Prevalence of dementia in population groups by protected characteristics

A systematic review of the literature
Prevalence of dementia in population groups by protected characteristics

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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Executive summary

Introduction
Dementia is a significant and growing problem. Over the last 20 years deaths from dementia have nearly doubled. This review examines how common dementia is and how much it varies between groups with the following characteristics: socio-economic position, race or ethnic group, religion, gender, sexual orientation and disability.

Methodology
This review builds on previous work. Using standard methods for reviewing literature, it considered scientific papers and those published by voluntary sector organisations. Systematic efforts were made to find all relevant papers on this topic. Data was extracted from all relevant articles and it was synthesised qualitatively. Due to the evidence search design, the approach primarily focused on developing insights into the differential prevalence of dementia.

Results
Dementia was more common in people from African-American, black-Caribbean or Hispanic background. There was no information published on people from south-east Asian backgrounds.

Dementia is more common in women. There was no information to help understand if religion or sexual orientation changed the prevalence of dementia. Learning disability and lower socio-economic position both increased the prevalence.

Risk factors known to increase dementia (diabetes, stroke and depression) also increase dementia in groups with increased prevalence, and education remains protective against dementia.

Discussion
In some groups people do not always appear to be diagnosed with dementia when they have it. Research should focus on the causes of this and how to increase the diagnosis of dementia.

Specific research is needed to understand how common dementia is in people from a south-east Asian background in the UK. Research is needed to investigate the exact impact of the known risk factors (depression, diabetes and stroke) across the protected characteristics, as this will help organise and target services.
Acknowledgments

Particular thanks should go to the following individuals who, on behalf of their organisations, kindly sent us document, papers, reports and evidence, without which this review would not have been possible.

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Rebecca Stanley, public health analyst, Age UK
Sharon Blackburn, policy and communications director, National Care Forum
Susan Rose, registry and library services officer, Public Health England

A wide range of organisations submitted documents to Public Health England in 2014. The information they submitted was shared with the review team and significantly contributed to the creation of this report. Those stakeholders included:

Alzheimer’s Society
Age UK
Mental Health Providers Forum
National Care Forum, Voluntary Organisations Disability Group
Race Equality Foundation
Women’s Health Equality Consortium
Young Dementia UK

The review team would also like to give special thanks to the following people for their extensive comments on early drafts, which significantly improved this report.

Nuzhat Ali, national health and wellbeing lead, Public Health England
Bola Akinwale, health equity programme lead, Public Health England
Prevalence of dementia in population groups by protected characteristics

Introduction

Dementia is a significant and growing problem. Over the last 20 years the crude death rates (Murray, 2014) and age-standardised death rates from dementia have nearly doubled (Lozano et al, 2012). Dementia has an impact far beyond the person with the condition (Audulv et al, 2014). It represents a significant economic burden on patients, families and health services (Schaller et al, 2015), and can significantly distress caregivers (Vu et al, 2014). People with dementia often have co-existing neurological conditions, commonly stroke and Parkinson’s disease (Vu et al, 2014).

The course of dementia is often a slow but unpredictable progression (Audulv et al, 2014). Recognising the impact of dementia underpins the current approach to dementia. The Department of Health (DH) currently has a number of priorities for securing improvements in dementia diagnosis, care and research:

Awareness

Improve public awareness and understanding of the factors that increase the risk of developing dementia, and of how people can reduce their risk by living more healthily.

Diagnosis

In every part of the country people with dementia have equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be six weeks following a referral from a GP (where clinically appropriate), and that no one should wait several months for an initial assessment of dementia.

Research

Dementia research should be a career opportunity of choice, and the UK the best place for dementia research via a partnership between patients, researchers, funders and society.

Funding for dementia research should double by 2025.

Increase investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, the NHS and the private sector. This would lead to world-class facilities and infrastructure, drive capacity building, and speed up discovery and implementation.
Cures or disease-modifying therapies should exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of resources such as cohorts and databases around the world.

Prevalence estimates for dementia vary considerably. The reported prevalence varies by ascertainment method and the diagnostic criteria used (Catindig et al, 2012).

Dementia prevalence increases with age, and age is an independent predictor of dementia (Adelman et al, 2011). In younger age groups (above the age of 60) the prevalence doubles every five years (Adelman et al, 2011, Jorm et al, 1987). The proportional increase slows in the very old, no longer doubling every five years. The prevalence at age 85 is 30% and 52% at age 95 (Borjesson-Hanson et al, 2011).

As they age relatively few people need institutional care (Hirdes et al, 2011). However, the likelihood of needing expensive institutional care increases significantly for people with dementia in comparison to people without dementia (Williams et al, 2009, Aguero-Torres et al, 2001).

This review builds on previous work by DH, in 2010-11, as part of the development of the Dementia Equalities Action Plan (DH, 2011). It examines evidence on how the prevalence of dementia varies with the following characteristics: socio-economic position, race or ethnic group, religion or belief, gender, sexual orientation and disability. These characteristics were considered to be potentially associated with different rates of dementia and/or different outcomes, especially in terms of speed of progression of the condition.
Aims and objectives

Public Health England (PHE) commissioned this review as part of informing an equitable risk reduction strategy. This review is for commissioners and providers of dementia services, PHE knowledge and intelligence team, researcher funding bodies and researchers and policy makers. Specifically this review aims to gain insight into the following questions.

Primary question
Are certain population groups, defined by specific characteristics, at increased risk of dementia?

Secondary questions
What are the causes of differences in prevalence of dementia in individuals with different characteristics including socio-economic groups, race and ethnicity, religion, culture or belief, gender, sexual orientation and disability? (NB. Not pregnancy.)

For people living with dementia, do dementia outcomes vary according to the presence of these characteristics?
Methodology

Literature search methodology

The search strategy was prepared by the PHE knowledge and library services team (KLS) and designed to build on previous work undertaken by DH as part of the development of the Dementia Equalities Action Plan (DH, 2011).

Inclusion criteria

- studies published between 2011-15 only
- subjects must have:
  - one or more of the following protected characteristics (within the Equality Act (2010))
    - ethnicity
    - religion or belief
    - gender
    - sexual orientation
    - disability
  - or documented evidence of their socio-economic position,
- subjects must have vascular dementia or Alzheimer’s disease, confirmed by medical diagnosis
- studies where prevalence of dementia is reported for each group
- countries to include:
  - UK
  - USA
  - Canada
  - Australia
  - New Zealand
  - mainland European countries
  - South Africa
  - Japan

Exclusion criteria

- dementia with Lewy bodies, Creutzfeldt-Jakob disease, fronto-temporal dementia and mild cognitive impairment.
- non-English papers
- pregnant individuals

Literature search

The PHE team searched Medline, Embase, CINAHL, PsycINFO, and Social Policy and Practice. Results were limited by date range, from 2011 to end of January 2015, and
English language papers only. Records were stored in an EndNote library and duplicates removed. Papers were then excluded by sifting through the title and abstract of each record in the EndNote library. From a total of 982 records, 653 were excluded, leaving 331 records for inclusion.

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<td>331</td>
</tr>
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</table>

Results of this search were handed over to the review team for abstract screening and selection of papers for full text review.

**Review and synthesis approach**

The methodology used to undertake this review balances the need for speed, precision, academic rigour and policy usefulness. Wherever possible, this methodology followed internationally recognised standards for the conduct and reporting of reviews of this nature.

Deriving full benefit of the data available in this field was thought likely to require mixed quantitative and qualitative methods to evidence synthesis. Our, a priori, assumption
was that a thematic synthesis approach would be taken to the evidence (Thomas and Harden 2008) and some areas the data would be of sufficient quality and homogeneity to aggregate statistically.

This review was done using the standards for developing reviews addressing questions of prevalence put forward by the Joanna Briggs Institute (Joanna Briggs Institute 2014, Munn et al 2014).

Due to the nature of the evidence search design, the approach primarily focused on developing insights into the differential prevalence of dementia. Wherever possible, the review aimed to also extract data and code thematic findings that would indicate differences in outcomes, the potential for early intervention or support, or possible drivers of differential outcomes.

Abstract screening
Two reviewers independently screened the 331 included records, and 89 papers were selected for full review. 23 papers contained information on the prevalence of dementia in people with the inclusion characteristics. An additional 22 papers were identified from the references of these 23 papers [See Reference snowballing] as potentially having information on populations with the inclusion characteristics or factors that increased their risk of developing dementia. 11 papers contained only information from countries other than those in the inclusion criteria. Eight papers contained only information about populations with mild cognitive impairment. 47 papers were reviewed and considered then excluded because they did not contain any relevant information on populations with the characteristics of interest.

Grey literature
This review builds on previous work between PHE and a wide range of stakeholder organisations. To ensure that this review took account of this work, the following organisations were contacted to request reports, unpublished papers, reviews or evidence relevant to this review.

Those stakeholders (in alphabetical order) included:

Age UK
Age UK Camden
Alzheimer’s Society
Care England
Care Quality Commission
Carers Trust
Carers UK
Dementia UK
Disability Partnership
Disability Rights UK
Innovations in Dementia
Life story network
Men's health forum
Mental Health Foundation
National Care Forum
National LGB&T Partnership
Race Equality Foundation
Sense Deaf Blind Charity
Stonewall Housing
Sue Ryder
United Kingdom Homecare Association
Voluntary Organisations Disability Group
Volunteering Matter
Women’s health and Equality Consortium
Young Dementia UK

26 papers were received and reviewed as part of this evidence review.

**Proposed review methodology**

**Approach to sorting the evidence**

It was anticipated that the evidence portfolio would be divided into groups by protected characteristic, so that the volume of evidence pertinent to each characteristic would be apparent.

As part of the process for developing inter-reviewer consistency, for each characteristic for which there were more than five papers, one paper would be selected at random for general review (independent review by each team member then joint discussion of the individual reviews) and one additional paper for each team member to individually review.

The team members would then compare the appraisal and data extraction conducted for inter-rater reliability (Kappa coefficient), the coding for common identification of themes and for likely approaches to synthesis. At this time the team would also identify any issues that the evidence presented for appraisal, extraction, coding or synthesis and consensus developed on the approach to be taken to overcome any issues.

Having then agreed the approaches, this would then be tested on the characteristics for which there were less than five papers, with all papers being reviewed by all team members. At this stage the exact approach to synthesis would be agreed, dependent on the nature of the available data from the identified evidence.
The remaining data would then be divided randomly in a 1:2:3 ratio between the team members for individual appraisal, data extraction and coding. This would allow for the optimum balance of timeliness, quality assurance and use of the least costly resources.

Ideally every paper would be independently appraised, extracted and coded by two team members, however the proposed method of aligning approaches and testing for inter-rater reliability was thought to be a suitable compromise. As the team members regularly work together conducting evidence reviews, this trade off was considered appropriate given the anticipated volume of evidence and the time and resource constraints.

**Full evidence appraisal, data extraction and coding**

The Joanna Briggs Institute’s Critical Appraisal Checklist for Studies Reporting Prevalence Data was used to inform the methodology for appraising the quality of the studies.

The lead quantitative reviewer, following the initial round of evidence overview and methodological harmonization, developed the quantitative data extract template.

The lead qualitative reviewer developed the framework for qualitative data extraction extract and coding structure development. This was part of the initial round of evidence overview and methodological harmonisation.

**Evidence synthesis**

The choice of a narrow five year window for the collection of the evidence meant that the review team focused on robust identification of potential differences as the primary concern. An accurate point estimate of any identified difference was not considered an over-riding concern. This then governed our approach to the evidence, which was planned to take two distinct approaches, firstly thematic synthesis.

The thematic synthesis followed three stages, coding of text, development of descriptive themes, and generation of analytical themes (Thomas and Harden 2008). Descriptive themes remained close to the primary studies, however analytical themes represented a process of interpretation that allowed the review to go beyond the primary studies and generate new interpretive constructs, explanations or hypotheses.

This process of interpretation was particularly used to explore factors that appeared to contribute to any differential risk in the study populations.

Secondly, in areas where data was of sufficient quality and homogeneity to aggregate statistically, we planned to perform formal statistical meta-analysis. We anticipated that
even where this data existed that there would still be a degree of heterogeneity in the
underlying data and that there would be a large range of sizes of studies. Given this, we
anticipated using a random-effects model for the meta-analysis.

Changes to the proposed methodology

Proposed inclusion criteria

The inclusion criteria was originally designed to include only those studies published
2011-15 in the UK, USA, Canada, Australia, New Zealand, Europe, South Africa and
Japan.

Actual inclusion criteria

Where it became apparent that additional directly relevant information was referenced
within the retrieved papers, particularly reference to primary or secondary research, the
team took a pragmatic view to obtain and include these papers within the review.

The intention had been to exclude any papers from the final set of papers for review
which focused on study subjects from countries outside those in the inclusion criteria.
However, due to the small volume of data, the team separately reviewed these papers
as a way of triangulating the emerging themes from the countries in the inclusion
criteria.

Proposed exclusion criteria

Mild cognitive impairment (MCI) was considered for the exclusion criteria. This is
because MCI is more common than dementia, and there is not a direct conversion from
it to dementia (only 10-20% of people with MCI go on to develop dementia).

Actual use of exclusion criteria

The intention had been to exclude any papers from the final set of papers for review
that focused on study subjects with MCI and not dementia. However, due to the small
volume of data, the team separately reviewed these as a way of triangulating the
emerging themes relating to dementia.

Proposed approach to develop inter-reviewer consistency

The evidence portfolio was to be divided into groups by protected characteristic, so that
the volume of evidence pertinent to each characteristic is apparent.

For each characteristic for which there are more than five papers, one paper was to be
selected at random for general review (independent review by each team member then
joint discussion of the individual reviews) and one additional paper for each team
member to individually review.
Having then agreed the approaches, this would then be tested on the characteristics for which there are less than five papers with all papers being reviewed by all team members. At this stage the exact approach to synthesis would be agreed, dependent on the nature of the available data from the identified evidence.

**Actual approach used to develop inter-reviewer consistency**

Following the screening of abstracts to select papers for full appraisal and extraction, only 89 papers remained across all characteristics. The team therefore selected ten papers randomly from all potential papers (using a pseudo-random number generator, Excel 2011 for Mac [See appendix I for the list of papers]).

These papers were each reviewed, critiqued and themes were extracted from them by each of the team members independently. These were then shared between the team discussion regarding any differences was resolved by consensus. Agreement was then formed regarding the final approach to the remaining papers.

**Proposed approach to complete data extraction**

The remaining data was then to be divided randomly in a 1:2:3 ratio between the team members for individual appraisal, data extraction and coding. This would allow for the optimum balance of timeliness, quality assurance and use of the least costly resources. The ideal was that every paper would be independently appraised, extracted and coded by two team members, was thought not to be possible as the review had a very tight timescale for completion and given the anticipated volume of papers to be considered.

**Actual approach used for complete data extraction**

The small volume of papers that remained for final consideration meant that thematic saturation was unlikely to be obtained in all areas and across all protected characteristics. The following changes were therefore made.

Firstly, each paper was allocated a primary reviewer and a second reviewer who reviewed all papers independently. This is in keeping with the ideal that every paper would be independently appraised, extracted and coded by two team members. This ensured that the maximum data was extracted from each paper and that the highest levels of reliability could be ensured.

Secondly, the abstract screening to select the final papers contained papers that related to protected characteristics but where the study subjects had mild cognitive impairment and not dementia. The intention had been to review these to see if they had also covered dementia and exclude them from the review if they did not. However, due to the overall small volume of data the team separately reviewed these, as a way of
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triangulating the emerging themes regarding dementia this synthesis is included in a separate section in the results.

**Proposed approach to statistical meta-analysis**

In areas where data was of sufficient quality and homogeneity to aggregate statistically we still anticipated a degree of heterogeneity in the underlying data, and that there would be a large range of sizes of studies. As such we anticipated using a random-effects model for the meta-analysis.

**Actual approach to statistical meta-analysis**

Many of the studies were of themselves of reasonable quality for the question that they sought to answer, but of much lower quality when considered for the purposes of answering the question posed by this review. There was considerable heterogeneity in the studies; they had different source populations, different age ranges, different methods of case ascertainment and different diagnostic approaches to dementia. Few of the studies presented data suitable for statistical meta-analysis, and because of this the team focused on qualitative review and evidence synthesis.
Search results

Limitations of the evidence

The search strategy used for this literature review did not set out to systematically identify information on risk factors for dementia. There are existing studies that have identified known risk factors for dementia and the Blackfriars Consensus represents a current position regarding those risk factors (Lincoln, 2014). However, there may be additional studies that have examined the prevalence of known risk factors for dementia in groups with the characteristics of interest to this review question. Therefore, there would be value in a full formal review of the differential prevalence of known risk factors for dementia in groups with the characteristics of interest [See Research recommendations].

Population-based dementia prevalence studies of identified groups with protected characteristics were limited. The studies were home care service based (Vu et al, 2014), hospital discharge based (Husaini et al, 2013) and community surveys (Adelman et al, 2011, Borjesson-Hanson et al, 2011). Many studies were retrospective reviews based on diagnoses made in the course of routine care.

The diagnosis of dementia is often based on subjective assessment and there are some studies indicating factors that lead to over diagnosis, for example subjective memory complaints (Pond et al, 2013), and others which indicate issues of under diagnosis (Connolly et al, 2011, Pond et al, 2013). It is not always clear how these issues differentially affect groups with protected characteristics. In the literature reviewed, there was not any evidence that this differentially effected groups with protected characteristics. However, the Race Foundation report presented some data that suggest a differential impact (Truswell, 2013).

Cautious interpretation is required of all the evidence that was found for this review, as many of the findings will be based only association and not have a causal relationship. Age boundaries of the cohorts were often different 50+ (Vu et al, 2014, Catindig et al, 2012), 55+ (Shooshtari et al, 2011), 60+ (Wu et al, 2014, Simning et al, 2014), 65+ (Husaini et al, 2013, Thyrian and Hoffmann, 2012), 75+ (Piguet et al, 2003), 95+ (Borjesson-Hanson et al, 2011). This is extremely important because age is the single strongest factor associated with increasing risk of dementia, so this has the potential to confound the comparison and synthesis of any studies and would require careful methodological evaluation, and statistical control.

The methods used to identify the source population varied considerably across the studies reviewed. Many of the studies that reported prevalence of populations with different protected characteristics were not studying it as their primary question. This
means that the reported prevalence was biased. For example, the large Tennessee-based hospital discharge study of patient over 65 (Husaini et al, 2013) had a smaller proportion of African-Americans in the hospitalised population than in the general Tennessee population (11% vs 14%). There was rarely sufficient data within the studies to make a valid judgement as to the way in which bias was likely to be affecting the results.

**Reference snowballing**

There were a number of additional relevant studies that were sourced through the references of the review studies, which were not identified as primary studies – often because they were outside the time inclusion criteria.

<table>
<thead>
<tr>
<th>Source</th>
<th>Additional reference(s)</th>
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<tr>
<td>(Vu et al, 2014)</td>
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<td>(Borjesson-Hanson et al, 2011)</td>
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</table>
Findings

Ethnicity

The largest body of evidence in this review concerns the prevalence of dementia in people from different ethnic groups. Ethnicity is a complex and contested concept. It has a social focus, relating to a real or putative shared identity based on one or more symbolic elements such as culture, language, religion, kinship, shared territory or physical appearance (Bulmer 1996). The labels commonly used to describe ethnic groups in England are generally those which are practical for statistical and policy purposes. However, it should be recognised, that ethnic identity can change over time, or depending on the social context. Ethnic group measurement also varies considerably by nation state. The labels used here reflect those used in included studies reviewed.

Only studies focused on dementia in people from African-American (black-Caribbean) or Hispanic ethnic groups were found in the literature focused on the countries in the inclusion criteria.

In a large Tennessee-based hospital discharge study of patient over 65 (Husaini et al, 2013) 3.6% had a diagnosis of dementia. People with a diagnosis of dementia were more likely to be African-American than Caucasian (4.2% vs 3.5%) and female than male (3.9% vs 3.2%). However, African-American people were less represented in the hospitalised population than in the general Tennessee population (11% vs 14%).

In this study, the increase in dementia appears to be particularly mediated through increased prevalence of stroke and diabetes. The prevalence of Alzheimer's disease in populations in Manhattan showed a two-fold increase in African-American and Hispanic populations compared with Caucasians (Mattiussi et al, 2012) and for dementia and cognitive impairment (Noble et al, 2012). These differential rates are consistent with other US based larger studies (Potter et al, 2009, Gurland et al, 1999). These differences were greatly reduced, but not entirely eliminated, when controlling for known risk factors (education, literacy, stroke, hypertension, heart disease and diabetes).

A study examining the prevalence of dementia in a small area of London, UK (Adelman et al, 2011) revealed an increased prevalence in people of black-Caribbean ethnicity. This increase remained even after controlling for socio-economic position.

There were many ethnicities not represented with the available studies. For example, there were no studies examining the prevalence of south-east Asians migrants or those of south-east Asian ethnicity within any of the countries of interest. The studies from countries outside of the scope of this review did not contain data examining the
prevalence of dementia in the south-east Asian population compared with the white population.

Complicating evidence regarding ethnicity

There is growing consensus that differences in inter-country dementia prevalence rates are not solely products of different ascertainment rates (Venketasubramanian et al, 2011).


This is also true for African-Americans where the elderly in their native countries (eg, Nigeria) show much lower rates of dementia (Hendrie et al, 2001). However, it is not clear to what degree this represents selection bias – it might be that only people without dementia in Nigeria live to be elderly.

Studies on internal migrants into and out of the 'stroke-belt' counties in the US (Glymour et al, 2011) suggest that there is some evidence to support the concept of childhood exposures establishing cognitive reserve and that the impact is different between different ethnicities with the greatest effect on African-Americans [See Education in risk factors section].

Diagnostic and screening tools need to be culturally appropriate (Adelman et al, 2011). When the diagnostic and screening tools are not culturally appropriate, over-diagnosis or misclassification (Kennedy, 2012) are potentially significant issues. This is a separate and distinct issue from the under diagnosis that is caused from failure to consider the possibility of dementia and therefore put people forward for potential diagnosis. Black and minority ethnic people with dementia may be at particular risk of misdiagnosis, particularly of being labelled as ‘mentally ill’ and treated with (inappropriate) medication (Blood and Bamford, 2010).

Religion, belief and culture

Different ethnic groups, especially Hispanic and African-American groups, received delayed and inadequate health care services for dementia (Chin et al, 2011). Efforts to narrow this health disparity will require understanding of how the cultural beliefs of these communities influence their understanding of dementia and their willingness to seek support from health services for these conditions. Across a wide range of countries and cultures gender, education and assets do not explain the variations in health service utilisation. Dementia is usually inversely associated with health service use (Albanese et al, 2011). Some of the culturally specific conceptualisations of dementia as a normal part of ageing or of having a spiritual, psychological or social
cause have prevented many groups from seeking support (Mukadam et al, 2011, Mukadam et al, 2013).

Specific work in Australia (Garvey et al, 2011) suggests that some of the causes are due to culturally mediated misconceptions and that culturally appropriate campaigns and educational interventions may be part of the approach needed. This is an area that has not been fully addressed in any of the literature available for this review.

Gender

Gender has long been widely reported as associated with the prevalence of dementia. The differential prevalence reported in the studies included in this review is in keeping with the much larger and longer standing body of evidence.

In a large survey of Canadian home care clients, Vu et al (2014) reported that a greater proportion of people with dementia were women (63.7%). In people with dementia receiving home care services, the women were much less likely to be married (26.9%, men 65.5%) and much more likely to be widowed (64.1%, men 24.1%). Similar figures come from equivalent studies in Australia (Karmel et al, 2012) - 61.7% of people with dementia in a residential care survey were women.

The interpretation of this is limited because it is unclear what the differential drivers of people needing home care are. As such, it is also unclear how different they are from the general population. The study reported that of the nearly 500,000 people aged 50-115 years expected to receive home care services for more than 60 days with a recent home based assessment, more than 21% had a diagnosis of dementia. How this maps to the general population is not clear in this study.

Borjesson-Hanson et al (2011) reported that a much greater proportion of the over-95-year-olds in Gothenburg, Sweden with dementia were women (85%) and a greater proportion of the women had dementia (56% vs 37% of men). Bernardi et al (2012) report a greater proportion of women having dementia even at younger ages.

Socio-economic position

Socio-economic position has long been seen as an independent predictor of dementia (Adelman et al, 2011). People with a low socio-economic position have increased prevalence of Alzheimer's disease. Such that it is routine practice to statistically control for socio-economic position when reporting rates of dementia. The mechanism by which this leads to dementia is not clear, as it appears to be, in part, independent of education. Rurality is an additional, rarely reported, factor that would interact with socio-economic position. Rural living, especially in early life, is associated with increased risk of dementia (Russ et al, 2012).
Sexual orientation

Although there were no studies published in the time period for this review that address the differential prevalence of groups classified by their sexual orientation or gender reassignment, an important issue was raised in the grey literature. This issue relates to people being unwilling to declare their sexuality on admission to residential care (Peel and McDaid, 2015). This would prevent diagnoses of dementia from being linked with sexual orientation data and therefore impede the ability of health services to identify issues that relate to dementia and sexual orientation.

Disability

Shooshtari et al (2011) focused their case-control study on adults with developmental disabilities. This study suggested that those developmental disabilities give rise to a more than four-fold increase in dementia.

Associations between Alzheimer’s disease and syndrome specific neurological phenotypes are well recognised. All individuals with Down’s syndrome have the characteristic neuropathology of Alzheimer's disease by the age of 40, and although not all will develop dementia, it is extremely common (Lott, 2012, Zigman, 2013).

Risk factors

The papers considered in this review identified four risk factors that recurred in the evidence regarding people with protected characteristics. Those four risk factors were diabetes, stroke, education and depression.

Diabetes

Diabetes doubles an individual's risk of dementia (Ott et al, 1999) (odds ratio 1.17 (Husaini et al, 2013)). In the hospital discharge study in Tennessee diabetes was more common among African-Americans with a diagnosis of dementia (50.6% vs 33.4%).

Type 2 diabetes has a Hazard Ratio of 1.6 for dementia and cognitive impairment. Estimates of the impact of reducing ethnic disparities in diabetic prevalence suggest that this could reduce dementia by around 17% in ethnic populations (Noble et al, 2012).

Stroke

Stroke appears to be a strong risk factor for dementia (Odds Ratio 8.5 (Husaini et al, 2013)) especially where mediated through hypertension (Odds Ratio 1.9 (Husaini et al, 2013)).
Prevalence of dementia in population groups by protected characteristics

Education

Levels of education are strongly inversely associated with dementia (Gurland et al, 1999, Adelman et al, 2011). Increased early life education, is associated with reduced risk of dementia (Meng and D’Arcy, 2012). However, after controlling for age and education differences in rates between ethnic groups are no longer consistent.

Depression

A diagnosis of depression was less common in very elderly people with dementia (Borjesson-Hanson et al, 2011). Although this could be due to a number of reasons; the primary reason appears to be that psychiatric diagnoses are heavily reliant on self-reporting, which become increasing unreliable with increasing severity of dementia. When patients with dementia are excluded from samples the apparent decline in depression in the very elderly disappears (Saunders et al, 1993).


These effects are specifically seen in some groups defined by protected characteristics. Adults with developmental disabilities are seen to have significantly increased rates of depression and in addition to their increased rates of dementia.

Grey literature

Information on the prevalence or risk of dementia was limited within the ‘grey literature’, except of that from the report ‘Black, Asian and Minority Ethnic Communities and Dementia – where are we now?’ (Truswell, 2013). The following excerpt summarises this report.

“In the UK there has been very little work done on the impact of dementia in black and minority ethnic communities. Little is known about the prevalence of dementia in the UK black and minority populations despite some of these communities being at higher levels of risk than the indigenous white population.

“There are increasing indications that the prevalence of dementia in Black African-Caribbean and South Asian UK populations is greater than the white UK population (Turner et al, 2012 from Truswell, 2013) and that the age of onset is lower for Black African-Caribbean groups than the white UK population.

“Policy guidance on understanding the issues for black and minority ethnic communities has not yet found its way into practice when implementing the UK National Dementia
Strategy. Information from the 2011 Census indicates that there are substantial increases in the number of people from black and minority communities likely to be living with dementia, but the understanding of dementia in such communities is limited and the illness highly stigmatised.

“The 2011 Census shows that 58% of the black ethnic groups (Black African-Caribbean, Black African and Black Other) live in London and also that the Black African-Caribbean population is demographically the 'oldest' of the black ethnic groups (Lievesley, 2013 from Truswell, 2013). From the 2011 Census data this would mean over 2,700 of those who identified as Black African-Caribbean in the capital over 65 are likely to be living with dementia. It is probable that this figure is considerably underestimated as it assumes that the Black African-Caribbean population has the same prevalence of dementia as the indigenous white population, when there are studies (prior to the timeframe of this review) that suggest that the prevalence rate is higher (Livingston et al, 2001; Adelman et el, 2009a; Banerjee & Lawrence, 2010 from Truswell, 2013).”

Results from evidence outside the stated inclusion criteria

Mild cognitive impairment

This review does not formally consider evidence regarding mild cognitive impairment. However, the evidence that coincidentally emerged in the course of this review (O’Bryant et al, 2013, Juarez-Cedillo et al, 2013, Su et al, 2014, Langa and Levine, 2014, Simning et al, 2014, Lee et al, 2012, Ward et al, 2012, Kennedy, 2012) was reviewed as part of the process of triangulating the themes that emerged from the review.

The evidence suggests that many of the themes here are replicated in evidence regarding mild cognitive impairment, with similar ethnic differences and protection of education and mediation by cerebrovascular risk factors such as diabetes and hypertension.
Implications

Ethnicity
Currently there appears to be system issues with regards to considering the potential diagnosis of dementia. This issue appears to differentially affect people from different ethnicities; people from certain minority ethnic groups are less willing to seek a diagnosis, and when they do health professionals appear not to consider the diagnosis as readily.

Diagnostic and screening tools need to be culturally appropriate, when they are not, over-diagnosis or misclassification are potentially significant issues. Where they are available, culturally specific tools should be used both in routine practice and research studies.

Learning Disability
In syndromes where it is extremely common for people to develop dementia, it should not be assumed that every individual will develop dementia.
Prevalence of dementia in population groups by protected characteristics

Recommendations

Research communities

1. Research communities should consider conducting future primary studies of the system causes of under diagnosis within specific groups with protected characteristics.

2. Qualitative research into the differential access of health services by different ethnic groups mediated by different cultural beliefs is needed. These studies should include the identification of barriers and enablers for those communities.

3. Further studies should be conducted to begin to explore the mechanism by which lower socio-economic position is associated with increased prevalence of dementia.

4. Research communities should also consider conducting future primary studies of the prevalence of dementia in people of south-east Asian ethnicity within the UK.

Public Health England

5. PHE should use evidence from this review to indirectly estimate the potential prevalence of dementia in specific groups. In particular, PHE should consider conducting modelling studies to begin to estimate the impact on increasing prevalence of dementia caused by known differential rates of:

- depression between groups
- diabetes between groups
- cardiovascular disease between groups

Local authority and health care commissioners

6. Commissioners and providers of health and care services should ensure that they fully consider those groups with protected characteristics who are at greatest risk of developing and are living with dementia in their population, when commissioning and providing services.
References


Carers Uk & Employers for Carers 2014. Supporting employees who are caring for someone with dementia. London: Carers UK the voice of the carers.


Prevalence of dementia in population groups by protected characteristics


Prevalence of dementia in population groups by protected characteristics


Prevalence of dementia in population groups by protected characteristics


Snowdon, J. & Lane, F. 2001. The prevalence and outcome of depression and dementia in Botany's elderly population.


Appendix I. Randomly selected papers to develop inter-reviewer consistency


Stolder, M. E. 2012. Memory self-efficacy in cognitively normal older adults and older adults with mild cognitive impairment. Ph.D., University of Iowa.

Appendix II. Grey literature

Those people acknowledged at the beginning who generously contributed relevant literature made significant contribution to this review. The following reports, articles and papers were sent to the review team and informed all aspects of this review:


Carers UK & Employers for Carers 2014. Supporting employees who are caring for someone with dementia. London: Carers UK the voice of the carers. (Carers UK and Employers for Carers, 2014)


Appendix III. Papers grouped by country

UK


USA


**Canada**


**Australia**

Snowdon, J. & Lane, F. The prevalence and outcome of depression and dementia in Botany's elderly population.


Prevalence of dementia in population groups by protected characteristics

New Zealand

The search found no studies that reported the prevalence of dementia in people with protected characteristics in New Zealand within the timeframe of the search.

Europe


South Africa

The papers retrieved included in several studies about multiple African countries but it was not possible to isolate the South African data.

Japan


Prevalence of dementia in population groups by protected characteristics

Studies from other countries

Malaysia
Momtaz et al, 2013
This paper estimated that in Malaysia education could be seen as a partial mediator between ethnicity and dementia accounting for approximately 8% of the total effect of ethnicity on dementia prevalence. The paper also reported that different rates of depression between different ethnic groups accounts for some of the differences in rates of dementia – with groups having higher rates of depression also having higher rates of dementia.

Lee et al, 2012
This paper identifies that risk factors for people with mild cognitive impairment increased with not exercising, obesity and being married (for women) even after adjustment for age, ethnicity and education. There are many potential confounding factors and the relative impact is not possible to assess from this study. It is unclear what driving factors influence this result and cause it to be the opposite to that reported in Canadian home care clients, where women with dementia were much less likely to be married (Vu et al, 2014).

Africa
George-Carey et al, 2012
This paper provided further evidence of the impact of gender on the prevalence of dementia with women being at greater risk. The paper also discussed the risk factors that appeared to most significantly contribute to this gender based inequality. This paper was supported by other papers suggesting that, in part, the gender inequality in this context was mediated by lower levels of educational attainment (Yusuf et al, 2011) and poorer socio-economic status (Gureje et al, 2011).

India
Gambhir et al, 2014
Within the context of India this paper identified four factors that appeared to be most significant in contributing to the prevalence of dementia: gender, literacy, malnutrition and obesity.

Brazil
Pastor-Valero et al, 2014
Dietary intakes of fruit and vegetables above the WHO recommended levels of 400g/day were significantly associated with a decreased prevalence of cognitive impairment.
China
Su et al, 2014
This paper identified the predictors of cognitive impairment in China as the following three factors: age, education and stroke
Wu et al, 2014
This paper reported that a series of prevalence studies for East Asia suggest a rising prevalence over time.

Korea
These papers reported prevalence of dementia in Korea increasing over time, doubling with each five-year age period.