RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

Feedback from Health Insurance Companies Regarding Evidence-Based Research for Dementia Care

Stakeholder Group Paper

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Prepared by:
Payer Stakeholder Workgroup

Additional information can be found at the Summit website (https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers) or the National Alzheimer's Project Act website (https://aspe.hhs.gov/national-alzheimers-project-act). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

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Prepared by

Elizabeth Cahn Goodman, DrPH, JD, MSW

For the

National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers

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In response to your request for feedback from the health insurance community, 10 health insurance companies were contacted and asked to participate in a short survey described below. Of the 10, 7 agreed. The participating companies include both regional (from several regions of the country) and national health plans. Some offer commercial insurance, and some offer Medicaid products. All offer Medicare Advantage products. At least one of each of the carriers' Medicare Advantage products is a fully integrated Medicare and Medicaid plan, meaning it covers the full portfolio of Medicare and Medicaid covered services available to members in the state in which the product is offered. As a result, each of the carriers has significant experience serving individuals with dementia and their caregivers.

Each insurer was contacted via email and telephone. Once participation was confirmed each insurer received an email which included Chapter 2 of the PCORI pre-summit materials entitled ”Engaging Decisionmakers” (June 7-8, 2017) as well as the dementia summit agenda. They were asked to review the materials and to answer the following questions:

1) In reviewing the attached qualitative research, do you agree that the information that would be most critical for your organization to obtain in making these decisions is evidence of improved quality and outcomes?
2) If yes, what measures of quality, if any, do you use to measure the health and functional status of individuals with dementia? If none, are there measures or areas for measurement that you believe would be meaningful to your organization?

3) Similarly, how would you measure improved outcomes sufficient to warrant covering a given service?
4) If no, what is the most critical information your organization would need to receive in order to make coverage decisions related to dementia care?
5) If your company offers products in Medicare Advantage and Medicaid, would the coverage determination process differ from that of commercial insurance? Other than a state or the federal government mandating payment, what else would be determinative in deciding whether to include or exclude dementia care services?
6) Would these services be thought of differently in a value- based insurance design model? a CSNP model for people with dementia?

Five insurers participated in telephone interviews, one responded in writing, and one participated in both a telephone interview and in writing.

Most of the insurers agreed with the results of the qualitative interviews conducted by PCORI that evidence of improved quality and outcomes would be critical to making coverage decisions. However, nearly all of them caveated that agreement by emphasizing the necessity to define quality and outcomes appropriate to the population being served.

One insurer discussed the company's focus on quality and outcomes this way:

> We're a plan that works off evidence-based medicine and so, for us, it's about what works and what has documented evidence of value. It's got to be about quality, reduction in inappropriate utilization, and/or significant positive impact to members' health and wellbeing.

Another said:

> The caveat to this is that the very measures of what amounts to "excellent" dementia care are nebulous out there, and there is no clear consensus on which population needs are best addressed on a wider scale vs. simply providing care on a case-by-case basis, depending on patient's resources, stage of disease, co-morbidities, etc.

Most of the insurers discussed the challenges in defining quality and outcomes given the fairly predictive trajectory dementia takes and difficulty in diagnosing dementia particularly in the early stages. One insurer put it this way:

> Dementia, in particular Alzheimer's, has a fairly predictive outcome where there is a change in functionality, this progression of disease. We understand this is going to happen. We have to just think about those quality metrics, the outcomes, and interventions in that light.

Many of them discussed the need to differentiate evidence of quality and outcome based on the specific type of dementia and the stage. Some also stated that it would be important to differentiate quality and outcomes based on the availability of caregiver supports.

Several respondents mentioned the need to focus on the presentation of the dementia, specifically with respect to behavioral symptoms. One described some of the behaviors common to individuals with dementia and emphasized the need to assure that quality measurement and performance outcomes are designed in a way that assure that those behavioral issues are appropriately avoided or addressed.

> I was thinking more along the lines of wandering... Sometimes there's some aggressive behaviors at times and sun-downing. I was thinking more about behaviors as opposed to behavioral health… There's a kind of dementia, which frontal temporal dementia or primary progressive aphasia, where there's almost always behavioral issues. It can be people do embarrassing things. It can also be physical behaviors like harming their caregiver. Then the other thing I thought of when we talked about behavioral problems is ... What do I want to say? There are some appropriate pharmacological treatments for behavioral problems, and then there are some inappropriate pharmacologic treatments for behavioral problems.

Several of the respondents discussed the issue of comorbid conditions among people with dementia and recommended that quality and/or outcomes measurement focus not (or not only) on care for the dementia or the dementia related symptoms but also on the avoidance or management of those co-morbid conditions. One responded described it as follows:

> I think at different stages what good care for patients with dementia is not just the medical piece. It's part of it. It's preventing other diseases. It's managing comorbidity in a patient that already has dementia and how that other comorbidity is now going to affect his diagnosis or this diagnosis affected the management of the other comorbidities.

With respect to how quality might be measured in this population, ideas offered by the respondents included:

- Avoidance, improvement or maintenance of comorbidities
- Quality of life of the patient
- Quality of life of the caregiver
- Caregiver stress burden including but not limited to caregiver level of depression and/or anxiety
- Ability to remain in the community environment
- Maintenance of choice in decision making, for example, did the individual’s life end in the environment they preferred

- Palliative care quality
- Advance planning (directives, guardianships) – one plan suggested a study of "Orphan elders" those who cannot make decisions but do not have a guardian and the impact of that status on health quality and cost
- Engagement of families and other non-professional support systems
- Inappropriate prescribing on plan suggested measuring evidence of the use of alternative therapies prior to chemical restraints, for example, prescribing an iPod before prescribing a psychotropic
- Polypharmacy
- Fall frequency, consequences and repetition
- Nutrition
- Management of behavioral issues
- Functioning relative to others at the same stage of the same disease (differentiating by type of dementia, stage and the availability of formal and informal supports)
- Presence and make up of a multidisciplinary care team
- Avoidance of care that would be futile for a patient with dementia
- The availability of choice in setting and service delivery for both the patient and their caregiver/self-direction
- Emergency department use
- 30 day readmissions
- SNF utilization
- Inpatient admissions

With respect to the method of measuring these quality metrics, nearly all of the respondents spoke to the need to benchmark any measures of quality to other patients with the same stage and type of dementia. One respondent recommended that measures of quality of life and/or experience of care be done using a longitudinal set of surveys over the course of the disease.

Among those respondents that recommended measuring caregiver stress and quality of life, none offered specific scales for that purpose.

With respect to the questions related to coverage decisions for dementia care and how those decisions differ in the Medicare Advantage, Medicaid, and Commercial markets, many of the respondents discussed the fact that the support services for beneficiaries with functional impairments (dementia or otherwise) and care for the families of individuals with dementia are not a part of the traditional health insurance benefit.

Some pointed out that the majority of individuals with dementia are beyond working age and therefore covered by either Medicare or retiree coverage which does not traditionally provide coverage for these services and, because Medicare is not family coverage, it is not designed in a manner to support coverage for the families of individuals with dementia. A few discussed the possibility that family caregivers may be able to obtain support within their behavioral health coverage but that leave, respite and other similar benefits are inconsistent among employers and not provided as a component of the health insurance benefit. One plan provides support to the local Alzheimer's Association to fund a care navigator available to their members and others in the community to assist with these issues, but this done as a charitable contribution, not as a part of the insurance package.

Among those plans that discussed specifically how coverage decisions are made, one insurer applies a hierarchy of criteria starting with statistically robust, well-designed randomized controlled trials, proceeding to statistically robust, well-designed cohort studies; large, multisite observational studies; and single-site observational studies. Where those don't exist, they develop medical policies based upon national consensus statements by recognized authorities including U.S. Preventive Services Task Force, National Institutes of Health clinical statements, Agency for Healthcare Research and Quality clinical statements, evidence-based nationally recognized clinical guidelines, CMS National Coverage Determinations (NCDs), clinical position papers of professional specialty societies when their statements are based on referenced clinical evidence, and expert opinion using Cochrane grading. Another insurer stated that coverage decisions for their Medicare products are based on CMS NCDs and Local Coverage Determinations (LCDs). Several respondents said that coverage decisions were limited by Medicare and Medicaid requirements. One respondent said that specifically for dementia "…We would typically look for evidence of clinically significant and sustained effects on disease trajectory and/or functional status." Another respondent said

> What would be determinative is whether it provides value to our members, who are more likely to have dementia than an insurer with a younger population. If an intervention or service meets our goal of members staying independent and thriving throughout, and ideally also has an effect on utilization patterns, then it would meet criteria.

Many of the respondents discussed the use of health and functional assessments as determinative in making individual service planning decisions. For example, one of the respondents said:

> We do exhaustive initial global assessments that include functional parameters such as ADLs, IADLs, cognitive health screening and evaluation of support structures. … In general, we make decisions based on a global evaluation of cognitive, health, functional and resource status.

Health and functional assessments are used by those respondents referencing them both as a mechanism to assess the patient/member's needs and as a tool to support service authorization. One respondent discussed the use of a dementia-specific functional assessment tool for some plan members. None of the respondents discussed the use of these assessments to measure quality (for example, longitudinal use of the assessment data to measure functional decline).

More generally, one respondent put the coverage decision-making process this way:

> There's very few things that we're going to do that are new, right, and that's always the problem. There's lots of things that we do that aren't new, because they're established practice. Things that are new that are not established practice have to show something that will have ideally some, if not directly tangible benefit, something that you can point to as an intangible that leads you somewhere.

Finally, with respect to the concept of a a dementia-specific chronic care special needs plan (CSNP) or a value-based insurance model, most of the insurers expressed significant reservations regarding a dementia specific model under current Medicare rules. Those concerns focused on the challenges of recruiting a dementia-specific population, the per member per month cost of adequately serving exclusively individuals with dementia and the existing Medicare coverage rules. The majority of their concerns, however, focused on the diversity of the population in terms of type, stage and presentation of the dementia and the wide array of comorbid conditions. One respondent said that is was possible that a well-designed value model that incorporates a truly interdisciplinary approach would bring value, but it would have to be well-researched to appropriately target needs. Specifically, they voiced concern about the lack of existing evidence regarding what the definition of value in serving this diverse community of patients/members.

Ideas that came up in these interviews as ripe for future research in this space included:

- Research on interventions for individuals at high risk of developing dementia, especially those at high risk of early onset dementia including those with Down syndrome, substance abuse disorders, certain behavioral health disorders and liver disease
- Research into effective caregiver training
- Research into effective training of physicians and other providers to identify and diagnose dementias
- Research regarding the effectiveness of caregiver support (especially in order to support advocacy around changes to the regulations governing Medicare Advantage to ease insurer’s ability to cover these services)
- Research into effective prevention techniques