

# How Medical Costs for People with Dementia Are Changing Over Time and Across the U.S

## Methods Document

### United States Cost of Dementia Project

#### About the U.S. Cost of Dementia Project

The [project](#) provides comprehensive, national, annual estimates of the total costs of dementia and builds national research capacity to address the economic consequences of dementia. It is funded by a cooperative agreement with the National Institute on Aging, National Institutes of Health through grant U01AG086827.

#### Sample Selection

Our sample is drawn from claims of 100% fee-for-service Medicare beneficiaries and is limited to those who are continuously enrolled in Parts A, B, and D for years  $t$  and  $t+1$ , from 2007 to 2023, allowing for death in  $t+1$ . In 2022, the sample includes a total of 15,751,252 beneficiaries, including 1,241,461 persons living with dementia.

#### Dementia Prevalence

We utilize the Schaeffer Dementia Algorithm to identify verified cases of dementia.<sup>1,2</sup> Complete details and SAS code can be found on [GitHub](#). Briefly, we utilize ICD-9 and ICD-10 diagnoses codes for dementia as defined by the Chronic Condition Warehouse (Table 1). In addition, we use Part D claims for prescription drugs used to treat dementia (donepezil, galantamine, rivastigmine, memantine) and ICD-9 and ICD-10 codes for symptoms of dementia (amnesia, aphasia, mild cognitive impairment, and apraxia and agnosia). To identify prevalent cases of dementia, we require a dementia diagnosis to be verified by one of the following: a second diagnosis, dementia symptom, prescription drug, or death within one year. Beneficiaries are defined as having dementia if they have a verified diagnosis in year  $t$ ; year  $t+1$  is used for verification purposes. Beneficiaries without a verified dementia diagnosis in year  $t$  are included in the group identified as “non-dementia.”

#### Medical Costs

We use methods for calculating costs published by [ResDAC](#). We obtain annual costs for all beneficiaries from variables in the Medicare Beneficiary Summary File (MBSF) costs and use files (Table 2). We calculate total costs, and costs by payer – Medicare, beneficiary, and other primary payer – and by type listed in Table 2. Costs reflect medical costs billed to Medicare only and paid by Medicare, beneficiaries, Medicaid, and other insurers (e.g. employers); long-term services and supports costs (e.g. nursing home paid by Medicaid or long-term care insurance) are not included. All costs are adjusted to reflect 2025 dollars using the Consumer Price Index from the Bureau of Labor Statistics.

#### Other Measures

The visualization tool allows users to view data based on beneficiary characteristics: age, race/ethnicity, sex, state, rurality, and dual eligible status. Age is reported in 5-year age bands (65-70, 70-75, 75-80, 80-85, 85-90 and 90+). Race/ethnicity is defined using the [Research Triangle Institute \(RTI\) race code](#) and includes 5 mutually-exclusive categories: non-Hispanic white, non-Hispanic Black, Hispanic, Asian, and American Indian/Alaska Native. State is determined using Social Security Administration’s 2-digit state

code as reported in the MBSF. Rurality is determined using beneficiaries' county and where it falls in the [Rural-Urban Continuum](#) developed by the US Department of Agriculture. Dual eligibility is reported in the MBSF.

**Table 1: ICD-9-CM and ICD-10-M codes for dementia and dementia symptoms**

Code Type	Code	Description
Dementia		
<b>ICD-9</b>	290.0	Senile dementia, uncomplicated
	290.10	Presenile dementia, uncomplicated
	290.11	Presenile dementia w/ delirium
	290.12	Presenile dementia w/ delusional features
	290.13	Presenile dementia w/ depressive features
	290.20	Senile dementia w/ delusional features
	290.21	Senile dementia w/ depressive features
	290.3	Senile dementia w/ delirium
	290.40	Vascular dementia, uncomplicated
	290.41	Vascular dementia, w/ delirium
	290.42	Vascular dementia, w/ delusions
	290.43	Vascular dementia, w/ depressed mood
	294.0	Amnestic disorder in conditions classified elsewhere
	294.10	Dementia in conditions classified elsewhere without behavioral disturbances
	294.11	Dementia in conditions classified elsewhere with behavioral disturbances
	294.20	Dementia, unspecified, without behavioral disturbances
	294.21	Dementia, unspecified, without behavioral disturbances
	294.8	Other persistent mental disorders due to conditions classified elsewhere
	331.0	Alzheimer's Disease
	331.11	Picks disease
	331.19	Other frontotemporal dementia
	331.2	Senile degeneration of brain
	331.7	Cerebral degeneration in disease classified elsewhere
	797	Senility w/out mention of psychosis
	331.82	Lewy body dementia
Symptoms		
	780.93	Amnesia
	784.3	Aphasia
	784.69	Other symbolic dysfunctions, apraxia, agnosia
	331.83	Mild cognitive impairment, so stated
Dementia		
<b>ICD-10</b>	F01.50	Vascular dementia, without behavioral disturbance
	F01.51	Vascular dementia, with behavioral disturbance

	F02.80	Dementia in conditions classified elsewhere without behavioral disturbance
	F02.81	Dementia in conditions classified elsewhere with behavioral disturbance
	F03.90	Dementia, unspecified, without behavioral disturbance
	F03.91	Dementia, unspecified, with behavioral disturbance
	F04	Amnesic disorder due to known physiological cond
	F05	Delirium due to known physiological cond
	F06.1	Catatonic disorder due to known physiological cond
	F06.8	Oth mental disorders due to known physiological cond
	G13.2	Systemic atrophy aff cnsl in myxedema
	G13.8	Systemic atrophy affecting central nervous system in other diseases classified elsewhere
	G30.0	Alzheimer's disease with early onset
	G30.1	Alzheimer's disease with late onset
	G30.8	Other Alzheimer's disease
	G30.9	Alzheimer's disease, unspecified
	G31.01	Picks disease
	G31.09	Other frontotemporal dementia
	G31.1	Senile degeneration
	G31.2	Oth disorders of brain in diseases classd eslew
	G91.4	Hydrocephalus in diseases classified elsew
	G94	Other disorders of brain in diseases classified elsewhere
	G31.83	Lewy body dementia
	R41.81	Age-related cognitive decline
	R54	Age-related physical debility
	F01.511	Vascular dementia, unspecified severity, with agitation
	F01.518	Vascular dementia, unsp severity, with other beh disturb
	F01.52	Vascular dementia, unsp severity, with psychotic disturb
	F01.53	Vascular dementia, unspecified severity, with mood disturb
	F01.54	Vascular dementia, unspecified severity, with anxiety
	F01.A0	Vascular dementia, mild, without beh/psych/mood/anx
	F01.A11	Vascular dementia, mild, with agitation
	F01.A18	Vascular dementia, mild, with other behavioral disturbance
	F01.A2	Vascular dementia, mild, with psychotic disturbance
	F01.A3	Vascular dementia, mild, with mood disturbance
	F01.A4	Vascular dementia, mild, with anxiety
	F01.B0	Vascular dementia, moderate, without beh/psych/mood/anx
	F01.B11	Vascular dementia, moderate, with agitation
	F01.B18	Vascular dementia, moderate, with other behavioral disturb
	F01.B2	Vascular dementia, moderate, with psychotic disturbance
	F01.B3	Vascular dementia, moderate, with mood disturbance
	F01.B4	Vascular dementia, moderate, with anxiety
	F01.C0	Vascular dementia, severe, without beh/psych/mood/anx
	F01.C11	Vascular dementia, severe, with agitation
	F01.C18	Vascular dementia, severe, with other behavioral disturbance

F01.C2	Vascular dementia, severe, with psychotic disturbance
F01.C3	Vascular dementia, severe, with mood disturbance
F01.C4	Vascular dementia, severe, with anxiety
F02.811	Dem in other dis classd elswhr, unsp severt, with agitation
F02.818	Dem in oth dis classd elswhr, unsp sev, with oth beh distrb
F02.82	Dem in other dis classd elswhr, unsp sev, with psych distrb
F02.83	Dem in other dis classd elswhr, unsp sev, with mood distrb
F02.84	Dem in other dis classd elswhr, unsp severity, with anxiety
F02.A0	Dem in other dis classd elswhr, mild, w/o beh/psych/mood/anx
F02.A11	Dem in other diseases classd elswhr, mild, with agitation
F02.A18	Dem in other dis classd elswhr, mild, with other beh distrb
F02.A2	Dem in other dis classd elswhr, mild, with psych disturb
F02.B0	Dem in other dis classd elswhr, mod, w/o beh/psych/mood/anx
F02.B11	Dem in other dis classd elswhr, moderate, with agitation
F02.B18	Dem in other dis classd elswhr, mod, with other beh disturb
F02.B2	Dem in other dis classd elswhr, moderate, with psych disturb
F02.B3	Dem in other dis classd elswhr, moderate, with mood disturb
F02.B4	Dem in other diseases classd elswhr, moderate, with anxiety
F02.C0	Dem in other dis classd elswhr, sev, w/o beh/psych/mood/anx
F02.C11	Dem in other diseases classd elswhr, severe, with agitation
F02.C18	Dem in other dis classd elswhr, sev, with other beh distrb
F02.C2	Dem in other dis classd elswhr, severe, with psych disturb
F02.C3	Dem in other dis classd elswhr, severe, with mood disturb
F02.C4	Dem in other diseases classd elswhr, severe, with anxiety
F03.911	Unspecified dementia, unspecified severity, with agitation
F03.918	Unsp dementia, unsp severity, with other behavioral disturb
F03.92	Unsp dementia, unspecified severity, with psychotic disturb
F03.93	Unsp dementia, unspecified severity, with mood disturb
F03.94	Unspecified dementia, unspecified severity, with anxiety
F03.A0	Unspecified dementia, mild, without beh/psych/mood/anx
F03.A11	Unspecified dementia, mild, with agitation
F03.A18	Unspecified dementia, mild, with other behavioral disturb
F03.A2	Unspecified dementia, mild, with psychotic disturbance
F03.A3	Unspecified dementia, mild, with mood disturbance
F03.A4	Unspecified dementia, mild, with anxiety
F03.B0	Unspecified dementia, moderate, without beh/psych/mood/anx
F03.B11	Unspecified dementia, moderate, with agitation
F03.B18	Unsp dementia, moderate, with other behavioral disturb
F03.B2	Unspecified dementia, moderate, with psychotic disturbance
F03.B3	Unspecified dementia, moderate, with mood disturbance
F03.B4	Unspecified dementia, moderate, with anxiety
F03.C0	Unspecified dementia, severe, without beh/psych/mood/anx

	F03.C11	Unspecified dementia, severe, with agitation
	F03.C18	Unspecified dementia, severe, with other behavioral disturb
	F03.C2	Unspecified dementia, severe, with psychotic disturbance
	F03.C3	Unspecified dementia, severe, with mood disturbance
	F03.C4	Unspecified dementia, severe, with anxiety
Symptoms		
	R41.1	Anterograde amnesia
	R41.2	Retrograde amnesia
	R41.3	Other amnesia
	R47.01	Aphasia
	R48.1	Agnosia
	R48.2	Apraxia
	R48.8	Other symbolic dysfunctions
	G31.84	Mild cognitive impairment, so stated

**Table 2: Cost Variables From MBSF**

Type	Payer	Variable Name MBSF Cost &Use Files
Inpatient	Beneficiary	acute_bene_pmt, oip_bene_amt
	Medicare	acute_mdcr_pmt, oip_mdcr_pmt, acute_perdiem_pmt, oip_perdiem_pmt
	Other Primary Payer	acute_prmry_pmt, oip_prmry_pmt
SNF	Beneficiary	snf_bene_pmt
	Medicare	snf_mdcr_pmt
	Other Primary Payer	snf_prmry_pmt
Hospice	Beneficiary	n/a
	Medicare	hos_mdcr_pmt
	Other Primary Payer	hos_prmry_pmt
HHA	Beneficiary	n/a
	Medicare	hh_mdcr_pmt
	Other Primary Payer	hh_prmry_pmt
Hospital Outpatient	Beneficiary	hop_bene_pmt
	Medicare	hop_mdcr_pmt
	Other Primary Payer	hop_prmry_pmt
Carrier	Beneficiary	asc_bene_pmt, anes_bene_pmt, ptb_drug_bene_pmt, phys_bene_pmt, dialys_bene_pmt, oproc_bene_pmt, img_bene_pmt, test_bene_pmt, othc_bene_pmt
	Medicare	asc_mdcr_pmt, anes_mdcr_pmt, ptb_drug_mdcr_pmt, phys_mdcr_pmt, dialys_mdcr_pmt, oproc_mdcr_pmt, img_mdcr_pmt, test_mdcr_pmt, othc_mdcr_pmt
	Other Primary Payer	asc_prmry_pmt, anes_prmry_pmt, ptb_drug_prmry_pmt, phys_prmry_pmt, dialys_prmry_pmt, oproc_prmry_pmt, img_prmry_pmt, test_prmry_pmt, othc_prmry_pmt

DME	Beneficiary	dme_bene_pmt
	Medicare	dme_mdcr_pmt
	Other Primary Payer	dme_prmry_pmt
Part D	Beneficiary	ptd_bene_pmt
	Medicare	ptd_mdcr_pmt
	Other Primary Payer	n/a

Note: DME = durable medical equipment

1. Thunell J, Ferido P, Zissimopoulos J. Measuring Alzheimer's disease and other dementias in diverse populations using medicare claims data. *Journal of Alzheimer's Disease*. 2019;72(1):29-33.
2. Haye S, Thunell J, Joyce G, et al. Estimates of diagnosed dementia prevalence and incidence among diverse beneficiaries in traditional Medicare and Medicare Advantage. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. 2023;15(3):e12472.