospital.
8	Improvement in Ambulation/ Locomotion (NQF #0167)	Percentage of home health episodes of care during which the patient improved in ability to ambulate.
9	Improvement in Bathing (NQF #0174)	Percentage of home health episodes of care during which the patient got better at bathing self.
10	Improvement in Bed Transferring (NQF #0175)	Percentage of home health episodes of care during which the patient improved in ability to get in and out of bed.
11	Improvement in Pain Interfering with Activity (NQF #0177)	Percentage of home health episodes of care during which the frequency of the patient’s pain when moving around improved.

Source: NQF. NQF-Endorsed Measures. National Quality Forum, 2014.

## 5.1 Dementia

As part of the ACOVE project, the RAND Corporation developed a list of quality indicators for dementia care of vulnerable elders.<sup>123</sup> Additionally, an interdisciplinary Dementia Measures Work Group (DWG) developed a list of ten measures that have been adopted by the American Association of Neurology (AAN).<sup>124</sup> The DWG was led by the AAN, the American Geriatrics Society, the American Medical Directors Association, the American Psychiatric Association, and the American Medical Association (AMA).<sup>124</sup> Although there are many similarities between the two lists, the ACOVE measures include some measures not recommended by the DWG such as medication review and adjustment, laboratory and HIV testing, cholinesterase inhibitor use, and the use of stroke prophylaxis.<sup>123</sup> Additionally, the DWG measurement set is relevant for all stages of dementia, suggesting annual reassessments and including measures for palliative care.<sup>124</sup> Table 2 shows the measures adopted by the AAN that have been selected for the Physician Quality Reporting System (PQRS) Measures list, with the exception of the ninth measure. Table 3 shows the National Quality Forum (NQF) measures for dementia.

**Table 2. Dementia Measures Work Group Measures Approved by the AAN**

#	Measure	Description
1	Staging of dementia (PQRS #280)	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 year period
2	Cognitive assessment (PQRS #281)	Patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results are reviewed at least once within a year period
3	Functional status assessment (PQRS #282)	Patients, regardless of age, with a diagnosis of dementia for whom an assessment of functional status is performed and the results are reviewed at least once within a year period
4	Neuropsychiatric symptom assessment (PQRS #283)	Patients, regardless of age, with a diagnosis of dementia for whom an assessment of neuropsychiatric symptoms is performed and the results are reviewed at least once within a year period
5	Management of neuropsychiatric symptoms (PQRS #284)	Patients, regardless of age, with a diagnosis of dementia who have one or more neuropsychiatric symptoms who receive/were recommended to receive an intervention for symptoms within a year period
6	Screening for depressive symptoms (PQRS #285)	Patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a year period
7	Counseling regarding safety concerns (PQRS #286)	Patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who were counseled or referred for counseling regarding safety concerns within a year period
8	Counseling regarding risks of driving (PQRS #287)	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 year period
9	Palliative care counseling and advanced care planning	Patients, regardless of age, with a diagnosis of dementia or their caregiver(s), who received comprehensive counseling regarding ongoing palliation and symptom management and end-of-life decisions AND have an advance care plan or surrogate decision-maker in the medical record or documentation on the medical record that the patient did not or was not able to name a surrogate decision-maker or provide an advance care plan within 2 years of initial diagnosis of assumption of care
10	Caregiver education and support (PQRS #288)	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 were referred to additional resources for support within a year period

Source: Odenheimer, G., et al. (2014). "Quality improvement in neurology: dementia management quality measures." *J Am Geriatr Soc* 62(3): 558-561.

**Table 3. Dementia Measures Approved by the National Quality Forum**

#	Measure	Description
1	Antipsychotic use in persons with dementia (#2111)	The percentage of individuals 65 years of age and older with dementia who are receiving an antipsychotic medication without evidence of a psychotic disorder or related condition.

#	Measure	Description
2	CARE – Consumer assessments and reports at end of life (#1632)	A mortality follow-back survey administered to the bereaved family members of adult persons (age 18 and older) who died of a chronic progressive illness receiving services for at least 48 hours from a home health agency, nursing home, hospice, or acute care hospital. The survey measures perceptions of the quality of care either in terms of unmet needs, family reports of concerns with the quality of care, and overall rating of the quality of care. The time frame is the last 2 days of life up to last week of life spent in a hospice, home health agency, hospital, or nursing home.
3	Persistent indicators of dementia without diagnosis – long stay (#2091)	Percentage of nursing home residents age 65+ with persistent indicators of dementia and no diagnosis of dementia.
4	Persistent indicators of dementia without a diagnosis – short stay (#2092)	Number of adult patients 65 and older who are included in the denominator (i.e., have persistent signs and symptoms of dementia) and who do not have a diagnosis of dementia on any Minimum Data Set (MDS) assessment.

Source: National Quality Forum, 2014.

## 5.2 Epilepsy

Research into quality measures for epilepsy treatment has led to the development of Quality Indicators for Epilepsy Treatment (QUIET) and a list of AAN-supported measures. Table 4 lists the AAN measures with any associated PQRS measure numbers. These measures are currently being updated by AAN.<sup>125</sup>

**Table 4. AAN List of Epilepsy Quality Measures**

#	Measure	Description
1	Seizure Type(s) and Current Seizure Frequency(ies) (PQRS #266)	Numerator: patient visits with seizure type(s) specified and current seizure frequency for each seizure type documented in the medical record. Denominator: all visits for patients with a diagnosis of epilepsy.
2	Documentation of Etiology of Epilepsy of Epilepsy Syndrome (PQRS #267)	Numerator: patient visits with etiology of epilepsy or with epilepsy syndrome(s) reviewed and documented if known, or documented as unknown or cryptogenic. Denominator: all visits for patients with a diagnosis of epilepsy.
3	Electroencephalogram (EEG) Results Reviewed, Requested, or Test Ordered	Numerator: patients who had the results of at least one electroencephalogram (EEG) reviewed or requested or if an EEG was not performed previously, then an EEG ordered. Denominator: all patients with a diagnosis of epilepsy seen for an initial evaluation.
4	Magnetic Resonance Imaging/Computed Tomography Scan (MRI/CT Scan) Results Reviewed, Requested, or Scan Ordered	Numerator: patients who had the results of at least one MRI or CT scan reviewed or requested or, if an MRI or CT scan was not obtained previously, then an MRI or CT scan ordered (MRI Preferred). Denominator: all patients with a diagnosis of epilepsy seen for an initial evaluation.
5	Querying and Counseling about the Anti-Epileptic Drug (AED) Side Effects	Numerator: patient visits with patient queried and counseled about Anti-Epileptic Drug (AED) side effects and the querying and counseling was documented in the medical record. Denominator: all visits for patients with a diagnosis of epilepsy.
6	Surgical Therapy Referral Consideration for Intractable Epilepsy	Numerator: patients who were considered for referral for a neurological evaluation of appropriateness for surgical therapy and the consideration was documented in the medical record within the past three years. Denominator: all patients with a diagnosis of intractable epilepsy.
7	Counseling about Epilepsy-specific Safety Issues	Numerator: patients (or their caregiver(s)) counseled about context-specific safety issues, appropriate to the patient's age, seizure type(s) and frequency(ies), occupation and leisure activities, etc. (e.g., injury prevention, burns, appropriate driving restrictions or bathing) at least once a year. Denominator: all patients with the diagnosis of epilepsy.

#	Measure	Description
8	Counseling for Women of Childbearing Potential with Epilepsy (PQRS #268; NQF 1848)	Numerator: Female patients counseled about epilepsy and how its treatment may affect contraception and pregnancy and documented in the medical record at least once a year. Denominator: all females of childbearing potential (12–44 years old) with a diagnosis of epilepsy.

Source: AAN (2010). *Epilepsy: Physician Performance Measurement Set*, American Academy of Neurology.

### 5.3 Multiple Sclerosis

The AAN does not currently have a list of quality measures for MS, although measures are in development.<sup>125</sup> Research into quality measures for assessing the quality of MS care has found 76 measures that meet the validity threshold.<sup>126</sup> Unfortunately, of these measures, the vast majority require chart abstraction or patient surveys, while the other 12 can be obtained using current administrative data.<sup>126</sup> Table 5 lists the domains and associated valid measures that have been found. MS-specific, health-related quality of life (HRQoL) measures have also been developed to investigate health and psychological outcomes including the Multiple Sclerosis Quality of Life Inventory, the Multiple Sclerosis Quality of Life-54, the Functional Assessment of Multiple Sclerosis, the Multiple Sclerosis Impact Scale-29, and the Leeds Multiple Sclerosis Quality of Life Scale.<sup>127</sup> Some of these measures use the foundation of basic HRQoL scales, such as the Medical Outcomes Study Short Form-36 with additional MS-specific measures, while others are developed entirely for patients with MS.<sup>127</sup> Due to the emphasis on effective medication management in MS, it is important to note the lack of measures associated with medication management.

**Table 5. Validated Multiple Sclerosis Quality Measures**

#	Measure Domain	Measure
1	Anxiety	Management of anxiety
2		Assessment of urinary symptoms
3		Assessment of UTI upon hospital admission
4	Bladder dysfunction/urinary tract infection (UTI)	Management of post-void residual urine
5		Avoid treatment of asymptomatic bacteriuria
6		Test for antibiotic susceptibility with recurrent UTI
7		Work-up or chronic subjective bladder symptoms
8	Bowel dysfunction	Assessment of bowel function
9		Management of constipation
10		Work-up of fecal incontinence
11	Cognitive dysfunction	Assessment for cognitive deficits
12		Management of cognitive deficits
13	Depression	Assessment for depression
14		Treatment for depression
15	Fatigue	Assessment of fatigue
16		Work-up for fatigue
17		Review of medications causing fatigue
18		Management of primary fatigue
19	Mobility/Falls	Assessment for mobility impairments
20		Work-up of mobility impairments of falls
21	Pressure ulcer	Assessment for risk of pressure ulcers
22		Assessment for pressure ulcers in long-term facility
23		Use of specialty mattresses
24		Prevention of pressure ulcer

#	Measure Domain	Measure
25	Relapses	Documentation of occurrence of relapses
26		Differentiate relapse from pseudo-relapse
27	Sexual dysfunction	Assessment of erectile dysfunction
28		Management of erectile dysfunction
29		Assessment of female sexual dysfunction
30		Work-up of sexual dysfunction
31		Referral to specialist with expertise in sexual problems
32	Spasticity	Assessment of spasticity
33		Work-up of spasticity
34		Management of persistent spasticity
35	Speech	Management of dysarthria
36	Swallowing	Assessment of dysphagia
37		Formal tests of swallowing function
38		Referral for swallowing dysfunction
39		Offer of feeding tube
40	At time of diagnosis: Medical Evaluation – appropriateness and timeliness	Documentation of diagnostic criteria
41		Timely initial diagnosis
42	At time of diagnosis: Patient education	Explanation of diagnostic work-up
43		Offer of information to newly diagnosed patient
44	Management of exacerbations and activities of daily living difficulties	Rehabilitation evaluation following an exacerbation
45		Assessment of ADL difficulties
46		Treatment with steroids
47		Communication of risks and benefits of steroids
48		Comprehension of risks and benefits of steroids
49	After diagnosis: Patient education	Assessment of informational needs
50	Disease-modifying agents	Treatment of clinically isolated syndrome
51		Disease-modifying agents for relapsing forms of MS
52		Lab tests for persons on interferon beta therapy
53		Lab tests for persons on high-dose interferon beta therapy
54		Documentation when starting mitoxantrone or natalizumab
55		Cardiac monitoring with mitoxantrone
56		Communication of risks and benefits of disease-modifying treatments
57		Comprehension of risks and benefits of disease-modifying treatments
58	Provision of community and social resources/patient self-management	Assessment of problems with work or education
59		Management of temperature
60		Complementary and alternative medications
61	Establishment, integration, and coordination of care	Visit to neurologist or physiatrist
62		Access to primary care provider
63		Follow-up of new medication
64		Contact for usual source of care
65		Documentation of consultation by referring physician
66	Health promotion	Assessment of exercise habits
67		Recommendation of exercise
68		Assessment of general symptoms
69	General preventive care	Mammogram
70		Pap smear
71		Colon cancer screening
72		Influenza immunization
73		Pneumococcal polysaccharide vaccine
74		Osteoporosis screening
75	Health insurance and disability programs	Awareness of health insurance and disability programs

Source: Cheng, E. M., et al. (2010). "Quality indicators for Multiple Sclerosis." *Mult Scler* 16(8): 970-980.

## 6. Conclusion

Complex chronic neurological conditions affect many Medicare beneficiaries and their families, and they account for a disproportionate share of Medicare costs. Individuals with these conditions have high health care costs due to the complex nature of their conditions, as well as high rates of associated comorbidities. The cognitive decline associated with many neurological conditions makes the care of these comorbidities even more problematic. Due to this decline, patients have increasing difficulty managing their health care and daily lives without assistance. Ultimately, as these conditions progress, care decisions not only involve a broader range of physicians and other care providers, but increasingly require the integral participation of caregivers. These caregivers are often spouses of similar age who must cope with their own medical issues, which can be exacerbated by the stress of caring for people with such complicated diseases. In dementia and MS, providing caregiver support is essential as patients' cognitive and functional abilities continue to decline over time. Numerous alternative care models exist to improve the care of patients with complex chronic neurological conditions such as dementia, epilepsy, MS, TBI, and complex headaches. For each, alternative care models focus on improving patient outcomes by providing coordinated, high-quality care, often utilizing complex care management. For epilepsy and MS in particular, medication management is critical due to the high drug burden of treating these conditions.

Despite the proliferation of alternative care models addressing the needs of these patient populations, neither stakeholder interviews nor the literature review identified any APMs implemented to date that specifically focus on complex chronic neurological conditions. Although some particularities are associated with these conditions, such as the importance of caregiver involvement, greater coordination for individuals with cognitive decline, and inclusion of a variety of therapy services, many enhanced care services needed for those with neurological conditions are similar to those for patients with other chronic diseases, including care coordination and medication management. Therefore, APMs that have been successful in supporting improved care for other chronic diseases could be applied to support neurological conditions as well.

Due to the collaborative nature of the care required to manage these conditions, APMs need to address payment for neurologists as well as other providers. For example, an add-on-type payment has the potential to properly incentivize coordination of care, particularly between specialty providers. Neurologists would receive a payment specifically for enhanced disease management, including collaboration with other providers. Beneficiaries with advanced cognitive decline or multiple comorbid conditions may benefit from a more sophisticated patient-centered medical home (PCMH) model. In these APMs, a neurologist would act as part of a complex care management team and thus would share in the payments given to support the team. In other cases, an episode-based payment model could be applicable to some discrete interventions, particularly with epilepsy patients. Finally, a comprehensive capitated payment provides the most incentive for care coordination and service expansion, but such a payment is less feasible, at least initially, due to its extensive shift away from the current FFS system.

Overall, the PMPM APMs might be viewed as an intermediate financing mechanism or bridge to more comprehensive, coordinated care and payment for patients with complex neurological conditions. In

these APMs, a portion of any additional value-based bonus payments or a shared savings component could be given to the neurologist, making that physician partially responsible for the overall health outcome of the patient.

The extensive evidence on alternative care models developed in complex chronic neurological care suggests that APMs in this space could lead to significant improvements in care. Developing and implementing sustainable APMs for patients with complex chronic neurological conditions is thus a critical element of the broader effort in the United States to improve health care outcomes and control total costs of care.

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## Appendix A. Stakeholder List

Organization	Stakeholder Type
Epilepsy Foundation	Advocacy/Patient Experience
Partnership to Improve Patient Care	Advocacy/Patient Experience
American Health Care Association	Advocacy/Patient Experience
American Academy of Neurology/Emory University School of Medicine/Emory HealthCare	Care Delivery/Provider
American Academy of Neurology/UCLA/LA VA Parkinson's Disease Center	Care Delivery/Provider
David Geffen School of Medicine at UCLA	Care Delivery/Provider
George Washington University	Care Delivery/Provider
Emory University	Care Delivery/Provider
UCSF Memory and Aging Center	Care Delivery/Provider
Head Injury Institute	Care Delivery/Provider
American College of Radiology/Weill Cornell Medical School	Care Delivery/Provider
Radiological Associates of Sacramento/American Society of Neuroradiology	Care Delivery/Provider
K. Long Health Economics Consulting	Health Services Research/Quality
Dartmouth Institute of Health Policy & Clinical Practice/Geisel School of Medicine at Dartmouth	Health Services Research/Quality
Center for Studying Health System Change	Health Services Research/Quality
Northwestern University/Veterans Affairs Health Services Research and Development Service	Health Services Research/Quality
University of Connecticut Health Center	Health Services Research/Quality
Institute of Medicine (formerly from the Alzheimer's Association)	Health Services Research/Quality
NYU Langone Medical Center	Health Services Research/Quality
Brookings Institution	Health Services Research/Quality
CMS	Payer
CareMore Medical Group	Payer
Aetna	Payer
American Geriatrics Society	Payment Policy
Physician Health Partners	Payment Policy

## Appendix B. List of Alternative Care Models

Care Model Name	Condition	Care Model Type	Description
<b>Aging Brain Care (ABC)</b>	Dementia	Practice/health system-based	Mobile model that integrates a medical home with a neurology-specific clinic to support PCPs. Includes numerous support tools available for all stages of care, care coordination, medication management, and transition support.
<b>Dementia Care Ecosystem</b>	Dementia	Practice/health system-based	Complex care management using a multidisciplinary care team. Care team navigators help coordinate all aspects of care with support from a robust, computer-based dashboard.
<b>University of California Los Angeles (UCLA), Alzheimer's and Dementia Care (ADC)</b>	Dementia	Practice/health system-based	Care managers help to develop a care plan and provide care coordination, caregiver support, and aid in accessing CBOs.
<b>New York University Caregiver Intervention Model (NYUCI)</b>	Dementia	Practice/health system-based	Caregiver support through in-person counseling and telephone support.
<b>Resources for Enhancing Alzheimer's Caregiver Health (REACH)</b>	Dementia	Practice/health system-based	Caregiver support utilizing a combination of home and telephone counseling and structured support groups.
<b>Assessing Care of Vulnerable Elders – Alzheimer's Disease (ACOVE AD)</b>	Dementia	Partnerships with community-based organizations	Proactive education and referral of patients to CBOs. Includes decision support, EMR workflow prompts, and data collection tools to aid physicians.
<b>Partners in Dementia Care (PDC)</b>	Dementia	Partnerships with community-based organizations	Complex case management offered through physician-CBO direct partnership. Telephone-based support program with care manager at provider's office and CBO. Two care managers work together to ensure adequate care is provided.
<b>Transitional Care Model (TCM) for Cognitively Impaired Elders</b>	Dementia	Transitional care	Care coordinators help navigate transition, provide support services, and coordinate care.
<b>Amedisys Care Transitions Initiative</b>	Dementia	Transitional care	Care coordinators help navigate transition, provide support services, and coordinate care.
<b>Epilepsy Centers of Excellence (ECOE)</b>	Epilepsy	Centers of excellence	Hub and spoke model where epilepsy-specific centers provide specialized diagnostics and care for local facilities.
<b>Web Epilepsy Awareness Support and Education (WebEase)</b>	Epilepsy	Self-management	Web-based intervention that addresses medication, stress, and sleep management.
<b>Multiple Sclerosis Centers of Excellence (MSCoE)</b>	Multiple Sclerosis	Centers of excellence	Hub and spoke model where MS-specific centers provide specialized services to support regional providers.