

Supplemental material with the manuscript

**Time until nursing home admission and death in persons with dementia: a
systematic review and meta-analysis**

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Supplementary data S1: PROSPERO protocol

The PROSPERO protocol can be found under this link:

https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=341507

Supplementary data S2: Search strategy

Embase

('dementia'/de/mj OR 'Alzheimer disease'/de/mj OR 'diffuse Lewy body disease'/de/mj OR 'Lewy body'/de/mj OR 'multiinfarct dementia'/de/mj OR 'frontotemporal dementia'/de/mj OR (DLB OR DLBD OR dement* OR alzheimer* OR lewy-bod* OR frontotemp*):ti,kw) ('survival'/exp OR 'mortality'/exp OR 'institutionalization'/de OR 'prognosis'/de OR (survival* OR mortalit* OR (death* NOT (cell* OR neuron*))) OR life-expectanc* OR institutionalis* OR institutionaliz* OR prognos* OR (nurs*-home* OR car*-home* OR elder*-home*) NEAR/3 (admission* OR time-to OR transition* OR risk-of OR time-until OR placement*)):ab,ti,kw) AND ('observational study'/exp OR 'cohort analysis'/exp OR 'longitudinal study'/exp OR 'retrospective study'/exp OR 'prospective study'/exp OR 'health survey'/de OR 'health care survey'/de OR 'epidemiological data'/de OR 'case control study'/de OR 'cross-sectional study'/de OR 'correlational study'/de OR 'population research'/de OR 'family study'/de OR 'major clinical study'/de OR 'multicenter study'/de OR 'comparative study'/de OR 'follow up'/de OR 'clinical study'/de OR 'clinical article'/de OR 'clinical trial'/exp OR 'randomization'/exp OR 'intervention study'/de OR 'open study'/de OR 'community trial'/de OR 'controlled study'/de OR (((observation* OR epidemiolog* OR famil* OR comparativ* OR communit* OR interven*) NEAR/6 (stud* OR data OR research)) OR cohort* OR longitudinal* OR retrospectiv* OR prospectiv* OR population* OR (national* NEAR/3 (stud* OR survey)) OR (health* NEAR/3 survey*) OR ((case OR cases OR match*) NEAR/3 control*) OR (cross NEXT/1 section*) OR correlation* OR multicenter* OR multi-center* OR follow-up* OR followup* OR clinical* OR trial OR random* OR (mixed NEAR/3 method*)):ab,ti,kw) NOT ((animal/exp OR animal*:de OR nonhuman/de) NOT ('human'/exp)) NOT ([Conference Abstract]/lim) NOT ('case report'/de OR (case-report*):ab,ti)

Medline

(exp *Dementia/ OR exp *Lewy Bodies/ OR *Dementia, Multi-Infarct/ OR *Frontotemporal Dementia/ OR (DLB OR DLBD OR dement* OR alzheimer* OR lewy-bod* OR frontotemp*):ti,kf.) AND (Survival/ OR Mortality/ OR Institutionalization/ OR Prognosis/ OR (survival* OR mortalit* OR (death* NOT (cell* OR neuron*))) OR life-expectanc* OR institutionalis* OR institutionaliz* OR prognos* OR ((nurs*-home* OR car*-home* OR elder*-home*) ADJ3 (admission* OR time-to OR transition* OR risk-of OR time-until OR placement*)):ab,ti,kf.) AND ("Observational Study"/ OR exp "Cohort Studies"/ OR "Health Surveys"/ OR exp "Epidemiologic Studies"/ OR "Case-Control Studies"/ OR "Cross-Sectional Studies"/ OR "Multicenter Study"/ OR "Comparative Study"/ OR "Clinical Study"/ OR "Clinical Trial"/ OR "Random Allocation"/ OR

((observation* OR epidemiolog* OR famil* OR comparativ* OR communit*) ADJ6 (stud* OR data OR research)) OR cohort* OR longitudinal* OR retrospectiv* OR prospectiv* OR population* OR (national* ADJ3 (stud* OR survey)) OR (health* ADJ3 survey*) OR ((case OR cases OR match*) ADJ3 control*) OR (cross ADJ section*) OR correlation* OR multicenter* OR multi-center* OR follow-up* OR followup* OR clinical* OR trial OR random* OR (mixed ADJ3 method*).ab,ti,kf.) NOT (exp animals/ NOT humans/) NOT (news OR congress* OR abstract* OR book* OR chapter* OR dissertation abstract*).pt. NOT (case report/ OR (case-report*).ti.)

Cochrane

((DLB OR DLBD OR dement* OR alzheimer* OR lewy-bod* OR frontotemp*):ti,kw) AND ((survival* OR mortalit* OR (death* NOT (cell* OR neuron*)) OR life-expectanc* OR institutionalis* OR institutionaliz* OR prognos* OR (((nurs* NEXT/1 home*) OR (car* NEXT/1 home*) OR (elder* NEXT/1 home*)) NEAR/3 (admission* OR time-to OR transition* OR risk-of OR time-until OR placement*)):ab,ti,kw) AND (((observation* OR epidemiolog* OR famil* OR comparativ* OR communit* OR interven*) NEAR/6 (stud* OR data OR research)) OR cohort* OR longitudinal* OR retrospectiv* OR prospectiv* OR population* OR (national* NEAR/3 (stud* OR survey)) OR (health* NEAR/3 survey*) OR ((case OR cases OR match*) NEAR/3 control*) OR (cross NEXT/1 section*) OR correlation* OR multicenter* OR multi-center* OR follow-up* OR followup* OR clinical* OR trial OR random* OR (mixed NEAR/3 method*)):ab,ti,kw) NOT "conference abstract":kw

Web of Science

TI=(((DLB OR DLBD OR dement* OR alzheimer* OR lewy-bod* OR frontotemp*))) AND (TI=(((survival* OR mortalit* OR (death* NOT (cell* OR neuron*)) OR life-expectanc* OR institutionalis* OR institutionaliz* OR prognos* OR ((nurs*-home* OR car*-home* OR elder*-home*) NEAR/2 (admission* OR time-to OR transition* OR risk-of OR time-until OR placement*)))))) OR AB=(((survival* OR mortalit* OR (death* NOT (cell* OR neuron*)) OR life-expectanc* OR institutionalis* OR institutionaliz* OR prognos* OR ((nurs*-home* OR car*-home* OR elder*-home*) NEAR/2 (admission* OR time-to OR transition* OR risk-of OR time-until OR placement*)))))) AND (TI=(((observation*) NEAR/5 (stud* OR data OR research)) OR cohort* OR longitudinal* OR retrospectiv* OR prospectiv* OR population* OR (national* NEAR/2 (stud* OR survey)) OR (health* NEAR/2 survey*) OR ((case OR cases OR match*) NEAR/2 control*) OR (cross-section*) OR correlation* OR multicenter* OR multi-center* OR follow-up* OR followup* OR clinical* OR trial OR random*

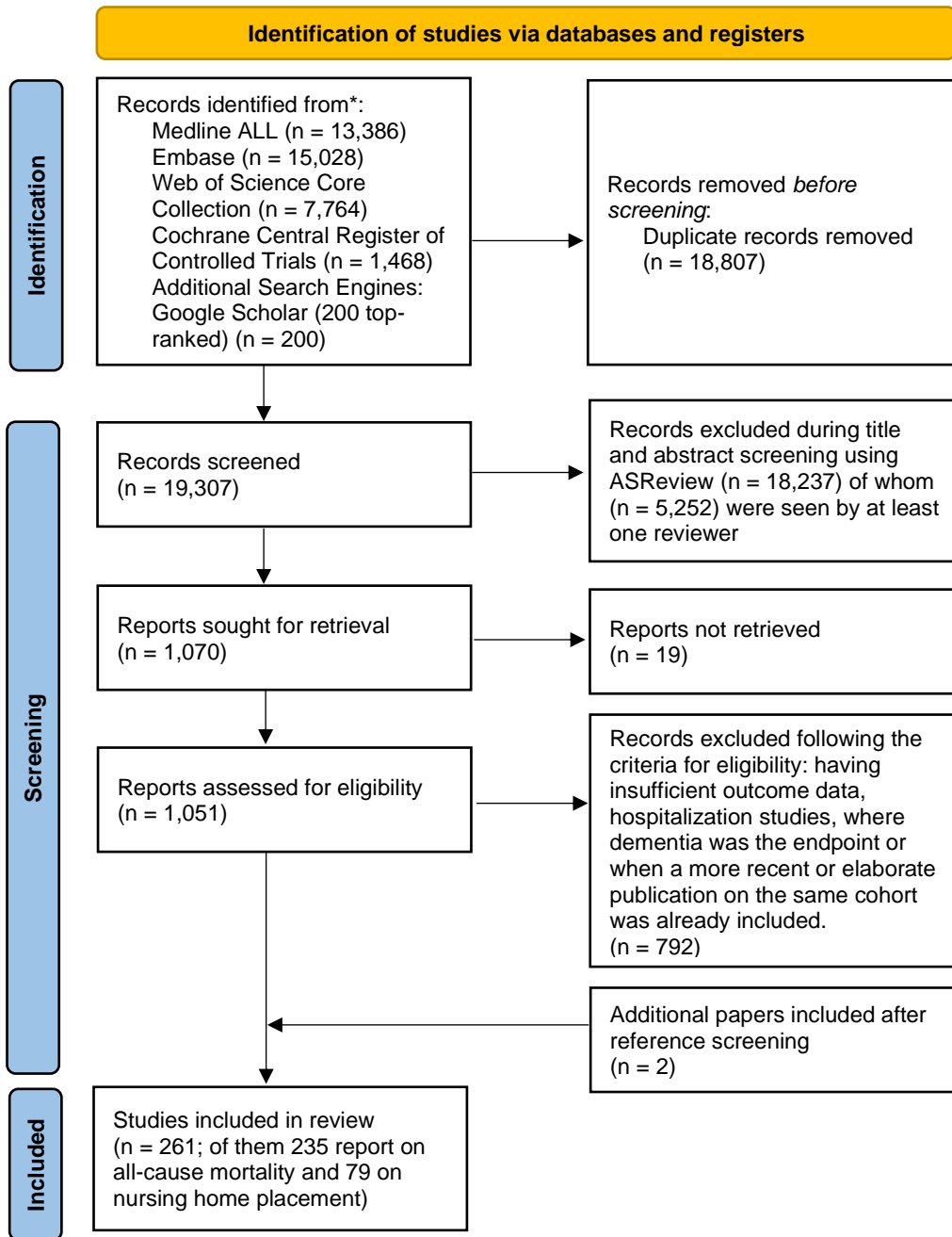
OR (mixed NEAR/2 method*)))) OR AB=((((observation*) NEAR/5 (stud* OR data OR research)) OR cohort* OR longitudinal* OR retrospectiv* OR prospectiv* OR population* OR (national* NEAR/2 (stud* OR survey)) OR (health* NEAR/2 survey*) OR ((case OR cases OR match*) NEAR/2 control*) OR (cross-section*) OR correlation* OR multicenter* OR multi-center* OR follow-up* OR followup* OR clinical* OR trial OR random* OR (mixed NEAR/2 method*)))) NOT TS=(((animal* OR rat OR rats OR mouse OR mice OR murine OR dog OR dogs OR canine OR cat OR cats OR feline OR rabbit OR cow OR cows OR bovine OR rodent* OR sheep OR ovine OR pig OR swine OR porcine OR veterinar* OR chick* OR zebrafish* OR baboon* OR nonhuman* OR primate* OR cattle* OR goose OR geese OR duck OR macaque* OR avian* OR bird* OR fish*) NOT (human* OR patient* OR women OR woman OR men OR man))) NOT DT=(Meeting Abstract OR Meeting Summary) NOT TI=(case-report)

Google Scholar

dementia|alzheimer|"lewy body|bodies" survival|mortality|institutionalised|institutionalized

Note: The results from Google Scholar were limited to the first 200 hits.

Supplementary data S3: Flowchart of Included Studies



Based on: Page MJ, et al. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

Supplementary data S4: Detailed methods for patient characteristic extraction

In addition to age, sex, race/ethnicity, and dementia subtype, we extracted more in-depth patient characteristic data on education, living alone, marital status, number of children, family history of dementia, history of stroke, history of heart disease, history of other vascular burden, history of cancer, current smoking, body mass index, diabetes, hypertension, depression, NPI score, MMSE score, CDR score, function score (e.g. ADL, IADL), mobility issues, comorbidity index. Due to substantial variability in reporting standards, meaningful extraction of data for most of these additional characteristics was not possible. Data was available, although still limited, for education, living alone and/or marital status (combined into one cohabitation variable) and mean baseline MMSE score. As education was most often reported as mean or median number of years of education at baseline compared to categorical reporting which also differed across studies, we extracted mean or median number of years of education at baseline . Information on living alone and marital status was combined into one cohabitation variable with marital status taking priority when information on both was provided. Finally, we extracted information on mean or median MMSE score at baseline.

Supplementary data S5: Modified Newcastle-Ottawa Scale for Quality assessment

| Item | Criterion | Rating Categories | N (%) of survival samples (n=404) | N (%) of nursing home samples (n=85) |
|-----------------------|--|---|--|---|
| 1 | Dementia diagnosis assessment | 2 = clinical exam or direct access to medical records 1 = reported by relative or caregiver, or based on registry data (e.g., ICD-10 coding) 0 = not specified or screening test only (e.g. MMSE) | 250 (61.9) 140 (34.7) 14 (3.5) | 62 (72.9) 22 (25.9) 1 (1.2) |
| 2 | Time of inclusion (incident or prevalent dementia) | 1 = incident, or prevalent with reported dementia duration 0 = not specified, or prevalent without reported dementia duration | 231 (57.2) 173 (42.8) | 41 (48.2) 44 (51.8) |
| 3 | Patient characteristics reported | 2 = age, sex, ethnicity and dementia type reported 1 = at least age and sex reported 0 = not specified | 54 (13.4) 256 (63.4) 94 (23.3) | 18 (21.2) 59 (69.4) 8 (9.4) |
| 4 | Outcome assessment | 2 = registry-linked or medical records linked 1 = informant based 0 = not specified | 257 (63.6) 54 (13.4) 93 (23.0) | 28 (32.9) 29 (34.1) 28 (32.9) |
| 5 | Maximum follow-up duration | 1 = ≥ 5 years for survival studies or ≥ 3 years for nursing home studies 0 = < 5 years for survival studies or < 3 years for nursing home studies | 295 (73.0) 106 (27.0) | 55 (64.7) 30 (35.3) |
| 6 | Attrition | 2 = $< 10\%$ attrition 1 = 10% - 20% attrition 0 = $> 20\%$ attrition or not specified | 74 (18.3) 15 (3.7) 315 (78.0) | 19 (22.4) 13 (15.3) 53 (62.4) |
| Overall quality score | | Sum of the scores of the individual quality criteria (range 0 to 10) | Mean score: 5.6 | Mean score: 5.6 |

Supplementary data S6: Data imputation

For the meta-regression analyses, missing data for study start year (4.3%), maximum follow-up time (6.6%), sex (15.0%), and age (19.1%) were imputed based on all other baseline study characteristics, using the “mice” package (version 3.16.0) with 50 iterations and 10 imputed sets. The continuous variables (age, sex proportion, and maximum follow-up time) were imputed using the predictive mean matching method, while a proportional odds model was used for the ordered, categorical variable (study start year in decades).

Figure 1 shows the density plots for continuous variables and Figure 2 shows the proportion plot for the categorical variable. The density of the imputed values follows the original, incomplete data well. For the study start year variable, the imputed values are more often earlier decades (1980 and 1990) and less often more recent decades (2000 and 2010) than in the original, incomplete data. This could however be due to publications based on older cohorts not reporting the study start. Finally, all four variables show stable mean and standard deviations across the 50 imputation iterations (Figure 3).

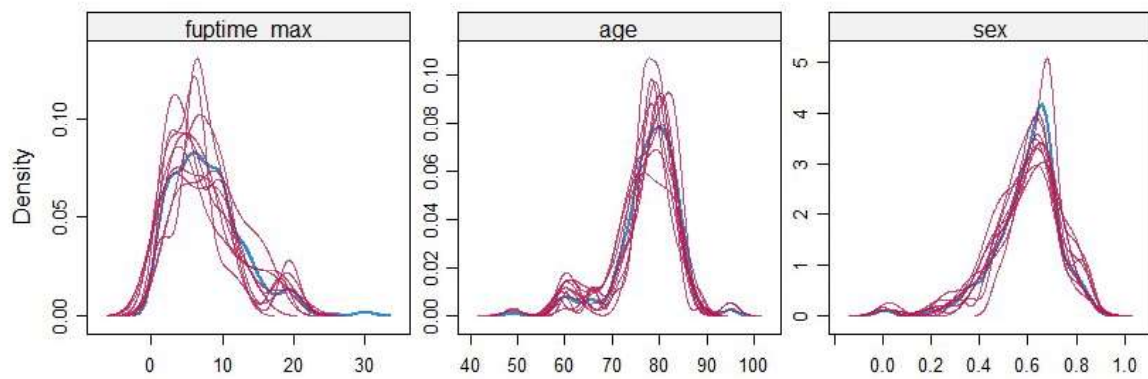


Figure 1: Imputation density plots for continuous variables.

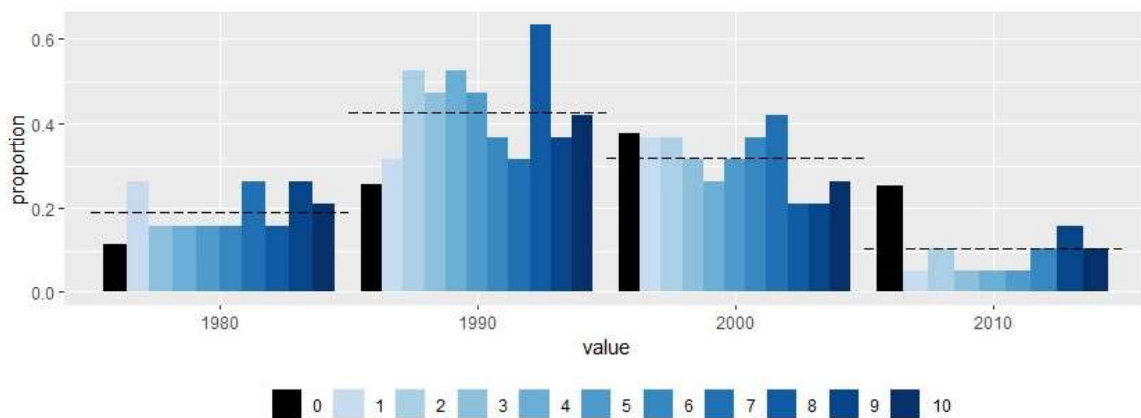


Figure 2: Imputation proportion plot for categorical variable, study start year in decades.

Legend: Each bar represents the proportion of the data in the category given on the x-axis in one (imputed) dataset. The black bars (0) show the distribution of the original, incomplete data. The blue bars (1-10) show the corresponding distribution in the imputed values from each of the imputed datasets. The dashed lines present the average proportion per category.

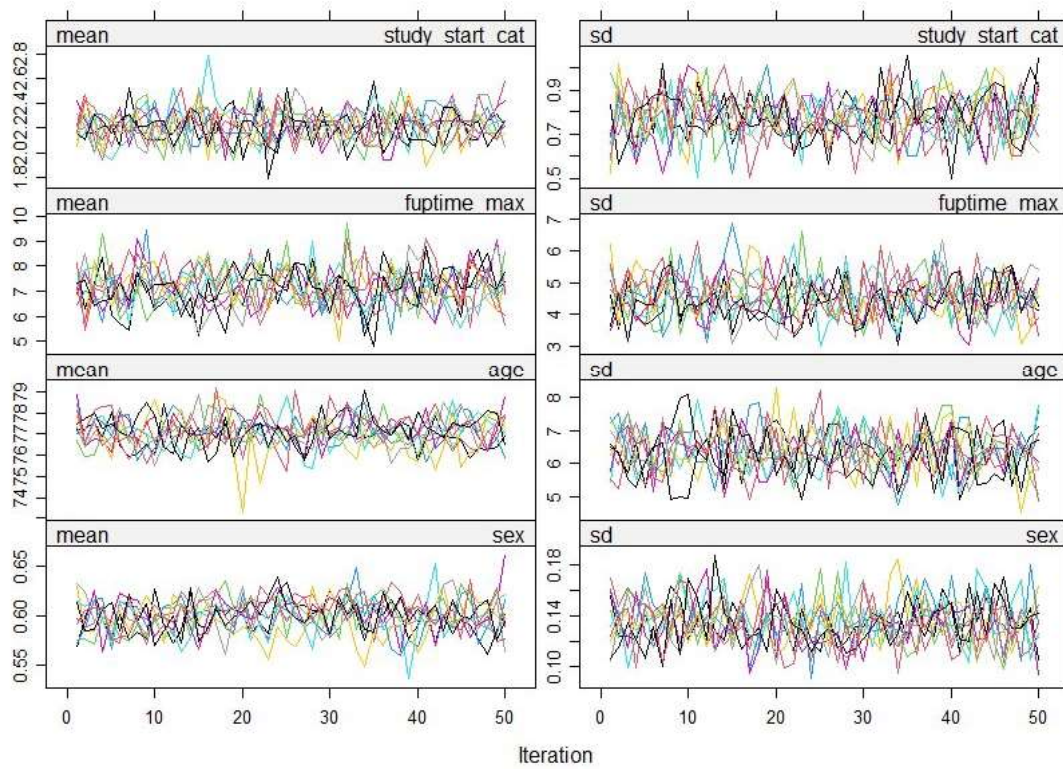


Figure 3: Mean and standard deviation of the imputed variable across the 50 iterations.

Supplementary data S7: Included Studies

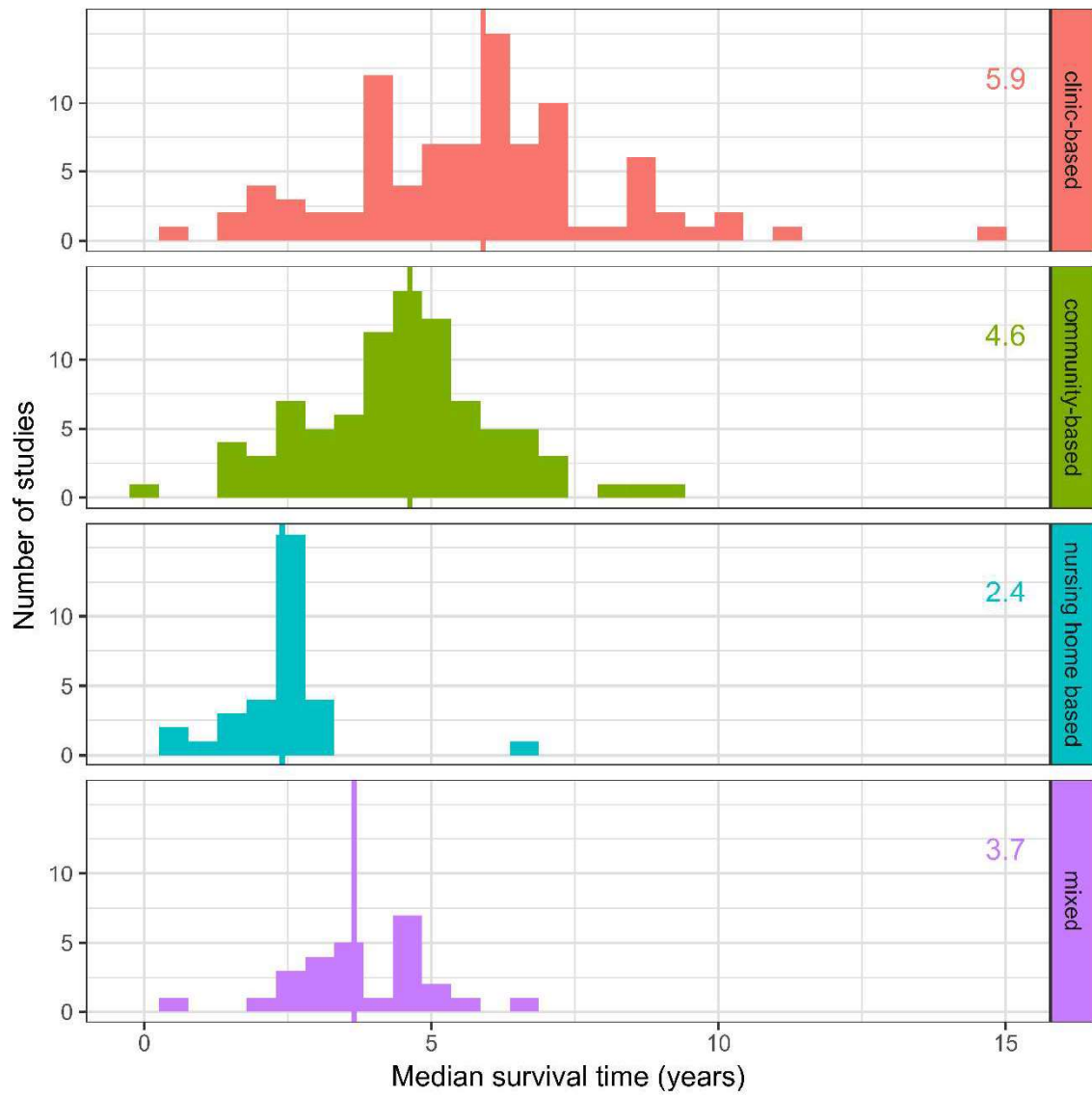
An overview of all studies included in the systematic review, along with study and population characteristics is presented in a supplementary excel file.

Supplementary data S8: Median survival and 5-year survival probability in contemporary studies

Legend: Estimated median survival and 5-year survival probability by age and sex and restricted to studies that included participants at time of diagnosis and were published from the year 2000 onwards.

| | Median survival (n=125 studies) | | 5-year survival (n=115 studies) | |
|--------|---------------------------------|-------|---------------------------------|-------|
| | men | women | men | women |
| Age 60 | 6.5 | 8.9 | 0.59 | 0.86 |
| Age 65 | 5.7 | 8.0 | 0.52 | 0.79 |
| Age 70 | 4.8 | 7.2 | 0.45 | 0.72 |
| Age 75 | 3.9 | 6.3 | 0.38 | 0.66 |
| Age 80 | 3.0 | 5.4 | 0.32 | 0.59 |
| Age 85 | 2.2 | 4.5 | 0.25 | 0.52 |
| Age 90 | 1.3 | 3.7 | 0.18 | 0.45 |

Supplementary data S9: Median survival by study setting



Supplementary data S10: Forest plot median survival



Note: Sample sizes can be lower than 150 as studies can have subsamples with fewer than 150 individuals.

Supplementary data S11: Determinants of 1-, 3-, 5- and 10-year survival after dementia diagnosis

Legend: Table depicts results of the fully adjusted meta-regression analysis on yearly survival probability. Presented estimates reflect the change in probability at the time point of interest, compared to the reference category or per unit increase for the continuous variable. Regression analyses were weighted by the number of patients in each study. The p-value for 'year of study start' reflects the trend across categories. Explained variance in the models (R^2) was 0.45, 0.50, 0.51 and 0.45 for year 1, year 3, year 5 and year 10, respectively.

| | Year 1 (n=244) | | Year 3 (n=219) | | Year 5 (n=193) | | Year 10 (n=87) | |
|----------------------|----------------------|--------|----------------------|--------|----------------------|--------|----------------------|--------|
| | β (95% CI) | p | β (95% CI) | p | β (95% CI) | p | β (95% CI) | p |
| Age, year | 0 (-0.01, 0) | 0.028 | -0.01 (-0.01, 0) | 0.004 | -0.01 (-0.02, 0) | 0.002 | -0.01 (-0.02, 0) | 0.034 |
| Women vs. men | -0.07 (-0.19, 0.06) | 0.284 | -0.04 (-0.27, 0.19) | 0.745 | 0.03 (-0.27, 0.34) | 0.838 | 0.1 (-0.43, 0.63) | 0.718 |
| Dementia Type | | | | | | | | |
| All-cause | Reference | | Reference | | Reference | | Reference | |
| Alzheimer's disease | 0.03 (0, 0.05) | 0.052 | 0.05 (0, 0.09) | 0.038 | 0.05 (-0.01, 0.1) | 0.091 | 0.04 (-0.06, 0.14) | 0.481 |
| Other | -0.02 (-0.06, 0.01) | 0.157 | -0.04 (-0.1, 0.01) | 0.096 | -0.08 (-0.14, -0.02) | 0.008 | -0.01 (-0.13, 0.12) | 0.884 |
| Study setting | | | | | | | | |
| Clinic | Reference | | Reference | | Reference | | Reference | |
| Community | -0.01 (-0.05, 0.02) | 0.398 | -0.05 (-0.1, 0) | 0.047 | 0 (-0.06, 0.07) | 0.889 | 0.11 (-0.01, 0.23) | 0.087 |
| Mixed | -0.06 (-0.12, 0) | 0.063 | -0.15 (-0.24, -0.06) | <0.001 | -0.14 (-0.28, 0.01) | 0.064 | NA | NA |
| Nursing Home | -0.13 (-0.18, -0.08) | <0.001 | -0.23 (-0.31, -0.15) | <0.001 | -0.17 (-0.28, -0.07) | 0.001 | 0.03 (-0.28, 0.34) | 0.865 |
| Continent | | | | | | | | |
| Europe | Reference | | Reference | | Reference | | Reference | |
| North America | -0.03 (-0.05, 0) | 0.055 | -0.03 (-0.08, 0.01) | 0.187 | -0.06 (-0.11, -0.01) | 0.031 | -0.11 (-0.22, 0) | 0.052 |
| Asia | 0 (-0.03, 0.03) | 0.924 | 0.03 (-0.02, 0.08) | 0.231 | 0.13 (0.07, 0.19) | <0.001 | 0.2 (0.1, 0.3) | <0.001 |
| Other | 0 (-0.07, 0.07) | 0.947 | -0.06 (-0.17, 0.05) | 0.286 | 0.02 (-0.12, 0.16) | 0.822 | NA | NA |
| Year of study start | | 0.969 | | 0.488 | | 0.008 | | 0.008 |
| <1990 | -0.02 (-0.07, 0.02) | | -0.08 (-0.15, -0.01) | | -0.12 (-0.21, -0.03) | | -0.2 (-0.34, -0.05) | |
| 1990s | 0.03 (0, 0.07) | | 0.02 (-0.04, 0.07) | | 0.04 (-0.03, 0.11) | | 0.05 (-0.07, 0.17) | |
| 2000s | Reference | | Reference | | Reference | | Reference | |
| >=2010s | 0 (-0.03, 0.03) | | -0.03 (-0.08, 0.01) | | 0.02 (-0.04, 0.07) | | 0.04 (-0.08, 0.15) | |
| Case ascertainment | | | | | | | | |
| Clinical examination | Reference | | Reference | | Reference | | Reference | |
| Medical Records | -0.05 (-0.1, 0) | 0.035 | -0.07 (-0.15, 0.01) | 0.072 | -0.1 (-0.2, -0.01) | 0.040 | -0.15 (-0.35, 0.06) | 0.174 |
| Registry | -0.03 (-0.06, 0) | 0.075 | -0.04 (-0.08, 0.01) | 0.132 | -0.09 (-0.15, -0.03) | 0.004 | -0.13 (-0.24, -0.01) | 0.035 |
| Other | -0.08 (-0.13, -0.02) | 0.007 | -0.07 (-0.16, 0.01) | 0.106 | -0.12 (-0.22, -0.01) | 0.027 | 0.02 (-0.31, 0.35) | 0.903 |
| Time of inclusion | | | | | | | | |
| Incident | Reference | | Reference | | Reference | | Reference | |
| Mixed | 0.01 (-0.06, 0.09) | 0.744 | 0.01 (-0.1, 0.12) | 0.813 | -0.01 (-0.16, 0.15) | 0.931 | 0.02 (-0.34, 0.38) | 0.896 |
| Prevalent | 0.01 (-0.02, 0.03) | 0.537 | 0.01 (-0.04, 0.05) | 0.800 | 0.01 (-0.04, 0.06) | 0.659 | 0.13 (0.03, 0.24) | 0.015 |

Estimate: estimate (\pm 95% CI), p: p-value.

Supplementary data S12: Impact of education, cohabitation status, and MMSE baseline score on median survival and time till nursing home admission.

Education: mean or median years of education; cohabitation status: proportion of study sample not living alone or being married, ranging from 0 to 1 (estimate represents the difference in survival/time to nursing home comparing a 100% married/living together population with an 100% unmarried/living alone population); MMSE baseline score: mean or median MMSE baseline score.

| | Number of studies | Mean/median |
|---|-------------------|------------------|
| Education (years; mean (SD)) | 36 | 10.5 (3.3) |
| Cohabitation status (yes/no; mean (SD)) | 40 | 0.53 (0.19) |
| MMSE score | 73 | |
| Mean (SD) | | 19.1 (3.6) |
| Median [IQR] | | 20 [17.3 - 21.6] |

Legend: Meta regression analysis of available studies, adjusted for sex in the education model, and for age and sex in the cohabitation status and MMSE models.

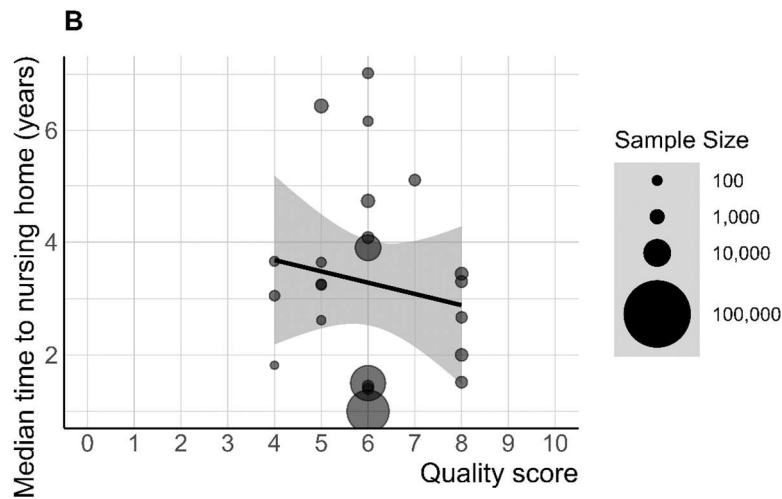
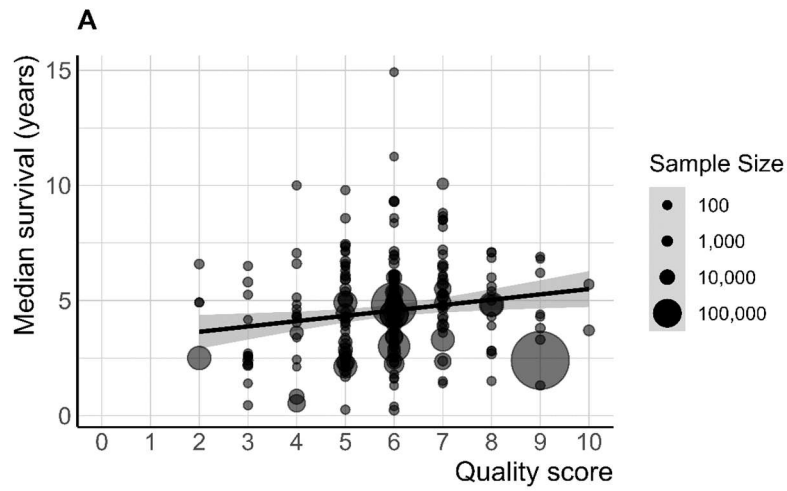
| | Number of studies | β (95% CI) | P |
|-------------------------------|-------------------|----------------------|-------|
| Survival | | | |
| Education (years) | 36 | -0.20 (-0.38, -0.03) | 0.028 |
| Cohabitation status (yes/no) | 40 | 6.22 (2.48, 9.96) | 0.003 |
| MMSE score | 73 | -0.02 (-0.22, 0.18) | 0.858 |
| Nursing home admission | | | |
| Education (years) | 9 | 0.33 (-0.4, 1.07) | 0.417 |
| Cohabitation status (yes/no) | 13 | 0.61 (-3.2, 4.42) | 0.762 |
| MMSE score | 15 | 0.11 (-0.19, 0.4) | 0.489 |

Study characteristics for studies (not) reporting education, cohabitation and MMSE

| Study characteristic | Education reported (n=68) | Education missing (n=371) | Cohabitation reported (n=102) | Cohabitation missing (n=337) | MMSE reported (n=152) | MMSE missing (n=287) |
|---|----------------------------------|----------------------------------|--------------------------------------|-------------------------------------|------------------------------|-----------------------------|
| Age (median, IQR) | 75.6 [73.1-77.6] | 79.7 [76.2-82.5] | 79.4 [75.6-82.1] | 78.8 [75.2-82.0] | 76.2 [73.5-79.2] | 80.8 [77.8-83.0] |
| Sex (median, IQR) | 0.59 [0.50-0.66] | 0.63 [0.55-0.69] | 0.60 [0.54-0.67] | 0.63 [0.53-0.69] | 0.61 [0.50-0.68] | 0.63 [0.56-0.68] |
| Dementia type (%) | | | | | | |
| All-cause | 30.9 | 45.8 | 56.9 | 39.5 | 29.6 | 50.9 |
| Alzheimer's | 48.5 | 29.1 | 30.4 | 32.6 | 45.4 | 25.1 |
| Disease | | | | | | |
| Other | 20.6 | 25.1 | 12.7 | 27.9 | 25.0 | 24.0 |
| Study setting (%) | | | | | | |
| Clinic | 76.5 | 37.2 | 49.0 | 41.5 | 69.1 | 29.6 |
| Community | 17.6 | 42.3 | 32.4 | 40.4 | 23.0 | 46.7 |
| Nursing home | 2.9 | 12.4 | 11.8 | 10.7 | 3.3 | 15.0 |
| Mixed | 2.6 | 8.1 | 6.9 | 7.4 | 4.6 | 8.7 |
| Geographical location (%) | | | | | | |
| Europe | 29.4 | 60.1 | 55.9 | 55.2 | 58.6 | 53.7 |
| North America | 54.4 | 21.6 | 35.3 | 24.0 | 28.9 | 25.4 |
| Asia | 14.7 | 13.2 | 1.0 | 17.2 | 9.2 | 15.7 |
| Other | 1.5 | 5.1 | 7.8 | 3.6 | 3.3 | 5.2 |
| Years of study enrolment (%) | | | | | | |
| <1990 | 6.3 | 12.3 | 2.1 | 14.2 | 6.4 | 13.9 |
| 1990s | 38.1 | 23.2 | 21.1 | 26.8 | 35.0 | 20.7 |
| 2000s | 31.7 | 38.9 | 44.2 | 36.0 | 36.4 | 38.6 |
| ≥2010s | 23.8 | 25.5 | 32.6 | 23.1 | 22.1 | 26.8 |
| Case ascertainment (%) | | | | | | |
| Clinical exam | 91.2 | 49.9 | 52.9 | 57.3 | 73.0 | 47.4 |
| Medical records | 5.9 | 7.3 | 4.9 | 7.7 | 3.9 | 8.7 |
| Registry | 2.9 | 37.2 | 32.4 | 31.8 | 19.7 | 38.3 |
| Other | NA | 5.7 | 9.8 | 3.3 | 3.3 | 5.6 |
| Time of inclusion (%) | | | | | | |
| Incident | 44.1 | 50.1 | 49.0 | 49.3 | 48.0 | 49.8 |
| Prevalent | 48.5 | 46.9 | 48.0 | 46.9 | 47.4 | 47.0 |
| Mixed/unclear | 7.4 | 3.0 | 2.9 | 3.9 | 4.6 | 3.1 |
| Maximum follow-up time (median, IQR) | 8.0 [3.0-13.0] | 7.0 [4.5-10.0] | 6.0 [3.0-9.0] | 8.0 [5.0-11.0] | 7.0 [4.0-10.4] | 7.6 [4.5-10.0] |

Supplementary data S13: Survival and nursing home admission after dementia diagnosis by study quality

Legend: Bubble plot of median survival (A) and median time to nursing home (B) according to quality score.



Supplementary data S14: Impact of quality

Legend: Results from a meta-regression analysis to determine the association of several patient and study characteristics with median survival for the full sample and the subsample restricted to high quality studies (≥ 6 on Modified Newcastle-Ottawa Scale). For categorical variables, numbers can be interpreted as differences in median survival (in years), as compared to the reference category. For age, the estimate depicts the change in median survival per year increase. Regression analyses were weighted by the number of patients in each study. The full model included all listed variables (age, sex, dementia type, study setting, geographical location, year of study start, case ascertainment, time of inclusion), as well as maximum follow-up time (log transformed).

Excluding low quality studies did not affect the point estimates or significance level of the investigated variables.

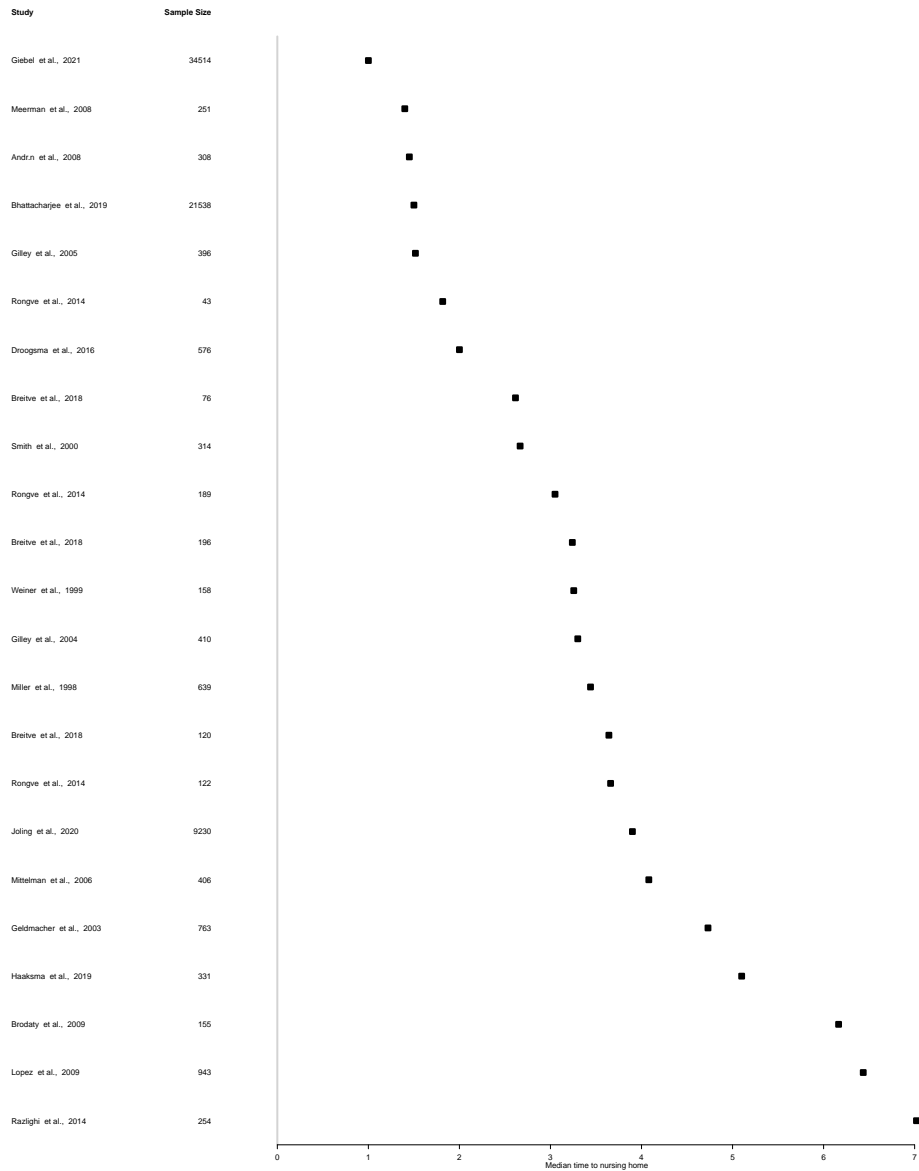
| Median Survival | All studies (n=238) | | High quality studies (≥ 6 ; n=149) | |
|--------------------------------|----------------------|---------|--|---------|
| | β (95% CI) | p-value | β (95% CI) | p-value |
| Age, year | -0.12 (-0.17, -0.07) | <0.001 | -0.12 (-0.17, -0.07) | <0.001 |
| Sex (men) | -0.41 (-2.66, 1.83) | 0.718 | -0.46 (-2.71, 1.78) | 0.687 |
| Dementia type | | | | |
| All-cause | Reference | | Reference | |
| Alzheimer's disease | 0.7 (0.21, 1.19) | 0.006 | 0.71 (0.22, 1.21) | 0.005 |
| Other | -0.76 (-1.33, -0.19) | 0.010 | -0.73 (-1.3, -0.15) | 0.014 |
| Study setting | | | | |
| Clinic-based | Reference | | Reference | |
| Community-based | -0.1 (-0.77, 0.58) | 0.778 | -0.08 (-0.76, 0.6) | 0.813 |
| Nursing home based | -1.03 (-1.91, -0.14) | 0.024 | -0.97 (-1.87, -0.07) | 0.037 |
| Mixed | 0.04 (-0.81, 0.89) | 0.928 | 0.05 (-0.81, 0.9) | 0.911 |
| Geographical location | | | | |
| Europe | Reference | | Reference | |
| North America | -0.41 (-0.88, 0.07) | 0.096 | -0.42 (-0.9, 0.06) | 0.088 |
| Asia | 1.09 (0.38, 1.8) | 0.003 | 1.14 (0.42, 1.85) | 0.002 |
| Other | -0.34 (-1.53, 0.84) | 0.571 | -0.21 (-1.44, 1.03) | 0.744 |
| Year of study start | | 0.562 | | |
| <1990 | -1.02 (-1.91, -0.13) | | -1.01 (-1.9, -0.11) | |
| 1990s | -0.28 (-0.9, 0.34) | | -0.28 (-0.9, 0.34) | |
| 2000s | Reference | | Reference | |
| ≥ 2010s | -0.24 (-0.77, 0.29) | | -0.22 (-0.75, 0.32) | |
| Case ascertainment | | | | |
| Clinical examination | Reference | | Reference | |
| Medical records | -0.71 (-1.56, 0.14) | 0.103 | -0.71 (-1.56, 0.14) | 0.103 |
| Registry | -0.61 (-1.13, -0.08) | 0.024 | -0.57 (-1.11, -0.04) | 0.037 |
| Other | -1.46 (-2.47, -0.44) | 0.005 | -1.34 (-2.4, -0.28) | 0.014 |
| Time of inclusion | | | | |
| Incident | Reference | | Reference | |
| Prevalent | -0.53 (-1.06, 0.01) | 0.055 | -0.44 (-1.03, 0.14) | 0.139 |
| Mixed | 1.01 (-0.27, 2.29) | 0.124 | 1.13 (-0.2, 2.45) | 0.096 |

Legend: Age- and sex-adjusted linear regression models were used to explore determinants of median time until nursing home admission for the full sample and the subsample restricted to high quality studies (≥ 6 on Modified Newcastle-Ottawa Scale). For categorical variables, numbers can be interpreted as differences in median time until nursing home admission (in years), as compared to the reference category. For age, the estimate depicts the change in median time to admission per year increase. Regression analyses were weighted by the number of patients in each study.

Excluding low quality studies did not affect the point estimates or significance level of the investigated variables, except for age which is no longer significant.

| Median time to nursing home | Full Sample (n=23) | | High quality studies (≥ 6 ; n=15) | |
|--------------------------------|---------------------|-------|---|-------|
| | β (95% CI) | p | β (95% CI) | p |
| Age, year | -0.3 (-0.46, -0.15) | 0.001 | -0.14 (-0.38, 0.09) | 0.258 |
| Women versus men | 0.59 (-4.83, 6) | 0.834 | -12.17 (-25.13, 0.79) | 0.099 |
| Dementia type | | | | |
| All-cause | Reference | | Reference | |
| Alzheimer's disease | -0.25 (-1.65, 1.16) | 0.737 | -0.38 (-2.02, 1.25) | 0.657 |
| Other | -1.7 (-4.32, 0.91) | 0.220 | NA | NA |
| Study setting | | | | |
| Clinic | Reference | | Reference | |
| Community | 0.74 (-1.78, 3.26) | 0.571 | 0.1 (-2.56, 2.75) | 0.945 |
| Mixed | 0.48 (-2.21, 3.17) | 0.729 | 0 (-2.79, 2.79) | 1.000 |
| Geographical location | | | | |
| Europe | Reference | | Reference | |
| North America | 0.05 (-1.34, 1.45) | 0.940 | 0.04 (-1.76, 1.85) | 0.964 |
| Other | 2.12 (-0.95, 5.19) | 0.194 | 0.08 (-3.95, 4.11) | 0.970 |
| Year Study Start | | | | |
| | | 0.706 | | |
| <1990 | 0.3 (-2.15, 2.76) | | 0.77 (-2.14, 3.68) | |
| 1990s | 0.95 (-0.55, 2.45) | | 1.17 (-0.74, 3.08) | |
| 2000s | Reference | | Reference | |
| ≥ 2010s | 1.29 (-0.3, 2.87) | | 1.01 (-0.74, 2.76) | |

Supplementary data S15: Forest plot time to nursing home



Note: Sample sizes can be lower than 150 as studies can have subsamples with fewer than 150 individuals.

Supplementary data S16: Meta-regression analysis of median time to nursing home and 1-, 3- and 5-year nursing home admission probabilities.

Legend: Age- and sex-adjusted linear regression models were used to explore determinants of median time till nursing home admission as well as probabilities by year.

Presented estimates reflect the change in probability at the time point of interest, compared to the reference category or per unit increase for the continuous variable.

Regression analyses were weighted by the number of patients in each study. The p-value for 'year of study start' reflects the trend across categories. Explained variance in the models (R^2) was 0.55, 0.36, 0.27 and 0.26 for median, year 1, year 3 and year 5, respectively.

| | Median time (n=23) | | Year 1 (n=56) | | Year 3 (n=42) | | Year 5 (n=23) | |
|-----------------------|----------------------|-------|---------------------|--------|---------------------|--------|---------------------|-------|
| | β (95% CI) | p | β (95% CI) | p | β (95% CI) | p | β (95% CI) | p |
| Age, year | -0.30 (-0.46, -0.15) | 0.001 | 0.01 (-0.01, 0.02) | 0.381 | 0.01 (-0.01, 0.02) | 0.381 | 0.01 (-0.01, 0.02) | 0.325 |
| Women versus men | 0.59 (-4.83, 6.00) | 0.834 | 0.11 (-0.26, 0.49) | 0.561 | 0.11 (-0.26, 0.49) | 0.561 | 0.08 (-0.39, 0.56) | 0.731 |
| Dementia type | | | | | | | | |
| All-cause | Reference | | Reference | | Reference | | Reference | |
| Alzheimer's disease | -0.25 (-1.65, 1.16) | 0.737 | -0.06 (-0.13, 0.02) | 0.147 | -0.06 (-0.13, 0.02) | 0.147 | 0 (-0.10, 0.10) | 0.966 |
| Other | -1.70 (-4.32, 0.91) | 0.220 | 0.34 (0.17, 0.52) | <0.001 | 0.34 (0.17, 0.52) | <0.001 | 0.33 (0.12, 0.54) | 0.004 |
| Study setting | | | | | | | | |
| Clinic | Reference | | Reference | | Reference | | Reference | |
| Community | 0.74 (-1.78, 3.26) | 0.571 | 0.03 (-0.07, 0.12) | 0.612 | 0.03 (-0.07, 0.12) | 0.612 | -0.02 (-0.15, 0.11) | 0.784 |
| Mixed | 0.48 (-2.21, 3.17) | 0.729 | 0.12 (-0.05, 0.29) | 0.167 | 0.12 (-0.05, 0.29) | 0.167 | 0.06 (-0.12, 0.23) | 0.541 |
| Geographical location | | | | | | | | |
| Europe | Reference | | Reference | | Reference | | Reference | |
| North America | 0.05 (-1.34, 1.45) | 0.940 | 0.01 (-0.06, 0.08) | 0.787 | 0.01 (-0.06, 0.08) | 0.787 | 0.04 (-0.07, 0.14) | 0.481 |
| Other | 2.12 (-0.95, 5.19) | 0.194 | -0.09 (-0.4, 0.22) | 0.573 | -0.09 (-0.4, 0.22) | 0.573 | -0.13 (-0.29, 0.03) | 0.122 |
| Year Study Start | | 0.706 | | 0.361 | | 0.626 | | 0.333 |
| <1990 | 0.30 (-2.15, 2.76) | | 0.04 (-0.12, 0.2) | | 0.04 (-0.12, 0.2) | | 0.21 (-0.05, 0.47) | |
| 1990s | 0.95 (-0.55, 2.45) | | -0.01 (-0.1, 0.09) | | -0.01 (-0.1, 0.09) | | 0.09 (-0.04, 0.21) | |
| 2000s | Reference | | Reference | | Reference | | Reference | |
| \geq 2010s | 1.29 (-0.3, 2.87) | | 0.05 (-0.04, 0.14) | | 0.05 (-0.04, 0.14) | | 0.08 (-0.04, 0.2) | |

Supplementary Data S17: Study characteristics by duration of follow up

Legend: Study characteristics for studies with short maximum follow up (<9 years) and long maximum follow up (>9 years). A cut off of 9 years was chosen as it was the median maximum follow-up in the studies reporting median survival.

| Study characteristic | <=9 years (n=296) | >9 years |
|-------------------------------------|-----------------------------|--------------------|
| Age (median, IQR) | 79.5 [76.5-82.9] | 76.7 [72.7-80.9] |
| Sex (median, IQR) | 0.62 [0.56-0.69] | 0.60 [0.52-0.66] |
| Dementia type (%) | | |
| All-cause | 48.7 | 35.7 |
| Alzheimer's Disease | 31.1 | 33.6 |
| Other | 20.2 | 30.8 |
| Study setting (%) | | |
| Clinic | 38.2 | 51.7 |
| Community | 39.0 | 42.0 |
| Nursing home | 16.1 | 2.1 |
| Mixed | 6.7 | 4.2 |
| Geographical location (%) | | |
| Europe | 54.7 | 57.3 |
| North America | 27.0 | 28.7 |
| Asia | 13.1 | 14.0 |
| Other | 5.2 | NA |
| Years of study enrolment (%) | | |
| <1990 | 11.0 | 14.5 |
| 1990s | 19.7 | 37.0 |
| 2000s | 40.6 | 31.2 |
| ≥2010s | 28.7 | 17.4 |
| Case ascertainment (%) | | |
| Clinical exam | 55.4 | 59.4 |
| Medical records | 8.2 | 5.6 |
| Registry | 30.3 | 32.2 |
| Other | 6.0 | 2.8 |
| Time of inclusion (%) | | |
| Incident | 37.1 | 66.4 |
| Prevalent | 58.1 | 31.5 |
| Mixed/unclear | 4.9 | 2.1 |