

Appendix 1: Methodology for the U.S. Cost of Dementia Model

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The U.S. Cost of Dementia Model (USCDM) combines data from several large, nationally representative surveys, including the Health and Retirement Study (HRS), the Medical Expenditure Panel Survey (MEPS) and the Medicare Current Beneficiary Survey (MCBS). The combination of datasets provides more comprehensive information than any single national survey. The USCDM is a dynamic microsimulation model¹. Underlying it are models of dementia onset, and changes in other physical and functional health measures, work status and earnings (transition models) using data from the 1998 to 2018 waves of HRS. The microsimulation begins with a nationally representative population of Americans aged 51 years or older in year 2010. The USCDM has a two-year cycle that mimics the frequency of the underlying survey data. At each two-year timestep, individual characteristics and outcomes are updated based on predictions from the transition models and subsequently, models of medical and long-term care costs (and by payer), quality of life, and care hours utilizing these updates individuals measure, are estimated, and then costs are calculated. The simulation is performed 75 times to produce stable results. More details on the methods are provided below.

■ Dementia

Respondents in the HRS are identified as having dementia based on their cognitive status. The cognitive functioning of HRS respondents ages 51 and older is assessed at each wave using an adapted version of the Telephone Interview for Cognitive Status (TICS). The respondent completes the assessment, or it is completed by a proxy, typically a spouse or other family member. We assign dementia based on scores from the assessments, proxy responses, functional limitations and interviewer's assessment from the Langa-Weir Classification of Cognitive Function.²

■ Medical and Long-Term Care Costs

The USCDM models medical and long-term care costs using data from the Medicare Current Beneficiary Survey for persons enrolled in Medicare, and the Medical Expenditure Panel for those not enrolled in Medicare. Aggregate health care expenditures are calibrated with data from the National Health Expenditure Accounts. The USCDM separately models costs borne by Medicare, Medicaid, other payers, and patients via out-of-pocket spending. Medical and long-term care costs of dementia are calculated by summing spending from all health care used by persons with dementia. We do not determine if the healthcare use was primarily due to dementia. We report medical costs separately for community dwelling persons and nursing home residents.

■ Hours of Care

HRS respondents indicate how many hours and days of care they receive from family and friends for activities of daily living (getting across a room/ dressing/ bathing/ eating/ getting in and out of bed/using the toilet) and hours received in a typical month for instrumental activities of daily living (prepare meals/shop for groceries/make telephone calls/take medications/manage money) from family or other people not including professional help. This was converted to a yearly number of hours of care received among HRS respondents identified as having dementia. The number of hours was calculated separately for receipt of care by spouses and care by other family and friends. USCDM estimates care hours received from 2010 to 2020, using 3 models of care: any hours received, full-time care if receiving any care, and the number of hours if receiving care but not full time. Simulations predict caregiving hours received for each cycle and an average for years 2024 and 2026 is the 2025 estimate.

¹ USCDM was developed from the Future Elderly Model (FEM) (Goldman et al. 2015 <https://schaeffer.usc.edu/wp-content/uploads/2025/02/FEM-Technical-Document.pdf>) and the Alzheimer's Disease FEM (Zissimopoulos J, Crimmins E, St Clair P. The Value of Delaying Alzheimer's Disease Onset. Forum Health Econ Policy. 2014 Nov;18(1):25-39).

² <https://hrsdata.isr.umich.edu/data-products/langa-weir-classification-cognitive-function-1995-2020>

■ Cost of Care Hours Received From Family and Friends

Cost of care hours received were calculated using the hours of care received by people with dementia and two methods for assigning a dollar value. The first is based on a replacement rate of \$34.50 per hour of care.³ This assumes an average hourly rate if one were to hire a paid caregiver. The second method is based on the opportunity cost of time of a respondent who was an unpaid care partner in 2016. To assign an hourly value to care partners' hours, all waves of HRS data are used on a reported wage rate at age 51. We estimate an hourly wage rate model and use this to predict a wage rate for persons with no wage data. We estimate separate models for HRS respondents who provide care to a spouse and those who provide care to a parent with dementia and multiply the wage rate (adjusted to \$2025) by the number of hours of care.

■ Cost of Loss to Quality of Life

USCDM models quality-adjusted life years (QALYs) using the Health Utility Index 3 (HUI3) assessed in year 2000 of the HRS.⁴ The HUI3 measures multiple aspects of health including vision, hearing, speech, ambulation, dexterity, emotion, pain, and cognition. It is mapped to a single score ranging from -0.36 to 1 where 0 represents death, negative scores are worse than death, and 1 is perfect health.⁵ To determine the loss in quality of life associated with living with dementia, USDCM simulates a counterfactual scenario in which people with dementia in 2010 instead had mild-cognitive impairment and would not progress to dementia between 2010 and 2025. The difference in total number of QALYs in this counterfactual scenario with the status quo scenario in 2025 was multiplied by \$150,000, the value for the loss of one QALY. To assess the impact on quality of life of care partners to persons with dementia, the number of respondents who provided care to parents or spouses with dementia in 2025 was multiplied with an external estimate of the differential quality-of-life for those who provide informal care, of 0.01 QALYs⁶. To obtain the economic valuation of the loss of quality of life, the number of QALYs lost was multiplied by \$150,000.

■ Annual Earnings Loss Due to Dementia Caregiving

USCDM models the likelihood of caring for a parent with dementia based on data from the HRS on respondents who report having a parent (or parent-in-law) with dementia and models the impact of caregiving on work and the impact of work on earnings. USCDM simulates parent characteristics including dementia status and respondents' labor force participation and earnings beginning in year 2016 and every two years thereafter. Earnings in 2025 are calculated for this baseline scenario.

USCDM then simulates a counterfactual scenario such that parents of respondents did not have and do not acquire dementia, and respondents do not provide care to parents. In this scenario respondents work and co-reside with parents at the same rate as respondents who do not have parents with dementia. Earnings are calculated under this counterfactual scenario. The difference between the baseline and counterfactual scenario is the earnings loss in 2025, averaging differences in years 2024 and 2026 for year 2025.

The United States Cost of Dementia Project will produce annual cost estimates each year. We continually strive to improve estimates and uncover other types of costs. We encourage you to regularly check the website for updates.

³ Genworth data on hourly cost in \$2025 for a home health aide (\$34.00 in 2024).

⁴ Data description at <https://hrsdata.isr.umich.edu/data-products/health-utilities-index-mark-3-hui3>

⁵ Furlong WJ, Feeny DH, Torrance GW, Barr RD. The Health Utilities Index (HUI) system for assessing health-related quality of life in clinical studies. *Ann Med*. Jul 2001;33(5):375-84. doi:10.3109/07853890109002092

⁶ Neumann PJ, Kuntz KM, Leon J, Araki SS, Hermann RC, Hsu MA, Weinstein MC. Health utilities in Alzheimer's disease: a cross-sectional study of patients and caregivers. *Med Care*. 1999 Jan;37(1):27-32. doi: 10.1097/00005650-199901000-00005. PMID: 10413389.