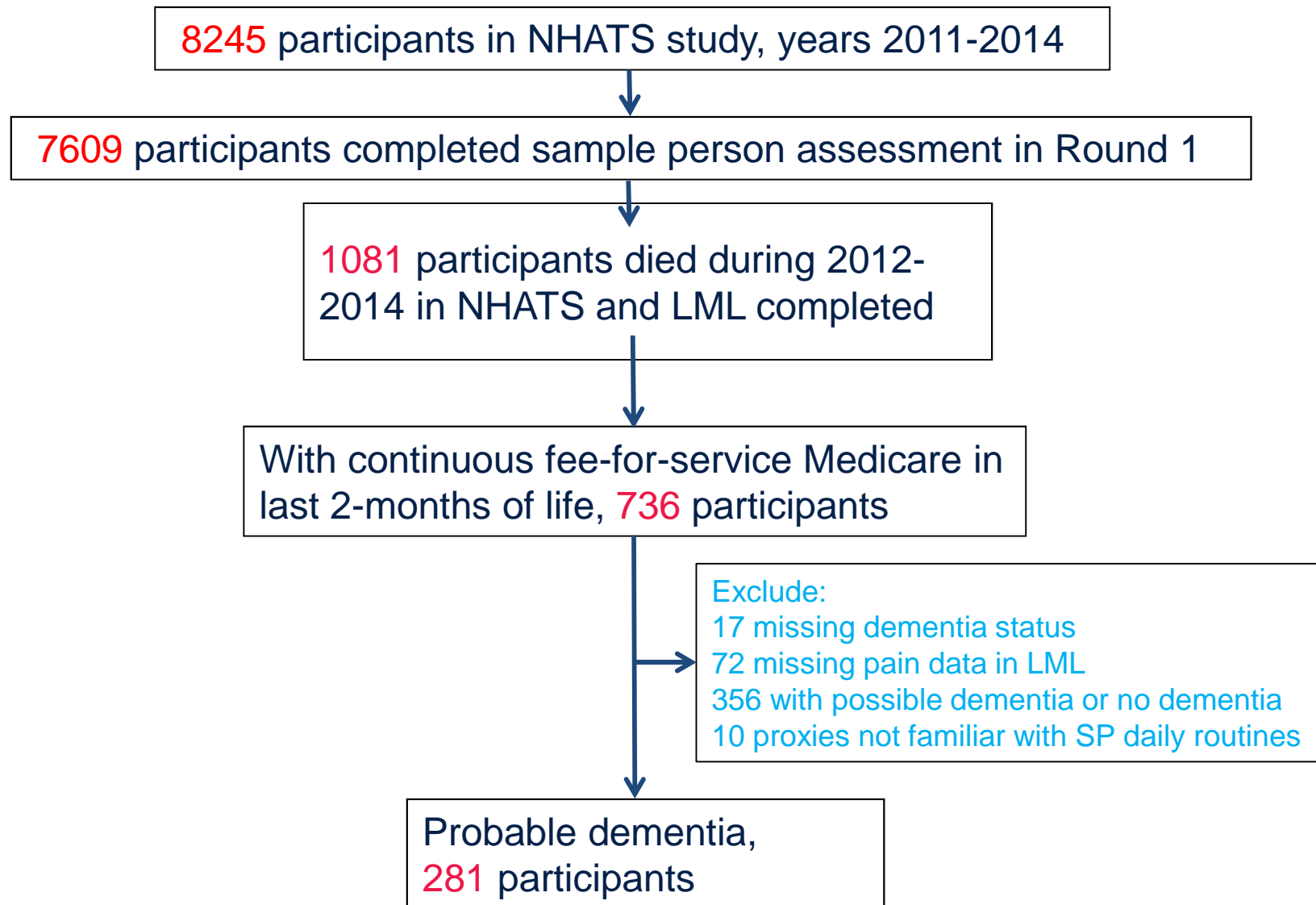


Supplemental Figure: Flow chart of analytic cohort



LML = last month of life interview

Supplement 2. Study Data Sources and Measurement Details

This supplement provides details on the data sources and measurement details used to construct variables for data analysis. Data sources for [Supplement 2 Table 1](#) include the National Health and Aging Trends Study (NHATS) surveys from Round 1 (2011), Round 2 (2012), Round 3 (2013), Round 4 (2014); the NHATS Last Month of Life Interview from Round 2 (2012), Round 3 (2013) and Round 4 (2014); the NHATS/Medicare Beneficiary Summary linked file; and NHATS/Medicare linked inpatient, outpatient, and Hospice claims files. In the NHATS survey, respondents include self-respondents, referred to as Sample Persons (SP), and proxy respondents if sample persons are unable to respond for themselves. Last Month of Life interviews are completed by proxy respondents familiar with the sample person.

[Supplement 2 Table 2](#) provides the International Classification of Disease, Ninth Revision primary diagnosis codes used to define diagnostic categories for assessing most frequent reasons for Emergency Department visits.

NOTE: NHATS has assisted secondary data analysts by providing a number of derived variables. Derived variables are created for variables with: 1) complex skip patterns; 2) calculation of scores; and 3) SP file variables that combine information from prior and current round (if, for example, the SP moved or had a change in marital status). Derived variables are indicated in variable naming with a “d” following the round year (e.g. r1dgender). See NHATS user guide for further information.¹

Supplement 2 Table 1. Data source and measurement details of characteristics and outcomes of NHATS decedents with dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable name (if applicable)	Operational Definition
Age at death	NHATS/Medicare Beneficiary Summary File	N/A	BENE_DEATH_DT	Continuous: <ul style="list-style-type: none"> • <u>Average age at death in years</u>
Gender	NHATS Round 1 Survey (2011)	{Are you/Is SP} male or female?	r1dgender (derived variable)	Dichotomous: <ul style="list-style-type: none"> • <u>Male</u> • <u>Female</u>
Race	NHATS Round 1 Survey (2011)	Do you consider yourself/Does SP consider {himself/herself} primarily 1) white/Caucasian; 2) black/African American; 3) American Indian; 4) Alaskan native; 5) Asian; 6) Native Hawaiian; 7) Pacific Islander; 8) Other; DK/RF {Do you/Does SP} consider {yourself/himself/herself} Hispanic or Latino? 1) Yes; 2) No	r1dracehisp (derived variable)	Categorical: <ul style="list-style-type: none"> • <u>White</u>=white, non-Hispanic • <u>Black</u>=black, non-Hispanic • <u>Hispanic/other</u>=Other (Am Indian/Asian/Native Hawaiian/Pacific Islander/other specify), non-Hispanic AND Hispanic AND DK/RF
Educational Attainment	NHATS Round 1 Survey (2011)	What is the highest degree or level of school {you/SP} completed? 1) No schooling completed; 2) 1 st -8 th grade; 3) 9 th -12 th grade no diploma; 4) High school graduate (high school diploma or equivalent; 5) vocational, technical, business or trade school certificate (beyond high school level); 6) some college but no degree; 7) associates degree; 8) bachelor's degree; 9) master's, professional or doctoral degree; DK/RF	el1higstschl	Ordinal: <ul style="list-style-type: none"> • <u>Less than high school</u>: No schooling completed OR 1st-8th grade OR 9th-12th grade no diploma • <u>High school graduate</u>: High school graduate (high school diploma or equivalent AND vocational, technical, business or trade school certificate (beyond high school level) AND some college but no degree AND associates degree; • <u>Bachelor's or higher</u>: bachelor's degree AND master's, professional or

Supplement 2 Table 1. Data source and measurement details of characteristics and outcomes of NHATS decedents with dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable name (if applicable)	Operational Definition
				doctoral degree
Income	NHATS Round 1 Survey (2011)	How much was {your/SP's}{and SP FIRSTNAME LASTNAME/SPOUSE/PARTNER FIRSTNAME LASTNAME}'s} total income before taxes for last year (this is, for the 12 months ending in December {CURRENT YEAR - 1})?	ia1totinc ia1totincim1-5: Imputed income if ia1totinc not completed. See NHATS Round 1 income imputation guide for more information. ²	Continuous: • <u>Median Income (\$)</u>
Marital Status	NHATS Round Prior to Death (2011, 2012, 2013)	Round 1 2011: {Are you/Is SP} currently married, living with a partner, separated, divorced, widowed, or never married? 1) Married; 2) Living with partner; 3) Separated; 4) Divorced; 5) Widowed; 6) Never married; DK/RF Round 2 (2012) and Round 3 (2013): At the time of the last interview in {LAST INT MONTH AND YEAR}, {you were/SP was} {married/living with a partner/separated/divorced/widowed/never married}. Has that changed? That is, did {you/SP} get married, separated, divorced, remarried, widowed, or start living with a (different) partner 1) Yes; 2) No; DK/RF	Round 1 (2011): hh1martlstat Round 2 (2012) and 3 (2013): hh2dmarstat; hh3dmarstat (derived variable)	Dichotomous: • <u>Married or living with partner:</u> Married AND Living with partner • <u>Widowed/divorced/separated/never married=</u> Separated AND Divorced AND Widowed AND Never Married

Supplement 2 Table 1. Data source and measurement details of characteristics and outcomes of NHATS decedents with dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable name (if applicable)	Operational Definition
Residential Care	NHATS Last Month of Life (LML) Interview (2012, 2013, 2014)	Was this the kind of place that provides care, such as an assisted living facility, board and care home, nursing home, or other long-term care facility? 1) Yes; 2) No; DK/RF	Round 2 (2012): r2dresidlml (derived variable) Round 3 (2013): r3dresidlml (derived variable) Round 4 (2013): r4dresidlml (derived variable)	Dichotomous: <ul style="list-style-type: none"> • <u>Living in residential care in LML</u> • <u>Not living in residential care in LML</u>
Impairment in Activities of Daily Living (ADL)	NHATS Round Prior to Death (2011, 2012, 2013)	<p>Eating: In the last month, did anyone ever help {you/SP} eat, for instance, by cutting up food or feeding {you/{him/her}}? 1) Yes; 2) No; DK/RF</p> <p>Bathing: In the last month, did anyone ever help {you/SP}{shower/take a bath/wash up}? 1) Yes; 2) No; DK/RF</p> <p>Dressing: In the last month, did anyone ever help {you/SP} get dressed, for instance, by getting clothing over {your/{his/her}} head, helping with clothing behind {your/{his/her}} back like a belt {or bra}, or helping {you/{him/her}}put on socks or shoes? 1) Yes; 2) No; DK/RF</p> <p>Toileting: In the last month, did anyone ever help {you/SP} use the toilet? 1) Yes; 2) No; DK/RF</p> <p>Transferring out of bed: In the</p>	<p>Round 1 (2011): sc1deathelp Round 2 (2012): sc2deathelp, Round 3 (2013): sc3deathelp</p> <p>Round 1 (2011): sc1dbathhelp Round 2 (2012): sc2dbathhelp Round 3 (2013): sc3dbathhelp</p> <p>Round1 (2011): sc1dreshelp Round 2 (2012): sc2dreshelp Round 3 (2013): sc3dreshelp</p> <p>Round 1 (2011): sc1dtoilhelp Round 2 (2012): sc2dtoilhelp, Round 3 (2013): sc3dtoilhelp</p> <p>Round 1 (2011): mo1dbedhelp Round 2 (2012): mo2dbedhelp Round 3 (2013): mo3dbedhelp</p> <p>Round 1 (2011): mo1dinsdhelp Round 2 (2012): mo2dinsdhelp Round 3 (2013): mo3dinsdhelp</p> <p>All of the above are derived variables</p> <p>Round 1 (2011): mo1douthelp</p>	Ordinal: <ul style="list-style-type: none"> • <u>0 ADL Impairments</u> • <u>1-2 ADL impairments</u> • <u>3 or more ADL impairments</u>

Supplement 2 Table 1. Data source and measurement details of characteristics and outcomes of NHATS decedents with dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable name (if applicable)	Operational Definition
		<p>last month {of {his/her}life}, did anyone ever help {you/SP} get out of bed?</p> <p>Going inside: In the last month, did anyone ever help {you/SP} get around inside {your/his/her} home {or building}? 1) Yes; 2) No; DK/RF</p> <p>Going outside: In the last month, did anyone ever help {you/SP} leave {your/his/her}{home/building}to go outside? 1) Yes; 2) No; DK/RF</p>	<p>Round 2 (2012): mo2douthelp Round 3 (2013): mo3douthelp</p> <p>Note: all of the above variables are derived variables.</p>	
Comorbidities	NHATS Round Prior to Death (2011, 2012, 2013)	Round 1 (2011): I will read a list of some diseases and conditions that a doctor may have said {you have/SP has}. Please tell me if a doctor ever told {you/him/her} that {you/he/she} had: 1) a heart attack or myocardial infarction?; 2) any heart disease including angina or congestive heart failure?; 3) high blood pressure or hypertension?; 4) arthritis (including osteo or rheumatoid arthritis)? 5) osteoporosis or thinning of the bones?; 6) diabetes?; 7) lung disease, such as emphysema, asthma, or chronic bronchitis?; 8) a	<p>Round 1 (2011):</p> <ol style="list-style-type: none"> 1. history of heart attack (hc1disescn1) 2. heart disease (hc1disescn2) 3. high blood pressure (hc1disescn3) 4. arthritis (hc1disescn4) 5. osteoporosis (hc1disescn5) 6. diabetes (hc1disescn6) 7. lung disease (hc1disescn7) 8. stroke (hc1disescn8) 9. cancer (hc1disescn10) 10. broken hip (hc1brokebon1) <p>Round 2 (2012):</p> <ol style="list-style-type: none"> 1. history of heart attack (hc2disescn1) 2. heart disease (hc2disescn2) 3. high blood pressure 	<p>Ordinal:</p> <ul style="list-style-type: none"> • <u>0-1 comorbidities</u> • <u>2-3 comorbidities</u> • <u>4+ comorbidities</u>

Supplement 2 Table 1. Data source and measurement details of characteristics and outcomes of NHATS decedents with dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable name (if applicable)	Operational Definition
		<p>stroke? 9) dementia or Alzheimer's Disease (*NOT INCLUDED IN OUR ANALYSIS*)?; 10) cancer? 1) Yes; 2) No; DK/RF</p> <p>Since age 50 has a doctor told {you/SP} that {you have/{he/she} has broken or fractured hip? 1) Yes; 2) No; DK/RF</p> <p>In Rounds 2 and 3, wording changed as follows: We are interested in new health conditions that {you have/SP has} learned about this year. Since the time of the last interview has a doctor told {you/him/her}that {you/he/she} had (same list as above)</p>	<p>(hc2disescn3) 4. arthritis (hc2disescn4) 5. osteoporosis (hc2disescn5) 6. diabetes (hc2disescn6) 7. lung disease (hc2disescn7) 8. stroke (hc2disescn8) 9. cancer (hc2disescn10) 10. broken hip (hc2brokebon1)</p> <p>Round 3: 1. history of heart attack (hc3disescn1) 2. heart disease (hc3disescn2) 3. high blood pressure (hc3disescn3) 4. arthritis (hc3disescn4) 5. osteoporosis (hc3disescn5) 6. diabetes (hc3disescn6) 7. lung disease (hc3disescn7) 8. stroke (hc3disescn8) 9. cancer (hc3disescn10) 10. broken hip (hc3brokebon1)</p>	
Pain in last month of life	NHATS LML Interview (2012, 2013, 2014)	During the last month of {SP}'s life, were there times when {he/she} experienced pain? 1) Yes; 2) No; DK/RF	Round 2 (2012): lm2pain Round 3 (2013): lm3pain Round 4 (2014): lm4pain	Dichotomous: • <u>Pain in the LML</u> • <u>No pain in the LML</u>
Unmet need for pain management in last month of life	NHATS LML Interview (2012, 2013, 2014)	Did {SP} get any help in dealing with {his/her} pain? 1) Yes; 2) No; DK/RF	Round 2 (2012): lm2painhlp Round 3 (2013): lm3painhlp Round 5 (2014): lm4painhlp	Dichotomous: • <u>Unmet need for pain management=No help OR Yes help but Help was less than was needed OR more than was needed</u> • <u>No unmet need for pain management=Yes help AND help was about the right amount</u>

Supplement 2 Table 1. Data source and measurement details of characteristics and outcomes of NHATS decedents with dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable name (if applicable)	Operational Definition
		More than was needed; 3) About the right amount; DK/RF		
Any ED visit	NHATS/Medicare linked inpatient and outpatient claims files	N/A	NCH_CLM_TYPE_CD=40, 60, 61 and Revenue Center Code 045X or 0981 or Healthcare Common Procedure Coding System (HCPCS) classification code 99281-99285	Dichotomous: <ul style="list-style-type: none"> • <u>Any ED visit</u>=yes/no Count: <ul style="list-style-type: none"> • <u>Any ED visit average</u> Ordinal (for Figure 1): <ul style="list-style-type: none"> • <u>0 visits</u> • <u>1 visit</u> • <u>2 or more visits</u>
Outpatient only ED visit	NHATS/Medicare linked outpatient claims files	N/A	NCH_CLM_TYPE_CD=40, and Revenue Center Code 045X or 0981 OR Healthcare Common Procedure Coding System (HCPCS) classification code 99281-99285	Dichotomous: <ul style="list-style-type: none"> • <u>Outpatient only ED visit</u>=yes/no Count: <ul style="list-style-type: none"> • <u>Outpatient only ED visit: average visit number</u>
ED visit with hospital admission	NHATS/Medicare linked inpatient and outpatient claims files	N/A	NCH_CLM_TYPE_CD=60, 61	Dichotomous: <ul style="list-style-type: none"> • <u>ED visit with hospital admission</u> =yes/no Count: <ul style="list-style-type: none"> • <u>ED visit with hospital admission: average visit number</u>
Hospice use	NHATS/Medicare linked hospice file	N/A	NCH_CLM_TYPE_CD=50	Dichotomous: <ul style="list-style-type: none"> • <u>Any hospice use</u>=yes/no Continuous: <ul style="list-style-type: none"> • <u>Hospice Length of Stay</u> (if any hospice use = yes), mean number of days

Supplement 2 Table 1. Data source and measurement details of characteristics and outcomes of NHATS decedents with dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable name (if applicable)	Operational Definition
Fee for service coverage	NHATS/Medicare Beneficiary Summary linked file	N/A	BENE_MDCR_ENTLMT_BUYIN_I ND_01 - BENE_MDCR_ENTLMT_BUYIN_I ND_12 BENE_HMO_IND_01 - BENE_HMO_IND_12	Dichotomous: <u>Fee for service:</u> yes/no

Supplement 2 Table 2: Top 10 Primary Diagnoses for Determining Frequency of Any ED visit and associated ICD-9 codes

Description	ICD-9 Codes
Septicemia	038.0, 038.10, 038.11, 038.12, 038.19, 038.40, 038.42, 038.43, 038.9
Cardiac arrest	427.5
Pneumonia and other respiratory diseases	466.0, 481, 482.0, 482.1, 482.42, 482.83, 482.9, 486
Malignancy	146.0, 150.5, 153.0, 153.1, 153.3, 153.8, 153.9, 154.0, 155.0, 157.1, 157.9, 158.9, 162.3, 162.5, 162.8, 162.9, 163.9, 183.0, 183.8, 185, 191.9, 192.1, 193, 197.6, 197.7, 198.3, 198.5, 202.83, 203.00, 225.2, 239.6, 259.2
Congestive heart failure	402.91, 404.91, 428.0, 428.21, 428.23, 428.31, 428.33, 428.40, 428.43,
Cerebrovascular disease	430, 431, 432.1, 432.9, 434.01, 434.91, 435.8, 435.9, 438.22, 438.89
Cystitis and other urological infections	590.10, 599.0,
Hip fracture and fractures of other bones	820.02, 820.03, 820.09, 820.21, 820.8, 821.00, 821.01, 733.11, 802.0, 802.8, 805.01, 805.02, 805.2, 805.4, 807.01, 807.03, 807.04, 807.06, 808.2, 808.8, 812.41, 822.0
Stomach/intestinal disorders	536.8, 552.20, 552.29, 557.0, 558.9, 560.1, 560.2, 560.89, 560.9, 564.00, 567.22, 569.83, 569.85, 787.91
Fluid and electrolyte disturbances	253.6, 276.0, 276.50, 276.51, 276.69, 276.7

Abbreviations: ICD=International Classification of Disease