

## 4. Older adults: Dementia

### 4.1. Introduction

'Dementia' covers a range of different progressive memory loss conditions (Table 1). As well as memory loss, different diseases may have other symptoms of cognitive and physical impairment as they progress. The vast majority of people with dementia are older adults whose symptoms begin after the age of 65, but the disease also affects a small number of people under 65.

GPs record data about who has dementia. This means we are able to explore detailed local data on this topic.

*Table 1: Types of dementia<sup>i</sup>*

| Type of dementia                 | Estimated proportion of all cases of dementia | Physical cause  | Symptoms other than memory loss  |
|----------------------------------|---|---|--|
| <b>Alzheimer's disease</b>       | 62%   | Damaged tissue building up in the brain                                 | May include difficulty communicating or learning new things as well as changes in mood, judgement and personality.   |
| <b>Vascular dementia</b>         | 17%   | A series of small strokes   | May come on more quickly than Alzheimer's disease. Symptoms may include changes in mood, hallucinations, physical impairment.  |
| <b>Mixed dementia</b>            | 10%   | A combination of more than one type of dementia                         | Vary according to the types of dementia present.   |
| <b>Dementia with Lewy bodies</b> | 4%  | 'Lewy bodies': tiny deposits of protein in nerve cells                  | Shares symptoms with Alzheimer's disease and Parkinson's dementia (see above and below). May also include problems with alertness and attention, and hallucinations. |
| <b>Frontotemporal dementia</b>   | 2%  | Death of nerve cells in the frontal and/or temporal lobes of the brain. | Vary depending on which parts of the brain are damaged. May include behaviour change or language difficulties.   |
| <b>Parkinson's dementia</b>      | 2%  | Parkinson's disease   | May include cognitive difficulties, emotional difficulties, hallucinations.  |
| <b>Other</b>                     | 3%  | Vary  | Vary   |

## 4.2. Causes and risk factors<sup>ii</sup>

Family history is associated with increased risk for both early- and late-onset dementia. In the case of early-onset dementia (affecting those under 65), particular genetic mutations explaining this link have been identified.

People with Down's syndrome and learning disabilities have a higher risk of developing dementia and have a younger typical age of onset. There is also evidence that those with a history of depression or severe and enduring mental ill health are at increased risk of dementia.

The single most important risk factor for dementia is advancing age (see Section 4.3.1). Other known risk factors include cardiovascular risk factors, such as smoking, high blood pressure, physical inactivity and obesity. These are direct risk factors for vascular dementia, but are also risk factors for stroke, which itself is a risk factor for both vascular dementia and Alzheimer's disease. It is estimated that a third of cases of Alzheimer's disease are attributable to potentially modifiable risk factors: diabetes, midlife hypertension, midlife obesity, physical inactivity, depression, smoking and low educational attainment.<sup>iii</sup>

Higher educational attainment and intelligence are a protective factor for dementia.

## 4.3. Local data and unmet need

### 4.3.1. Numbers affected – known to services

In April 2014, 789 people in Hackney and the City of London (0.3% of all residents registered with a GP) were recorded by their GPs as having dementia. Most of these patients (748) were aged 65 and over (3.7% of those in this age group registered with a GP), with almost all of the rest aged 50-64 (0.1% of those in this age group registered with a GP).

Separate data is not directly available for all City of London residents. However, the Neaman Practice, which serves the vast majority (81%) of City of London residents<sup>iv</sup> had a similar overall dementia diagnosis rate of 0.4% of those on the GP register (30 people). Data is not available for GP practices based in Tower Hamlets, which serve the Portsoken ward in the east of the City. For more information on GP registration, see Chapter 1 of the JSNA ([The People of Hackney and the City](#)).

In 2013/14, 339 people with a diagnosis of dementia living in Hackney and the City of London were receiving services from East London NHS Foundation Trust (ELFT), the main local secondary mental health service provider. Of these, 293 were being seen by the Dementia Care Team, which sees those with higher levels of need (see Section 4.7).

Figure 1 maps the crude and age standardised rates of recorded dementia across Hackney and the City.<sup>1</sup>

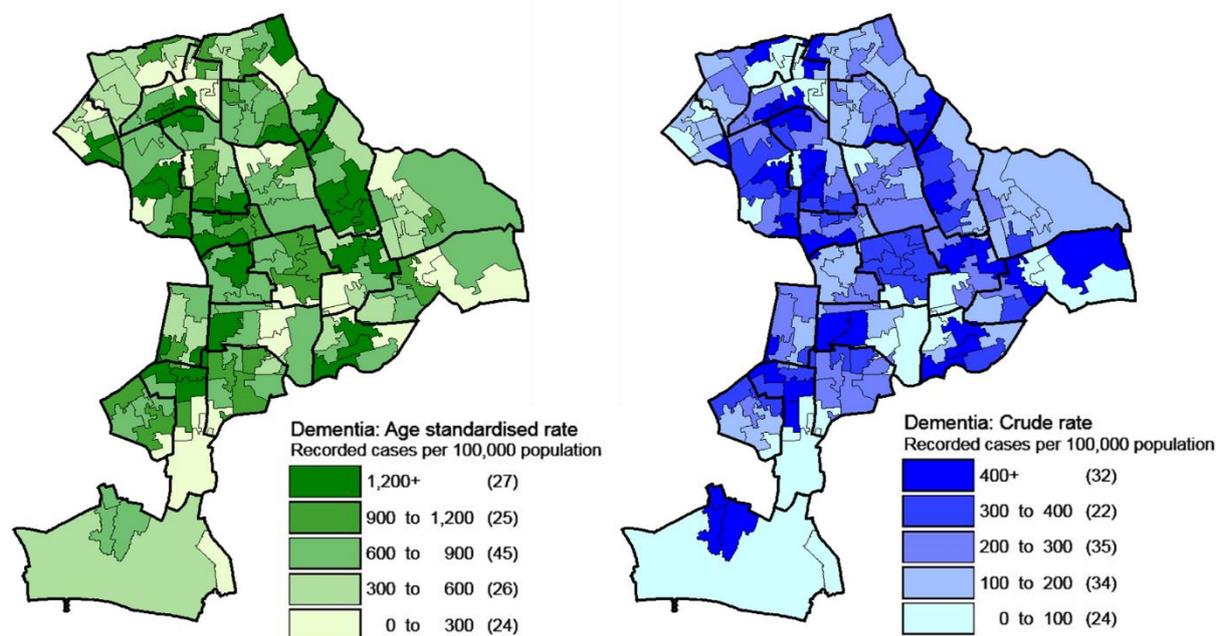
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<sup>1</sup> The crude rate of recorded dementia is the frequency with which dementia is recorded per 100,000 people age 65+. It is not adjusted to take account of any differences (for example the age distribution) in the

In Hackney, recorded rates of dementia are particularly high in Lea Bridge, to the east of the borough, and high in Clissold and Stoke Newington to the west of the borough. Cazenove, Shacklewell and Dalston all have high age standardised rates compared to the rest of the borough but lower crude rates, reflecting their younger age distribution, while Stamford Hill West has a comparatively low age standardised rate but a high crude rate, reflecting its older demographic.

In the City, crude rates of dementia are high in the north, but the older demographic means that when this is age standardised it is comparatively moderate. Both crude and age standardised rates in Portsoken ward in the east are low.

Figure 1: Geographic distribution of GP recorded dementia in Hackney and the City of London residents of all ages (2015)



Local data: Extracted from the GP register by Clinical Effectiveness Group (CEG), Blizard Institute, September 2015

Data cover Hackney and the City residents registered with a GP in Hackney, the City of London, Tower Hamlets and Newham.

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underlying population. The age standardised rate allows you to compare rates in two populations even if they have different age distributions: it is the rate that you would observe if every population had the same age distribution.

### 4.3.2. Numbers affected – estimated

The estimates below are based on national estimated prevalence figures and the gender and age distribution of Hackney and the City of London. They do not take into account ethnicity, deprivation, or other wider determinants of health.

It is estimated there are roughly 1,200 Hackney residents aged 65+ living with dementia (Table 2). About 800 of this group are estimated to have Alzheimer’s disease and about 200 are estimated to have vascular dementia.

It is estimated that there are roughly 90 City of London residents aged 65+ with dementia (Table 2). About 60 of this group are estimated to have Alzheimer’s disease and about 15 are estimated to have vascular dementia.

*Table 2: Estimated number of Hackney and the City residents (age 65+) with dementia*

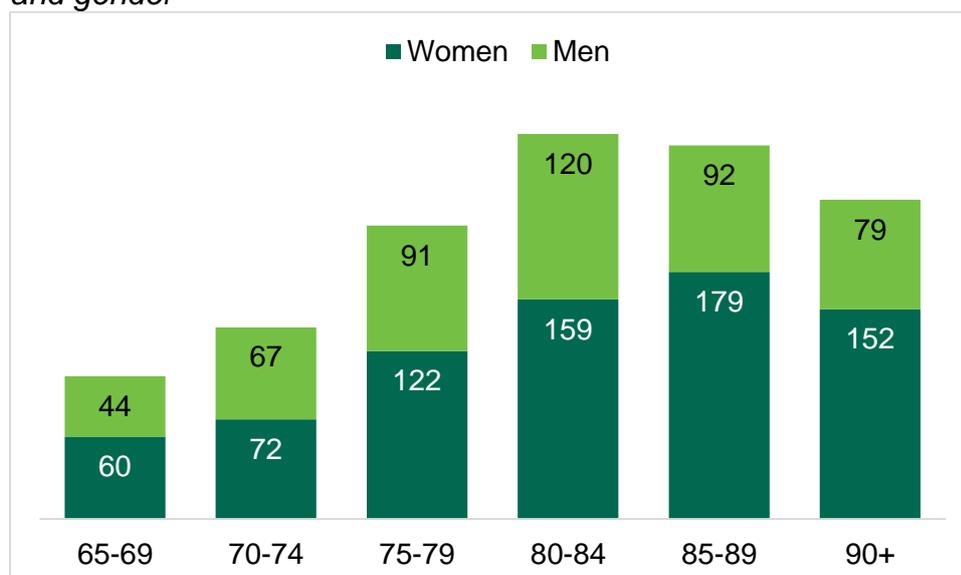
| Age band                         | National estimated prevalence <sup>v</sup> |        | Hackney estimated numbers | City of London estimated numbers | Total estimated numbers for City and Hackney |
|----------------------------------|--|--------|---------------------------|----------------------------------|--|
|                                  | Male                                       | Female |                           |                                  |  |
| <b>65-69</b>                     | 1.5%                                       | 1.8%   | 104                       | 7                                | 111  |
| <b>70-74</b>                     | 3.1%                                       | 3.0%   | 139                       | 10                               | 149  |
| <b>75-79</b>                     | 5.3%                                       | 6.6%   | 213                       | 15                               | 228  |
| <b>80-84</b>                     | 10.3%                                      | 11.7%  | 279                       | 18                               | 298  |
| <b>85-89</b>                     | 15.1%                                      | 20.2%  | 271                       | 22                               | 293  |
| <b>90-94</b>                     | 22.6%                                      | 33.0%  | 232                       | 22                               | 253  |
| <b>95+</b>                       | 28.8%                                      | 44.2%  | -                         | -                                | -  |
| <b>Total population aged 65+</b> |  |        | <b>1,237</b>              | <b>94</b>                        | <b>1,331</b>                                 |

Estimates: National prevalence estimates applied to population figures<sup>vi</sup>

Note: Due to rounding, columns may not sum to total

Figure 2 shows how the estimate of 1,237 residents with dementia in Hackney is distributed by age and gender. The total number of people with dementia in each age band is estimated to peak at ages 80-84, reflecting the very small number of residents aged 85+. The gender balance is increasingly skewed towards women at older ages, reflecting both the higher estimated prevalence in women than men and the fact that more women tend to reach very old age. For more details on the demographic profile of Hackney’s resident population, see Chapter 1 of the JSNA ([The People of Hackney and the City](#)).

Figure 2: Estimated number of Hackney residents with dementia (age 65+), by age and gender

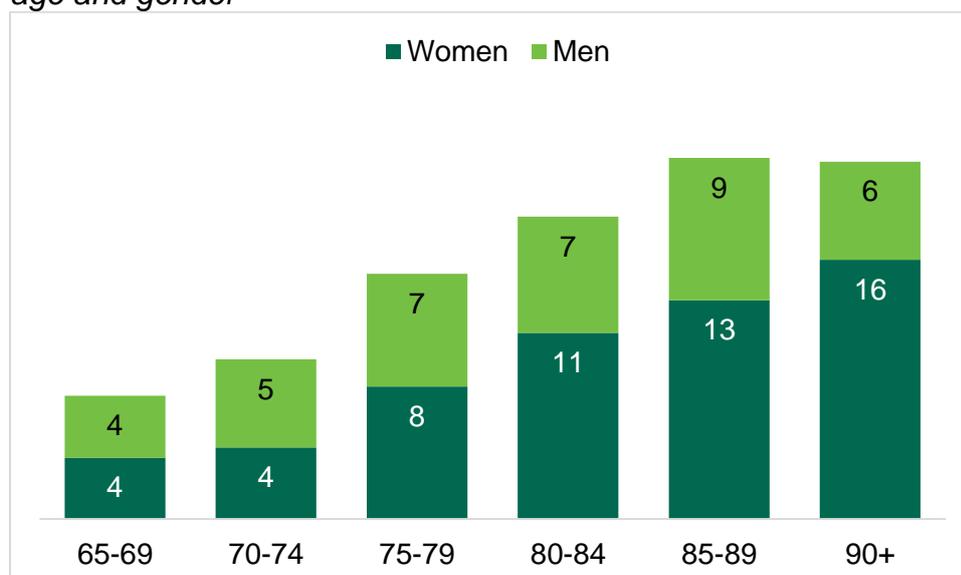


Estimates: See Table 2

Note: Due to rounding, figures may not sum to total

Figure 3 shows how the estimate of 94 residents with dementia in the City of London is distributed by age and gender. The total number of people with dementia in each age band is estimated to continue increasing up to the ages of 85-89, reflecting a larger proportion of older residents in the City than in Hackney. It is not until the 80-84 age band that the gender balance becomes skewed towards women, despite the fact that women have a higher estimated prevalence – this is because there are more men than women in the younger age bands living in the City. For more details, see Chapter 1 of the JSNA ([The People of Hackney and the City](#)).

Figure 3: Estimated number of City of London residents with dementia (age 65+), by age and gender



Estimates: See Table 2

Note: Due to rounding, figures may not sum to total

Just over half of cases of dementia are estimated to be mild, around a third are estimated to be moderate and the remainder are estimated to be severe (Table 3). Different types of dementia have different symptoms (see Table 1); when discussing all types of dementia together, the level of severity is defined not in terms of particular symptoms, but in terms of the extent of loss of abilities.

Table 3: Estimated number of dementia cases in Hackney and the City of London residents (age 65+) by severity

| Type            | Description <sup>vii</sup>   | Estimated proportion of cases <sup>viii</sup> | Hackney      | City of London | Total        |
|-----------------|--|---|--------------|----------------|--------------|
| <b>Mild</b>     | Loss of short term memory, some loss of cognitive skills and ability to carry out everyday tasks | 55.4%   | 686          | 52             | 737          |
| <b>Moderate</b> | Clear loss of cognitive skills and ability to carry out everyday tasks                           | 32.1%   | 397          | 30             | 427          |
| <b>Severe</b>   | Total loss of cognitive skills and ability to carry out everyday tasks                           | 12.5%   | 155          | 12             | 166          |
| <b>Total</b>    |  |   | <b>1,237</b> | <b>94</b>      | <b>1,331</b> |

Estimates: National prevalence estimates applied to population figures<sup>ix</sup>

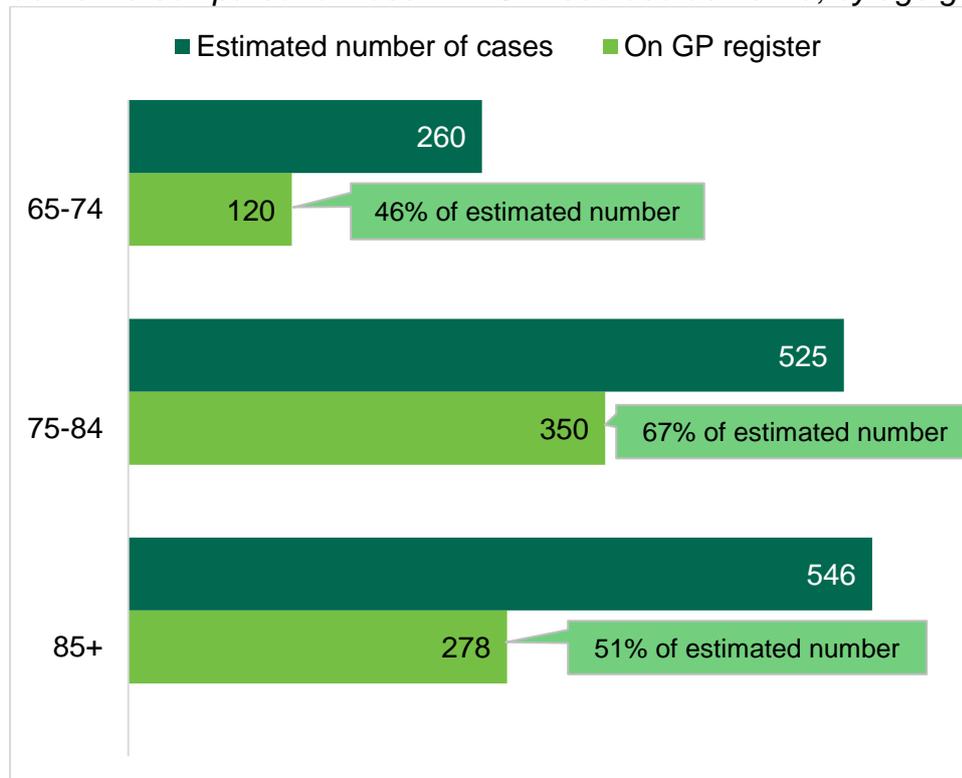
Note: Due to rounding, columns may not sum to total

### 4.3.3. Unmet need

Only just over half (56%) of the projected City and Hackney population age 65+ with dementia are have this recorded by their GP. This may be due to undiagnosed dementia, or dementia not being recorded correctly on GP records. Separate data is not available for the City of London.

Figure 4 shows that ‘coverage’ (i.e. the proportion affected who are on the GP register) is highest for those aged 75-84 years (67%), and lowest for those aged 65-74 (46%). An estimated 583 people aged 65+ (268 aged 85+) predicted to have dementia are not on the register and therefore may not be receiving the care and support they need.

*Figure 4: Estimated number of Hackney and the City residents (aged 65+) with dementia compared to those with GP recorded dementia, by age group*



Local data: Section 4.3.1  
Local estimates: Table 2

Two hundred and ninety-three Hackney and the City of London clients were seen by the Dementia Care Team (see Section 4.7) in 2013/14. This is more than the 166 people estimated to have severe dementia, for whom this service is primarily designed (Table 3).

## **4.4. Health inequalities**

### **4.4.1. Age**

Given the strong link between age and dementia prevalence, local data on associated health inequalities are presented in Section 4.3.1.

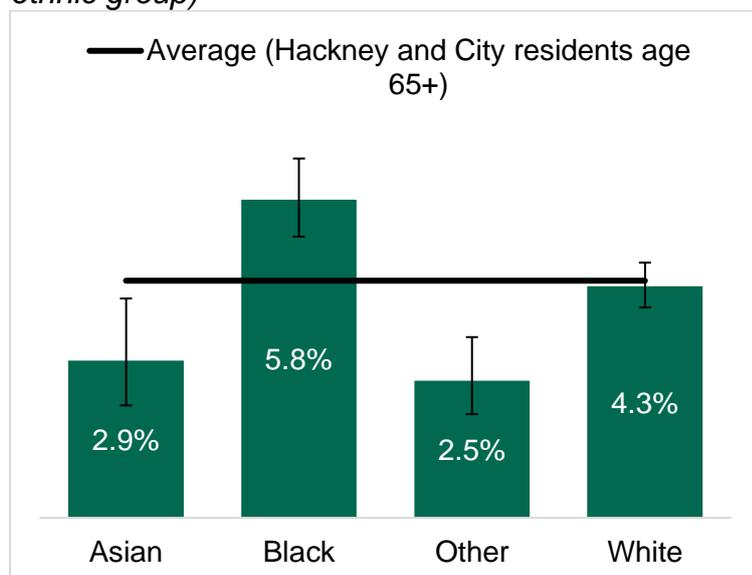
Stakeholders consulted for the 2014 Mental Health Needs Assessment stated that there was limited service provision and support available following diagnosis for people with early onset dementia (i.e. under 65), whose needs differ from those of older people with dementia as they are more likely to be in employment or have dependent children.

### **4.4.2. Ethnicity**

There is currently no robust national evidence on variations in dementia prevalence in different ethnic groups.<sup>x, xi</sup> A 2011 Social Care Institute for Excellence research briefing reported that BME groups were under-represented in dementia service user caseloads, and suggested that this could be due to stigma and low awareness of the condition in some communities.<sup>x</sup>

Locally, ethnicity data is missing from GP records for approximately 10% of those aged 65+. This means that the following data is indicative only. However, the data suggests that recorded dementia is more common amongst Black adults and less common amongst Asian and Other ethnic groups. This may point to under-diagnosis in Asian and Other ethnic groups, a different age profile within different communities, or other ethnicity-related factors affecting the risk of developing dementia.

Figure 5: Proportion of Hackney and the City residents (all ages) with GP recorded dementia by ethnicity (as a proportion of all those registered with a GP (age 65+) in ethnic group)



Local service data extracted from the GP register by CEG, Blizard Institute, April 2014  
Data cover Hackney and the City residents registered with a GP in Hackney, the City of London, Tower Hamlets and Newham.

Note: Approximately 10% of ethnicity data is missing for registered patients aged 65+  
Black bars are 95% confidence intervals. This are a statistical indicator of how closely the reported figures are likely to reflect the 'true' or underlying pattern.

#### 4.4.3. Gender

Nationally, a larger number of women than men are estimated to have dementia. As described in Section 4.3.2, this is for two main reasons: first, dementia is more common amongst women in most age bands (see Table 2); and second, dementia is strongly linked to age and women live longer than men on average. It is also the case that women are more likely to present to health services than men, so they may have higher detection rates.<sup>xii</sup>

This is reflected in the local data, with a higher proportion of women than men on the GP dementia register; 4.4% and 3.6% respectively.<sup>xiii</sup>

#### 4.4.4. Deprivation

For older adults living in the community in urban areas, there is evidence that higher neighbourhood deprivation is linked to lower cognitive function. This link is independent of education or individual socioeconomic circumstances.<sup>xiv</sup>

Nationally, mortality from dementia in an area has no link with the level of deprivation in that area.<sup>xv</sup> In interpreting this result, the strong link between dementia and age should be noted. Those in areas of low deprivation (or greater affluence) are more likely to reach very old age, when dementia is more prevalent.

#### 4.4.5. Other equality areas

Other legally protected characteristics<sup>xvi</sup> are disability, gender reassignment, marriage and civil partnership, religion or belief and sexual orientation. Local information was not available at the time of writing to analyse how dementia prevalence or dementia service provision is linked to any of these characteristics.

### 4.5. Comparisons with other areas and over time

Estimates are available for national, regional and local area diagnosis rates through NHS England's Primary Care Web Tool.<sup>xvii</sup>

Stakeholders working with older adults have noted an increase in referrals for memory services. They suggest this may be a positive outcome that could be due to an ongoing drive to increase detection and diagnosis.

The NHS England tool estimates that, in March 2015, the City and Hackney diagnosis 'coverage' rate was 70%, compared to an estimate of 66% for London and 61% for England (Figure 5). No information on whether this difference is statistically significant is available.

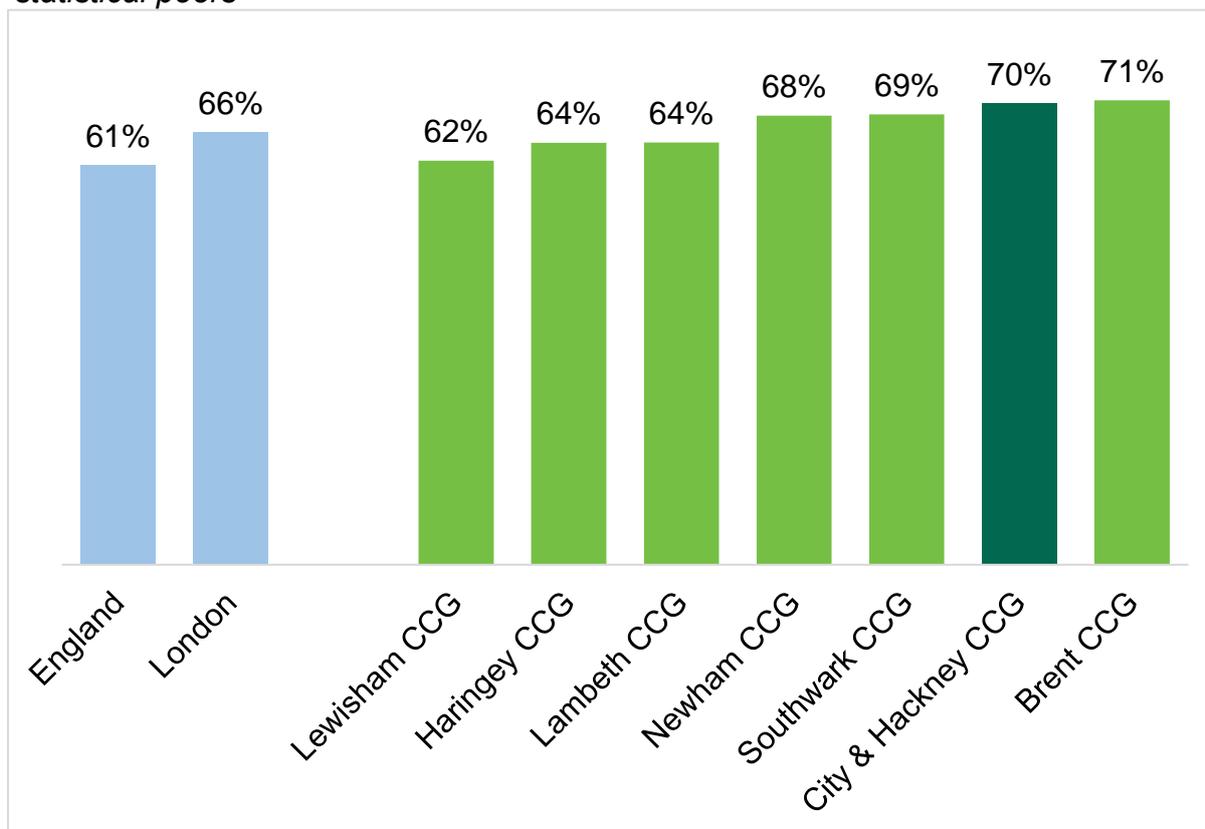
A 'coverage' rate of 70% means that seven out of every 10 people estimated to have dementia have been diagnosed with the condition.

Please note: The estimate provided by this tool differs from the earlier estimate of a diagnosis 'coverage' rate of 56% (reported in section 4.3.3); this is because the methodologies used to provide these two estimates are different.<sup>2</sup> We recommend using the 56% figure for service planning as this is a more accurate local estimate. However, when making comparisons with other areas, the 70% figure should be used as this is calculated using a consistent (and therefore comparable) methodology.

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<sup>2</sup> The tool's estimates use the population registered with GP practices within the area, rather than the estimated resident population. This allows for a fair comparison between different areas, but does not reflect that some residents are registered elsewhere or not registered, and that some people registered in the area are not residents. (See Chapter 1 of the JSNA, *The People of Hackney and the City*.) Information is not available on the source of the prevalence estimates.

Figure 6: Estimated dementia coverage rate for England, London and Hackney's 'statistical peers'<sup>3</sup> xvii

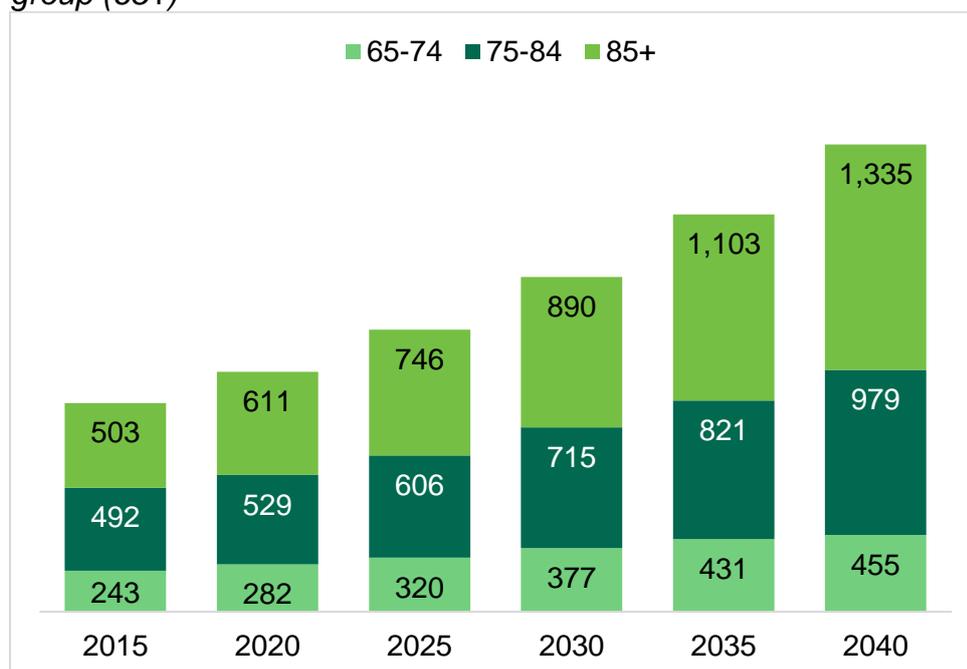


No data is available on past trends.

Assuming that prevalence of dementia remains the same, the estimated number of people aged 65+ with dementia in Hackney will increase by approximately a third between 2015 and 2025 (Figure 7).

<sup>3</sup> Local authorities with a similar demographic make up to Hackney, used for the purpose of comparisons. This chapter of the JSNA follows the 2014 *Mental Health Needs Assessment*, which used a previous version of Hackney's statistical peers ('London Cosmopolitan'): Brent, Haringey, Lambeth, Lewisham, Newham and Southwark.

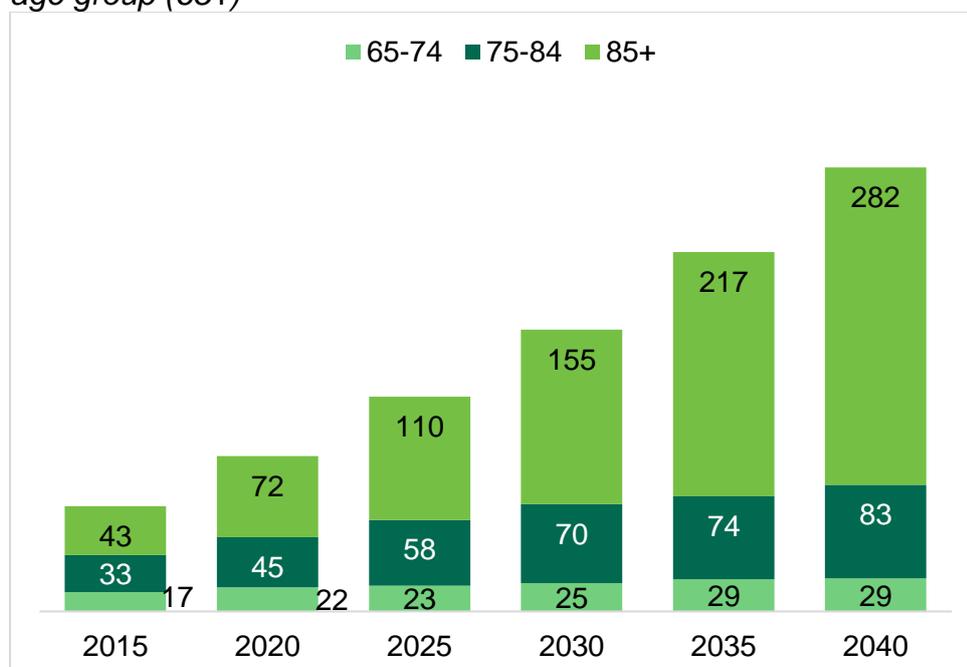
Figure 7: Predicted number of cases of dementia in Hackney 2015-2040 by age group (65+)



Estimates: National prevalence estimates (Table 2) applied to projected population figures<sup>xviii</sup>

Assuming that prevalence of dementia remains the same, the estimated number of people aged 65+ with dementia in the City of London will double between 2015 and 2025 (Figure 8), with this increase due in part to an estimated three-fold rise in the number of residents aged 90+ over this period (from 74 in 2015 to 255 in 2025).

Figure 8: Predicted number of cases of dementia in the City of London 2015-2040 by age group (65+)



Estimates: National prevalence estimates (Table 2) applied to population figures<sup>xix</sup>

## 4.6. Evidence for what works

### 4.6.1. Prevention

It is estimated that a third of cases of Alzheimer's disease are due to factors that are potentially modifiable: diabetes, midlife hypertension, midlife obesity, physical inactivity, depression, smoking and low educational attainment (Section 4.2). This suggests that lifestyle factors such as quitting smoking, being physically active and maintaining a healthy weight can reduce the probability of developing Alzheimer's disease, as can individual or population level work aimed at reducing the prevalence of diabetes or depression, or raising educational attainment.

### 4.6.2. Identification<sup>ii</sup>

General population screening is not recommended for dementia. Everyone who works with older people in the health, social care and voluntary sectors should be provided with training that allows them to spot early signs and symptoms suggestive of dementia. People with suspected dementia should be referred to a specialist memory assessment service for diagnosis and initial management.

When older adults become inpatients due to physical ill health, this also provides an opportunity for assessment and referral through a hospital liaison psychiatry service.

### 4.6.3. Treatment, care and support<sup>ii</sup>

*Box 13: Local case study: Holistic dementia care*

E was a woman in her late eighties with a diagnosis of mixed dementia. She was being looked after by her son.

As her condition deteriorated, she became more agitated and distressed. Her sleep was poor, her anxiety worsened, and she appeared to be responding to auditory hallucinations. This was very difficult for both her and her son.

Her dementia care team at ELFT stepped up her treatment, increasing her contact with services and changing her medications; she and her son were given additional support while she was adjusting to this.

As her mental distress decreased, her team was able to discover that she was in pain and constipated, which was adding to her agitation. This new information allowed her psychiatrist, GP and palliative care team to work together to reduce both her physical and mental symptoms.

E became much less distressed and her son was able to leave her alone for longer periods of time.

*Adapted with permission from a case study provided by ELFT.*

People with mild to moderate dementia should be offered structured group programmes aimed at stimulating thoughts, language use, recall and other cognitive functions.

Medication is only appropriate in certain circumstances and should only be initiated by specialists. In particular, there is strong evidence of the overuse of anti-psychotic medications in treating non-cognitive symptoms (such as agitated or aggressive behaviour or delusions).

Valid consent should always be sought from people with dementia. This includes ensuring as far as possible that the person understands their options, is not being coerced and continues to consent over time. The individual should be supported to make and update advance statements and other documents to be used if they lose the capacity to make a decision.

Services for older adults should be accessible and joined-up, taking into account the fact that older adults are more likely than working age adults to have multiple physical and mental health needs. For more details, see Section 6 of this chapter.

Service providers should help and encourage individuals to maintain their independence where possible, and to minimise any loss of independence and its impact. This includes mobility and manual dexterity as well as mental decline.

## 4.7. Services and support available locally

### 4.7.1. Prevention

For information on services and support aiming to reduce lifestyle risk factors, see: [Smokefree Hackney](#); [City of London Stop Smoking Services](#); [Hackney Council Sports and Leisure](#); [City of London Exercise Classes](#).

See Section 2 of this chapter for information on services and support aiming to reduce depression.

### 4.7.2. Identification

#### *Diagnostic Memory Clinic*

The Diagnostic Memory Clinic is a joint clinic run by ELFT and Homerton University Hospital NHS Foundation Trust (HUHFT) provided by a multi-disciplinary team in geriatric medicine, neuropsychology and psychiatry, and overseen by a care coordinator. The clinic provides initial assessment and diagnosis of dementia and cognitive impairment in people of all ages (although most service users are age 65+).

#### *Hospital Liaison Psychiatry Service – Older People*

This is a specialist team within HUHFT consisting of psychiatric nurses and a psychiatrist who assess dementia and other mental health problems in older adult inpatients. The team also provides advice to colleagues in other teams across the

trust on the treatment and management of older adult inpatients with mental health problems.

### 4.7.3. Treatment, care and support

Most dementia is managed in primary care by GPs.

Action being taken by the Clinical Commissioning Group (CCG) to improve identification and management of older people with dementia in primary care includes:

- an audit of dementia prevalence to improve diagnosis rates and increase the number of patients with dementia recorded by their GP – this has already had some success;
- Alzheimer's Society Dementia Advisors in every GP practice;
- educational sessions on dementia for GPs and practice staff;
- work with the HUHFT Hospital Liaison Psychiatry Service Development Team on dementia care pathways;
- developing links within the [One Hackney](#) integrated care scheme around dementia care.

ELFT also runs a Community Dementia Care Team for those with higher levels of need. This is an integrated multi-disciplinary mental health and social services team staffed by community mental health nurses, social workers, an occupational therapist, psychologists, psychiatrists and support workers. The team provides psychiatric and social needs assessment, risk assessment, intervention and treatment, including commissioning of care packages.

Psychological input provided by ELFT includes neuropsychological support to dementia diagnosis, cognitive stimulation therapy groups, work with families, and music therapy.

#### *A Dementia Friendly City*

The City of London's Dementia strategy 2012-2015 outlines the City's commitments to creating a 'Dementia Friendly City' where residents and local retail outlets and services have a keen understanding and awareness of the disease and offer support in a respectful and meaningful way. The City of London was awarded with Dementia Friendly City status by the Alzheimer's Society in August 2015. A significant amount of training and awareness has been undertaken to support the City of London's commitment to being a dementia friendly area

The City of London also commission a Dementia Support Group, which has been delivered by Age UK Camden since November 2013. The service runs a weekly City Memory Group for anyone who feels they are experiencing difficulties with their memory, including those living with dementia in the City.

## 4.8. Gaps in current services

A full review and detailed mapping of current service gaps will be undertaken in 2016. A summary gap analysis will be added to this chapter once the review and mapping is complete.

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- <sup>ii</sup> National Collaborating Centre for Mental Health. (2007). Dementia: The NICE-SCIE guideline on support people with dementia and their carers in health and social care. NICE CG 42. <http://www.nccmh.org.uk/downloads/Dementia%20full%20guideline%20Amended%20December%202012.pdf>
- <sup>iii</sup> Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., & Brayne, C. (2014). Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *The Lancet Neurology*, 13(8), 788-794. <http://www.thelancet.com/journals/laneur/article/PIIS1474-4422%2814%2970136-X/fulltext>
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- <sup>vi</sup> Greater London Authority. (2015) GLA 2014 Round SHLAA Capped Household Size Model Short Term Migration Scenario Population Projections. <http://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables>
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- <sup>viii</sup> Knapp, M. & Prince, M. (2007). Dementia UK: The full report. Alzheimer's Society. <http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2>
- <sup>ix</sup> Greater London Authority. (2015) GLA 2014 Round SHLAA Capped Household Size Model Short Term Migration Scenario Population Projections. <http://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables>
- <sup>x</sup> Moriarty, J., Sharif, N. & Robinson, J. (2011). Black and minority ethnic people with dementia and their access to support and services. Social Care Institute for Excellence. <http://www.scie.org.uk/publications/briefings/files/briefing35.pdf?res=true>
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- <sup>xiii</sup> Local data extracted from the GP register by CEG, Blizzard Institute, April 2014
- <sup>xiv</sup> Lang, I. A., Llewellyn, D. J., Langa, K. M., Wallace, R. B., Huppert, F. A., & Melzer, D. (2008). Neighborhood deprivation, individual socioeconomic status, and cognitive function in older people: analyses from the English Longitudinal Study of Ageing. *Journal of the American Geriatrics Society*, 56(2), 191-198. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2007.01557.x/abstract>
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- <sup>xvi</sup> Equality Act 2010. <http://www.legislation.gov.uk/ukpga/2010/15/contents>
- <sup>xvii</sup> NHS England. Primary Care Web Tool. Retrieved on 9<sup>th</sup> June 2015 from <https://www.primarycare.nhs.uk/>
- <sup>xviii</sup> Greater London Authority. (2015) GLA 2014 Round SHLAA Capped Household Size Model Short Term Migration Scenario Population Projections. <http://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables>

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<sup>xix</sup> Greater London Authority. (2015) GLA 2014 Round SHLAA Capped Household Size Model Short Term Migration Scenario Population Projections. <http://data.london.gov.uk/dataset/gla-population-projections-custom-age-table>