**Online Supplementary Table 1. Characteristics and outcome of studies investigating the rate of undetected dementia in the community**

| Author Date | Study location | N with dementia (total screened) | Total N invited[1] (response rate) | Sample characteristics | Sampling strategy | Method of identification | Standard of comparison | Number of undetected dementia (%) |
|---|---|---|---|---|---|---|---|---|
| O'Connor 1988[1] | Cambridge, UK | 208 (2616) | 2823 (93%) | Age ≥75 years | Identified from registers of six general practices | CAMDEX | GP rating: definitely not demented, possibly demented, or definitely demented | 87 (42%) |
| Lagaay 1992[2] | Leiden, Netherlands | 13 (977) | 1037 (94%) | Age ≥85 years | Identified from registers of four general practices | MMSE | Medical record | 4 (31%) |
| Worrall | Newfound land, | 20 (222) | 230 | Age ≥70 years (mean 76.1 | Identified from | CMSQ | Medical record | 15 |

[1] Excluding those who had died, were too ill to participate, or could not be contacted.

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|---|---|---|---|---|---|---|---|---|
| 1993[3] | Canada | | (97%) | years)<br>52.4% female<br>Rural area | register of one community clinic | | | (75%) |
| Callahan<br><br>1995[4] | Indiana, USA | 206 (3954) | 4129<br><br>(96%) | Age ≥60 years (mean 68 years)<br>69% female | Identified from register of one ambulatory care practice | SPMSQ | Medical record | 156<br><br>(76%) |
| Eefsting<br><br>1996[5] | Netherlands | 71 (2191) | 2536<br><br>(86%) | Age ≥65 years | Identified from registers of eight general practices | MMSE and CAMDEX<br><br>According to DSM-III-R criteria | GP rating: dementia, CI or no impairment | 43<br><br>(61%) |

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|---|---|---|---|---|---|---|---|---|
| Valcour 2000[6] | Hawaii, USA | 26 (297) | 930<br>32% | Age ≥65 years (74.6 ± 6.18)<br>21% female | Identified from register of outpatient practice | CASI | Medical record | 17<br>(65%) |
| Zunzunegui Pastor 2003[7] | Leganés, Spain | 63 (527) | 868<br>(61%) | Age ≥70 years | | MMSE and SPMSQ<br>According to DSM-IV criteria | Previous diagnosis of dementia | 44<br>70% |
| Boise 2004[8] | Portland, Oregon, USA | 221 (553) | 1207<br>(46%) | Age ≥75 years<br>64% female | Identified through registers of 34 primary care physicians | CERAD | Medical records | 103<br>(47%) |

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|---|---|---|---|---|---|---|---|---|
| Boustani 2005[9] | Indianapolis, USA | 107 (3340) (93%) | 3573 | Age ≥65 years<br>Mean age 75.6 (6.2)<br>63% female | Identified from registers of seven primary care centres | CSI-D; CERAD; ICD-10 criteria | Medical record | 87 (81%) |
| Borson 2006[10] | Washington, USA | 160[2] (371) (100%) | 371 | Age and gender not given | Identified from register of university volunteers | Mini-Cog and CASI | Medical records | 90 (56%) |
| Chan 2007[11] | Baltimore and Maryland, USA | 349 (512) (71%) | 724 | Mean age 81.7 years<br>81% female | Secondary data from the Memory and Medical Care Study (MMCS) | Neuropsychological battery of 4 tests<br>Mirrors NINCDS-ADRDA criteria | Previous clinical diagnosis | 190 (66%) |

[2] Excludes MCI

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|---|---|---|---|---|---|---|---|---|
| Wilkins 2007[12] | St Louis, USA | 411 (543) (64%) | 850 | Age ≥55 years Mean age 80.9 (7.7) | Identified from Memory and Aging Project Satellite | CERAD, MMSE and SDT | Medical records | 232 (56%) |
| Jitapunkul 2009[13] | Bangkok, Thailand | 23 (420) (99.5%) | 422 | Age ≥50 years Mean age 67.1 (6.5) 61% female | Identified from population-based cohort study | DSM-IV | Medical records | 22 (96%) |
| Chen 2013[14] | Six provinces, China | 377 (7072) (90%) | 7821 | Aged >=60 years | Identified from a random sample | The 10/66 algorithm dementia research package | Recorded the doctor-diagnosed dementia in the face-to-face interview | 351 (93.1% [95% CI 90.1%-95.4%]) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Eicheler 2015 [15] | Germany | 243 (406) | 692 (59%) | >70 years | Identified from GP-based for a randomised controlled intervention trial including patients with DelpHi tril (DemTect score<9) | DelpHi trial (DemTect score<9): MMSE score and categorisation indicating as no cognitive impairment (score27-30), moderate (score 10-19) and severe impairment(score 0-9) | GP | 146 (60%) |

*Abbreviations: MMSE: Mini Mental State Examination; DSM-III/IV: Diagnostic and Statistical Manual of Mental Disorders 3rd/4th Edition; ICD-10: International Classification of Diseases 10th Edition; CASI: Cognitive Abilities Screening Instrument; CERAD: Consortium to Establish a Registry for Alzheimer's Disease; CAMDEX: Cambridge Mental Disorders of the Elderly Examination; CMSQ: Canadian Mental Status Questionnaire; SPMSQ: Short Portable Mental Status Questionnaire; CPS: Cognitive Performance Scale; CSID: Community Screening Interview for Dementia*

**Online Supplementary Table 2. Characteristics and outcome of studies investigating the rate of undetected dementia in the setting of residential/ nursing care only, or mixed community and residential setting**

| Author Date | Study location | N with dementia (total screened) | Total N eligible[3] (response rate) | Sample characteristics | Sampling strategy | Method of diagnosis | Standard of comparison | Number of undetected dementia (%) |
|---|---|---|---|---|---|---|---|---|
| Ólafsdóttir 2000[16] | Linköping, Sweden | 57 (350) | 358 (98%) | Age ≥70 years | Community and residential care<br><br>Identified from register of primary care centre | According to DSM-III-R criteria | Medical record | 42 (74%) |
| Löppönen 2003[17] | Lieto, Finland | 112 (1260) | 1533 (82%) | Age ≥64 years (mean 82.4 years) | Community and residential | DSM-IV | Medical records | 58 (52%) |

[3] Excluding those who had died, were too ill to participate, or could not be contacted.

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|---|---|---|---|---|---|---|---|---|
| | | | | 68% female | care<br><br>Identified through longitudinal community health survey | | | |
| Nygaard 2003[18] | Bergen, Norway | 73 (127) | 127<br><br>(100%) | Mean age 84.2±7.8 years<br><br>68% female | Identified from 12 nursing homes | SPMSQ and CDR<br><br>According to ICD-10 criteria | Medical record | 23<br><br>32% |
| Magsi 2005[19] | Nebraska, USA | 133 (230) | 391<br><br>(59%) | Age ≥65 years<br>Mean age 83.3 (8.3)<br>78% female | Identified from 7 assisted living facilities | MMSE | Facility medical record | 84<br><br>(63%) |
| Collerton 2009[20] | Newcastle, UK | 105 (1042) | 1400<br><br>(74%) | Age ≥85 years | Community and residential care | Standardized MMSE scores | GP medical records | 56<br><br>(53%) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | Identified from registers of general practices | | | |
| Ferretti 2010[21] | Lausanne, Switzerland | 425 | 1764 | Mean age 84.4±6.2 years<br><br>66% female | Identified from academic postacute rehabilitation facility | MMSE | Previous diagnosis | 301 (71%) |
| Lithgow 2012[22] | Glasgow, UK | 351 (403) | 422 (95%) | | Identified from residents in 48 nursing homes | SMMSE and FAST | Diagnosis of dementia written into their care plans or GP records | 128 (36%) |
| Bartfay 2013[23] | Ontario, Canada | 39692 (601030) | 601030 (100%) | Mean age 80.1±12.9 years<br><br>66% female | Identified from all institutional care facilities | CPS, ADL | Institution assessment | 28078 70.7% |

*Abbreviations: MMSE: Mini Mental State Examination; DSM-III/IV: Diagnostic and Statistical Manual of Mental Disorders 3rd/4th Edition; ICD-10: International Classification of Diseases 10th Edition; SPMSQ: Short Portable Mental Status Questionnaire; CPS: Cognitive Performance Scale; FAST: Functional Assessment Staging Tool; ADL: Activities of Daily Living*

**Online Supplementary Table 3. Determinants of undetected dementia in 23 identified studies**

| First Author, year of publication | Factors explored in the study influencing the under-detection, |
|---|---|
| O'Connor, 1988[1] | Severity (mild 50%, moderate 38%, severe 22%); Activities of daily living; strain experienced by relatives; contact with GP |
| Worrall, 1993[3] | Severity of impairment |
| Callahan, 1995[4] | Severity of impairment (SPMSQ scores detected 6.2 v undetected 7.1, p<.05)<br><br>Not determinants: age, gender, race, education, body weight, smoking history, alcohol consumption, comorbidity or health care utilisation. |
| Eefsting, 1996[5] | Severity of dementia (mild 86%, moderate/severe 53% undetected); Sex (men 56%, women 65% undetected); Contact with GP (0-3: 72%, 4-7: 62.5%, >7 40% undetected).<br><br>Not determinants: age (<80 64%, ≥80 61% undetected). |
| Valcour, 2000[6] | Severity of cognitive impairment (undetected CDR 1.13, detected CDR 1.95, p=.02); functional impairment (undetected ADL score 2.87, detected ADL score 8.45, p=.01); behavioural disturbance score (undetected 2.22, detected 9.00, p=.004); informant report of cognitive impairment (undetected 3.77, detected 4.50, p=.007). |

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| | Not determinants: age, education, depression, number of office visits in previous 2 years, decline in social or occupational function. |
| Zunzunegui Pastor, 2003[7] | Severity (light 95%, moderate 69%, severe 36%); Contact with primary care services |
| Boise, 2004[8] | Severity of cognitive impairment (54.7% mild impairment, 29.4% moderate-severe impairment) |
| Borson, 2006[10] | Severity of impairment (CDR 0.5: 94%; CDR 1: 59%, CDR 2: 41%, CDR 3: 5% undetected), type of dementia (Prob AD and AD/VaD 38-44%, VaD and other 55-60% undetected), local language speaker (55%, non-English speaker 70% undetected),<br><br>Not determinants: education, literacy, income, health insurance, contact with the GP. |
| Ólafsdóttir, 2000[16] | Severity of impairment (mild 76%, moderate 85%, severe 40%, p=.008); Duration of dementia (p=.025) |
| Löppönen, 2003[17] | Severity of cognitive impairment (undetected mean MMSE score 17.0, detected mean MMSE score 12.7); Type of dementia (undocumented <AD, p=.001); Male (72% undetected v 42% of women); Living at home (66% undetected v 38% detected); Severity of functional impairment (undetected mean IADL score 2.6, detected mean IADL score 1.2); Family history (yes: 42% undetected, no: 57% undetected); Depression (66% undetected compared to 44% without depression).<br><br>Not determinants: age (under-detection went up with age but ns), marital status, education, regular visits from another, contact with GP. |
| Magsi, 2005[19] | Severity of impairment (mild 72%, moderate 54%, severe 50% undetected) |

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| Eichler, (2015) [15] | After a positive screening for dementia, 74 of 146 patients remained not receiving a formal diagnosis of dementia. They were more likely to be male, less cognitive impairment, and better performance of activities of daily living. |
| Boustani, 2005[9] | Increased age (65-69: 78.9%; 70-79: 79.1% ≥80: 88.5%) |
| Wilkins, 2007[12] | Increased age, female, live alone, non-spouse caregiver, hypertension<br><br>Not determinants:Race, comorbidities |
| Ferretti, 2010[21] | Age (detected 83.3 v undetected 84.9, p=.015); living alone (detected 50% live alone, undetected 61% live alone); functional ability (detected mean 1.8, undetected mean 2.3); severity of cognitive impairment (detected mean MMSE 16.3, undetected mean MMSE 20.2, p<.001)<br><br>Not determinants: Gender, formal home care prior to admission, depression |
| Chen, 2013[14] | Living in a rural area (odds ratio 6.65,2.55-17.4), educational level <=primary school (4.19, 1.08-16.3), occupational class of <=manual labour (2.81, 1.03-7.63), "help available when needed" ( 4.91, 1.20-20.2), and inversely to having a blood-related relatives having mental illness (0.05, 0.01-0.31) and low ADL score (0.25, 0.09-0.69) |

| | |
|---|---|
| Bartfay, 2013[23] | Age (77 v 83.8 years), more likely male (36.4% v 31.8%), never married (20.1% v 5.8% - adjOR 2.10, 19.1-2.29), resident of hospital based facility compared to residential continuing care facility (21.0% v 14.9% - adjOR 1.43, 1.48-1.69), length of time since admission, comorbid depression (adjOR 1.23, 1.16-1.29) or schizophrenia (adjOR 1.43, 1.22-1.69), no difference for Parkinson's or anxiety disorder. Those with no diagnosis more likely to have adequate vision (43.8% v 41.2%) and hearing (62.5% v 57.2% - adj OR 1.06, 1.01-1.10). Diabetes adjOR 1.32, 1.26-1.40) |
| Lagaay, 1992[2] | *Not investigated* |
| Chan, 2007[11] | *Not investigated* |
| Jitapunkul, 2009[13] | *Not investigated* |
| Nygaard, 2003[18] | *Not investigated* |
| Collerton, 2009[20] | *Not investigated* |
| Lithgow, 2012[22] | *Not investigated* |

**Online Supplementary Appendix 1. Narrative reviews of the community-based studies, the residential-based studies and the mixed community and residential-based studies.**

*Community-based studies* (Table 1)

Studies that looked at the medical records of people with dementia living in the community found a wide range of estimates of undetected dementia. The lowest estimate was from the Netherlands, where 31% of 13 dementia cases identified from four practices using the MMSE had no diagnosis in their medical records. [2] As well as having a very small sample, this study selected participants from the oldest-old age group (≥85 years of age), and it is possible that these patients had more severe symptoms that were easier for their GP to identify, thus leading to low estimated rates of undetected dementia. In a larger study conducted in Oregon, USA, [8] 47% of people with dementia according to Consortium to Establish a Registry for Alzheimer's Disease neuropsychological battery (CERAD) criteria, over the age of 75 years and represented by a large number of primary care physicians, had no recorded dementia diagnosis, referral or symptoms in their medical records from the 3 years prior to record review. Response rate to the study was low at under 50% but it is unclear what effect, if any, this may have had on the findings.

Five further studies offered more mid-range estimates of undetected dementia, between 56% and 70%. In St. Louis, USA, Wilkins et al. [12] identified 411 people with dementia – predominantly of African-American heritage and of low income – from screening using the CERAD criteria. Fifty-six percent had no previous diagnosis. In a similar sample but this time using the Mini-Cog and Cognitive Abilities Screening Instrument (CASI) assessments, Borson et al. [10] identified 160 people (ages unknown) with dementia. Again, 56% had no recorded diagnosis or suspicion of dementia or cognitive impairment written into their medical records. Chan et al. [11] analysed secondary data from the community-based Memory and Medical Care Study (MMCS) in Maryland, USA. The study used a neuropsychological test battery mirroring the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association (NINCDS/ADRDA) to identify dementia. Sixty-six percent had no previous diagnosis, based on either medical record over the past two years, caregiver report or Medicare claims over the past two years. In Germany, Eichler et al [15] recruited 4064 patients from 108 GP practices for screening dementia, of which 406 patients were eligible

for the DelHi trial (DemTect score<9) and agreed to participate in the trial. They identified 243 individuals with dementia using DemTect score<9, and found that 146 (60%) did not have a formal diagnosis of dementia by GP. After screening, 74 of 146 patients remained not receiving a formal diagnosis of dementia, which were more likely to be male, less cognitive impairment, and better performance of activities of daily living. A community survey of elderly aged ≥70 years in Laganés, Spain found that 70% of 63 dementia cases were previously undetected by health services.[7] These mostly large studies suggest a higher rate of undetected dementia in these regions, around two thirds of cases.

Three studies in North America estimated undetected dementia to be higher than 70%. Of 20 community-dwelling elderly with dementia who were attending a rural community clinic in Newfoundland, Canada, 75% of them had no mention of dementia, Alzheimer's disease or confusion in their medical records. [3] Although this study had a high response rate (>95%), participants represented only two physicians, limiting how far these findings can be generalised compared to studies representing multiple practices. In a larger study in Indiana, USA, Callahan et al. [4] identified 206 elderly with moderate to severe dementia of whom 76% had no diagnosis of dementia in their medical record. Again, patients were represented across a single university-affiliated general practice. The authors also suggested that as the Short Portable Mental Status Questionnaire (SPMSQ) is not a test for dementia specifically, some people with cognitive impairment without dementia or due to other psychiatric illness may have been included in this sample, inflating the estimate of undetected dementia. Boustani et al. [9] also used the CERAD and Cognitive Screening Interview for Dementia (CSI-D) criteria to identify dementia in elderly who were registered to one of seven primary care centres in Indianapolis, USA. Eighty-one percent of the 107 people with dementia had no previous diagnosis in their medical records. Positive detection was based on strict criteria, requiring ICD-9 diagnostic codes for dementia rather than record of memory or cognitive problems, thus excluding cases where cognitive difficulties had been recognised but no specific codes were used.

Two community-based studies were conducted in middle-income countries in Asia. Jitapunkul et al. [13] investigated dementia detection in a small population study in Bangkok, Thailand. From 420 people screened, they identified 23 people with dementia according to a clinical assessment in line with the DSM-IV guidelines. Twenty-two of the 23 (95.6%) identified had no previous diagnosis of dementia in their medical records. Overall prevalence of dementia in the population was within normal limits (5.5%, 95% CI 3.3–7.7%), so it is

unlikely that this led to bias. Chen et al. [14] analysed data from a multi-province study of dementia in China. A random sample of 7072 community-dwelling residents aged ≥60 years were screened for dementia using the 10/66 algorithm dementia research package. Of the 377 people identified as having dementia, 351 (93.1%) did not have a previous diagnosis of dementia by the physicians.

Three studies within the community asked GPs to make a forced choice about whether their patients had dementia or not. [1,5,6] In the UK, 42% of 208 people aged <75 years with dementia were rated by their GP as definitely not having dementia.[1] A further 25% were rated as only possibly having dementia, meaning that 66% had no firm diagnosis. A similar figure was seen in the Netherlands, [5] where 37% of 98 people with dementia were rated as not impaired by their GP, and a further 33% rated as having cognitive impairment only. In another – albeit small – study of people attending a routine appointment at an outpatient practice in Honolulu, Hawaii, GPs failed to detect 67% of those with dementia despite knowing in advance of the appointment that they would be asked to rate each patient. [6]

*Residential-based studies* (Table 2)

Five studies were conducted investigating the rate of undetected dementia in nursing homes and other care facilities. Nygaard et al.[18] screened elderly admitted to 12 nursing homes in Bergen, Norway. They identified 73 people with dementia using the SPMSQ and clinical interview, of whom just 32% had no previous diagnosis in their medical record. Lithgow et al. [22] diagnosed dementia in a random sample of nursing home residents in Glasgow, UK using the SMMSE and FAST tools, finding 36% of cases were undetected in care plans or medical record. Notably, 89% of participants had seen their physician within the previous 12 months.

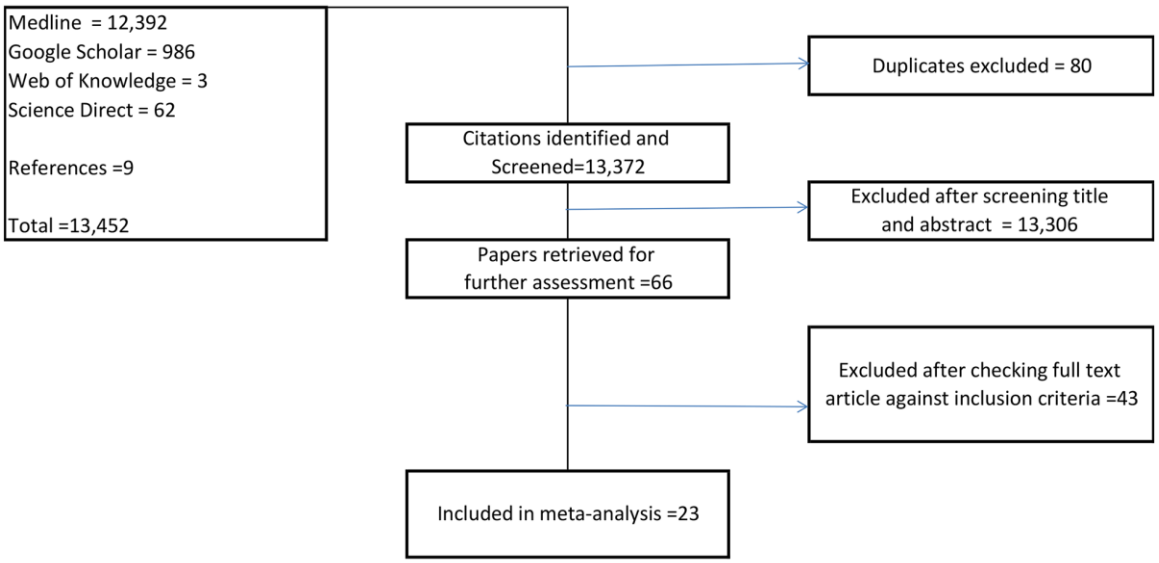
Two studies showed higher levels of undetected dementia in residential settings in North America. Magsi et al. [19] screened 230 elderly from seven assisted living facilities in Nebraska using the MMSE and found 63% had no diagnosis of dementia according to their care notes. Bartfay et al. [23] also found a much higher rate of undetected dementia in institutional care facilities in Canada, with almost 71% of residents identified as having dementia were undocumented in a particularly large study. Although these figures do not account for those diagnosed before admission (these participants were removed from

analysis), the authors reported that adjusting for them had little impact on the under-detection rate while in nursing homes (adjusted to 69.5%).

One study examined the rate of undetected dementia among admissions to a postacute rehabilitation facility in Lausanne, Switzerland over 3 years. [21] Of 1764 eligible admissions, 425 elderly patients (mean age 84 years) with dementia were identified using the MMSE and NINCDS-ADRDA (for Alzheimer's disease), ADDTC (for Vascular dementia) and Newcastle's (for Lewy Body dementia) criteria. Of these, 301 (71%) had no mention of dementia in the discharge summaries from their hospital stay.

*Community and residential-based studies*

Three studies included participants living in the community and those living in residential care. A small Swedish study of elderly living either in the community (*n*=35) or in a care institution (*n*=22) representing 11 practitioners showed a high rate of undetected dementia (74%) according to GP records. [16] In a larger study, data from the Newcastle 85+ study in the UK found the rate of undetected dementia (based on both GP and secondary care records) to be slightly lower at 50% across 53 general practices.[20] Dementia in this Newcastle study was estimated using the SMMSE and a range of other neuropsychological tests, rather than by more sensitive clinical assessment, so some patients may have been misclassified and thus the rate of under-detection affected. It is unclear whether the rate differed between the samples living in the community and care institutions in these studies. However, a study [17] directly compared between community and residential care groups in a representative survey of elderly living in Lieto, Finland, in which 52% of cases were undetected. Of those living in the community (*n*=56), the rate was 66%, while for those living in institutions (*n*=56) the rate was much lower at 38%.




Online Figure 1. Flowchart to show process of selecting articles for inclusion in this review

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