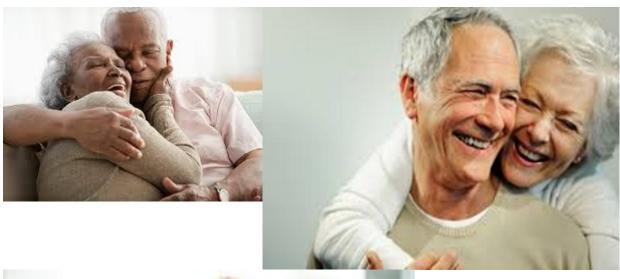
# **Dementia Health Needs Assessment 2015/16**





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### 1. Executive Summary

### Aims and objectives of the Needs Assessment:

- To provide an assessment of needs with regards to dementia in Merton and the extent of health inequalities or unmet needs
- To identify modifiable risk factors to dementia, and evidence-based public health interventions to reduce the burden of dementia
- To describe current health and social care provision and how this compares with best practice
- To identify gaps in service provision and make recommendations about how to address them particularly in relation to reducing health inequalities
- To consult with key stakeholders including carers to obtain a wide range of views on local needs
- To make recommendations for further action to improve care and outcomes for individuals with dementia and their carers.

### Methodology

The methodology used was based on the traditional model of epidemiological, corporate and comparative healthcare needs assessment developed by Stevens and Rafferty<sup>1</sup>. Multiple methods were used including analysing quantitative data, from various sources namely:

- Health and Social Care Information Centre(HSCIC)
- Projecting Older People Population Information (POPPI)
- Public Health Outcomes Framework (PHOF)
- Secondary Users Services (SUS)
- Projecting Adults Needs and Services Information System (PANSI)
- Demographic census data on the Merton population.

Qualitative data was collected through focus groups, and a Commissioner and Provider stakeholder engagement event held at the Dementia Hub including representatives from statutory and voluntary service sectors. A systematic literature review was carried out on the topic of best practice around dementia care and risk factors of dementia. This needs assessment incorporated demographic data on Merton, projected population changes in the next fifteen years, prevalence and incidence of dementia and other risk factors. A population health perspective was used to provide an evidence base for the setting of priorities regarding good quality comprehensive dementia care. The needs assessment also looked at the extent of health inequalities.

### Limitations

• Dementia Prevalence Calculator (DPC)<sup>2</sup> prevalence data does not give estimates of prevalence in different ethnic groups or early onset dementia therefore modelling was used to obtain indicative values for Merton.

<sup>&</sup>lt;sup>1</sup> Stevens A. Rafferty J. Health Care Needs Assessment: The Epidemiologically Based Needs Assessment Reviews, Vol. 1. Oxford: Radcliffe Medical Press

- Only three of the 39 participants in the focus groups with carers of people with dementia and people with dementia were of Black, Asian and Minority Ethnic (BAME) background therefore the BAME voice was captured to a limited degree.
- There was limited data on hospital admissions for people with a primary or secondary diagnosis of dementia as the reason for admission is often not coded as dementia but the presenting symptoms of the patient for example urinary tract infection.

### **HIGHLIGHTS**

- 1. There is a forecast of growth in demand for all dementia care for people with dementia and their carers.
  - The number of people (aged 65 and over) predicted to have dementia is forecast to grow by 51% from (1782) in 2015 to (2683) in 2030<sup>3</sup>
  - The numbers seen by the Community Mental Health Team (CMHT) for dementia ranged from 228 in (2011/12) to 325 in (2014/15)<sup>4</sup> and the number of patients seen by the CMHT over four years shows an upward trajectory showing a constant increase in demand on the service.
- 2. Carers of people with dementia in Merton play a pivotal role in dementia care and need to be supported with advice and empowered to enable them to fulfil this role without detriment to their own quality of life.
  - The Dementia Prevalence Calculator (DPC)<sup>5</sup> estimates that 1590 (83%) of people with dementia live in the community and 336 (17%) live in residential/nursing care. Due to the large proportion of people in the community, unpaid/informal carers play a substantial role in caring for people with dementia.
  - During focus groups, carers expressed a desire for better out of hour crisis support and respite care.
- 3. The cohort of people with Early onset Dementia in Merton is small however, their needs are complex.
  - The indicative number of people with early onset dementia in Merton in 2015 is 46 people. As a proportion of all cases of dementia in Merton in 2015, early onset dementia represents 2.38%.
  - There will be an estimated 28.2% growth (from 46-59 cases) in the total number of cases of early onset dementia in the next fifteen years (2015-2030)<sup>6</sup>.
  - As the number of people is small, it may be better to work on a sector level with other South West London boroughs to develop a pathway or service for this cohort as this would give the economies of scale necessary to develop a service of good quality.
- 4. Considerable progress has been made in increasing diagnosis rates<sup>7</sup> but there is still variation between GP Practices and between localities within Merton in diagnosis rates.
  - According to the DPC and Merton Clinical Commissioning Group (MCCG), the Merton diagnosis rate is 72% as at March 2015 meaning that 28% of people with

<sup>&</sup>lt;sup>2</sup> The Dementia Prevalence Calculator enables health and care communities to gain a better understanding of their local estimated prevalence of dementia in the community, and among people living in local care homes

<sup>&</sup>lt;sup>3</sup> Projecting Older People Population Information (POPPI)

<sup>&</sup>lt;sup>4</sup> Source: South West London and St George's Mental Health NHS Trust

<sup>&</sup>lt;sup>5</sup> Source: South West London and St George's Mental Health NHS Trust

<sup>&</sup>lt;sup>6</sup> PANSI Projecting Adults Needs and Services Information System

<sup>&</sup>lt;sup>7</sup> **Diagnosis rates** are calculated as the number of people with a dementia diagnosis (QOF dementia register) compared to the number of people estimated to have dementia in the population (the ANDP% from the DPC)

- dementia remain undetected or without a formal diagnosis; this is known as the dementia gap<sup>8</sup>
- There is marked variation between GP Practices and Localities within in dementia diagnosis rates and this is suggestive of health inequalities in relation to dementias diagnosis, this is an area for further investigation locally
- The average diagnosis rate in East Merton is 57%, in Raynes Park is 78% and in West Merton the average is 68%.

#### **Dementia Risk Factors**

#### Modifiable

The key modifiable risk factors to dementia are:

- Vascular disease
- Obesity and Diabetes
- Depression
- Smoking
- Excessive alcohol consumption
- Physical inactivity<sup>9</sup>
- Cognitive inactivity or lower educational attainment and;
- Other risk factors i.e. sleep quality

#### Non-Modifiable

The key non-modifiable risk factors for dementia include age, having learning disabilities, genotype/genetics and brain damage and head injury

### **Dementia Best Practice**

There is a plethora of best practice guidelines and policy documents that outline good quality services and principles of good dementia care. The guidance documents have been summarised in relation to the following primary themes for simplicity:

- Prevention
- Health and Social Care Deliver and Commissioning
- Identification, Assessment and Diagnosis
- Early Intervention and Treatments
- Living Well with Dementia, Supporting Carers and Dementia Friendly Communities
- Good Dementia Care in Hospital and Liaison Psychiatry
- · Reablement and Dementia
- End of Life Care (EoLC)
- People with Learning Disabilities who develop Dementia

<sup>&</sup>lt;sup>8</sup> **The 'Dementia Gap'** is the percentage of patients on the practice list with dementia who are undiagnosed. This is calculated by subtracting the QOF dementia register from the ANDPR number, and expressing that figure as a percentage of the ANDPR. It is possible to have a negative dementia gap if the practice has more patients on the dementia register than would be expected from the ANDPR. The maximum Dementia Gap is 100%.

<sup>&</sup>lt;sup>9</sup> Barnes DE, Yaffe K. <u>The projected effect of risk factor reduction on Alzheimer's disease prevalence</u>. The Lancet Neurology, Early Online Publication, July 19 2011

### **DEMENTIA BEST PRACTICE PRINCIPLES**

#### 1. Prevention

The biggest message in prevention of dementia is **what is good for your heart is good for your head.** The six pillars of Alzheimer's prevention<sup>10</sup> are regular exercise, healthy diet, mental stimulation, quality sleep, stress management and an active social life. The best practice principle for dementia prevention is strengthening each of the six pillars in daily life, this in turn contributes to a healthier brain

### 2. Health and Social Care Deliver and Commissioning

 An integrated/ whole-systems approach to commissioning should be adopted meaning; developing integrated health and social care plans where possible as well as involving the public, people with dementia, their carers and families when commissioning services<sup>11, 12</sup>.

### 3. Identification, Assessment And Diagnosis

- Good-quality early diagnosis and intervention for all; if dementia is diagnosed early, more can be done to delay progression of the disease.

### 4. Early intervention and treatments

- Commissioners should plan to increase access to behaviour and social interventions for people with dementia, which can reduce inappropriate use of antipsychotic drugs<sup>13</sup>.
- Ensuring equitable access and no discrimination
- Ensuring that people with dementia are fully involved in making important decisions and providing valid consent in all aspects of their investigation, diagnosis and treatment.

# 5. Living Well with Dementia, Supporting Carers and Dementia Friendly Communities

- A dementia friendly community as one "in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them"<sup>14</sup>.
- The implications of **The Care Act 2014**<sup>15</sup> are that commissioners and providers will have to be cognisant of new safeguarding duties, a duty to integrate, cooperate and work in partnership between partners and Local authorities. As of April 2015 there will be new rights for carers, more people with dementia should have access to an independent advocate to help navigate decisions about their care.

<sup>&</sup>lt;sup>10</sup> Alzheimer's: Six pillars of prevention <a href="http://www.cognitivehealthjh.org/perch/resources/pillars-of-brain-health.pdf">http://www.cognitivehealthjh.org/perch/resources/pillars-of-brain-health.pdf</a>

NICE commissioning guidance (CMG48) Support for Commissioning Dementia Published April 2013 https://www.nice.org.uk/guidance/cmg48

<sup>&</sup>lt;sup>12</sup> NICE and Social Care Institute for Excellence (SCIE) commissioning guides [CMG48] Published date: April 2013 https://www.nice.org.uk/guidance/cmg48/

<sup>&</sup>lt;sup>13</sup>Support for commissioning dementia care NICE and Social Care Institute for Excellence (SCIE) commissioning guides [CMG48] Published date: April 2013 <a href="https://www.nice.org.uk/guidance/cmg48/">https://www.nice.org.uk/guidance/cmg48/</a>
<sup>14</sup> Building dementia-friendly communities: A priority for everyone, The Alzheimer's society, August 2013

Building dementia-friendly communities: A priority for everyone, The Alzheimer's society, August 2013 <a href="http://www.alzheimers.org.uk/site/scripts/download\_info.php?fileID=1916">http://www.alzheimers.org.uk/site/scripts/download\_info.php?fileID=1916</a>

<sup>&</sup>lt;sup>15</sup> The Care Act 2014 is a significant piece of legislation in the social care sector and replaces numerous laws providing a coherent approach to adult social care in England <a href="http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted">http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted</a>

### 6. Good dementia care in Hospital (and Liaison Psychiatry)

- Hospitals have an important role to play in helping to identify patients with dementia, ensuring they are treated with compassion and discharged to an appropriate care setting
- People with suspected or known dementia using inpatient services should be assessed by a liaison service that specialises in the treatment of dementia and older people's mental health<sup>16</sup>.
- National Institute of Clinical Excellence (NICE) also states that care should be planned jointly by the trust's hospital staff, liaison teams, relevant social care staff, the person with suspected or known dementia and carers.

### 7. Reablement and Dementia

People should not be excluded from reablement based on a dementia diagnosis but should be assessed based on their needs and strengths without prejudice about their potential to be 'reabled'17.

### **End of Life Care (EoLC)**

- A key commissioning priority should be supporting primary care to identify people with dementia and add them to palliative care registers when they approach the end of their life<sup>18</sup>.
- EoLC should be a key part of the dementia care plan<sup>19.</sup> However, this is a topic that needs to be broached sensitively to people with dementia and their carers and gradually after an individual has had an opportunity to come to terms with their diagnosis.

### Best practice for people with learning disabilities who develop dementia

The overarching principle of best practice for people with learning disabilities it the principal of "reasonable adjustments". These adjustments entail training staff about what people with learning disabilities are likely to need. This is in line with the disability Discrimination Act (DDA).

http://www.alzheimers.org.uk/site/scripts/documents info.php?documentID=428 Accessed 15 April 2015

<sup>&</sup>lt;sup>16</sup> NICE

<sup>&</sup>lt;sup>17</sup> Maximising the potential for dementia reablement

http://www.scie.org.uk/publications/guides/guide49/dementia.aspSocial

<sup>&</sup>lt;sup>19</sup> End of Life Care. The Alzheimer's society

#### The Merton Dementia service user and stakeholder voice

### KEY THEMES FROM STAKEHOLDER ENGAGEMENT

1. The overarching themes from the Commissioners and Provider stakeholder engagement event held on the 12<sup>th</sup> of March 2015 at the Dementia Hub were:

### Theme 1: The need for a change in strategic focus

Significant progress had been made particularly around increasing diagnosis rates, closing the diagnosis gap and coping with the increase in service demand however, there is now a need to change the strategic focus to ensuring that the post –diagnostic support was of good quality. Areas for improvement given this proposed new direction of strategic focus are:

- Ensuring sufficient capacity of the Community Mental Health Team (CMHT)
- Increasing capacity in Improving Access to Psychological Therapies (IAPT)
- Increasing capacity in Occupational Therapy
- Developing stronger links between services

### Theme 2: Service gaps in Merton

### Dementia CQUIN<sup>20</sup>

Acute Trusts had the option of discontinuing the Dementia CQUIN

### Older person's psychiatric liaison resource in hospital

There is no older person's psychiatric liaison resource at both St. Georges and at Epsom and St Helier for Merton residents. There is a Psychiatric liaison service that covers all age groups and the resource dedicated to older people at St Georges hospital is only for Wandsworth residents, the resource for older people at Epsom and St Helier is only for Sutton residents leaving a clear gap for Merton older residents

### "Culturally appropriate" community activities for BAME

There are limited "culturally appropriate" community activities for BAME groups this was an expressed need by both commissioners and providers.

### Theme 3: Considerations for the future Dementia Strategy 2015-2020

#### The Care Act 2014

A key future consideration is the Care Act 2014, which places a series of new duties and responsibilities on local authorities about care and support for adults. The personalisation agenda, which entails enabling individuals to have complete choice and control through receiving their own budget and deciding how they wish to spend it will have an impact on existing activities for people with dementia. Post-diagnostic supports needs to remain intact in light of influences from the personalisation agenda.

### Building and developing effective links with new service developments

Ensuring effective links with new service developments such as the Community Dementia Nurse Specialists (DNSs), Better Care Fund (BCF), Holistic Assessment and

<sup>&</sup>lt;sup>20</sup> The dementia CQUIN aims to help identify patients with dementia and other causes of cognitive impairment, alongside their other medical conditions and to prompt appropriate referral and follow up after they leave hospital. Commissioning for Quality and Innovation (CQUINs) payments framework encourages care providers to share and continually improve how care is delivered and to achieve transparency and overall improvement in healthcare.

### Rapid Intervention(HARI).

- 2. The overarching themes from engagement with the carers of people with dementia and people with dementia were:
  - i. A need for more respite care and crisis response options
  - ii. Misinformation on options for those who are self-funding
  - iii. A perception of limited availability of General Practitioners
  - iv. Carer Privacy
  - v. Improved post diagnostic support, sources, and methods of communication
  - vi. The difficulty of conversations about End of Life Care (EoLC)
- 3. The overarching themes from engagement with People with dementia were :
  - i. Stigma around Dementia is still a real concern
  - ii. EoLC remains a sensitive, contentions and challenging area
  - iii. Improved shared care monitoring arrangements with Primary Care
  - iv. Having no single individual to ring with concerns of dementia

### **Gaps and Recommendations**

**TABLE 1: GAPS AND RECOMMENDATIONS** 

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
PREVENTION	<ul> <li>The biggest cohort is those with Alzheimer's disease (62%) then vascular dementia (17%), which is modifiable by improving vascular health</li> <li>The prevalence of dementia in BAME people aged 65 and over is 5.5%. This is a higher prevalence to the dementia (all ages, all ethnicities) in Merton of 0.9%.</li> <li>Targeted interventions towards BAME groups was a gap identified in the baseline review of the 2010 Local Dementia Strategy but little progress has been reported in this area</li> </ul>	1. Consider implementing prevention of vascular risk factors with a focus on atrial fibrillation  a. Consider targeted interventions at the BAME population as they have a higher prevalence of vascular disease and are more at risk of vascular risk factors  b. Interventions could align with physical health services such as diet and nutritional advice and consider joint working practices between stroke services and dementia services
- More people are being identified in primary care, the diagnosis rate is was 72% as at March 2015 and exceeded the national target of 67%  - From 2011-2015 there has been a 49.3% growth in the number of referrals for dementia to the CMHT and a 42.5% growth in number of patients seen by the CMHT  - People with Dementia and carers are not always aware of the different services and sources of information in Merton - The proportion of referral from GPs and Social Workers to the Dementia Adviser and Dementia Support Worker at the Dementia Hub is smaller than 4% in both services The provider landscape is changing due to the Better Care Fund (BCF), new MDT Locality teams, the Holistic Assessment Rapid Investigation (HARI) service, the Adult Social Care (ASC) Redesign and the		<ol> <li>Consider ensuring that there is sufficient capacity to meet with the increase in demand particularly in the Memory Assessment re-design that is underway in Merton, and all post-diagnostic support services. Also ensure that any service developments (in the Memory clinics) are in line with Memory Services National Accreditation Programme (MSNAP)<sup>21</sup> recommendations</li> <li>Consider effectively promoting the services at the Dementia Hub, raising the profile and developing strong links between existing services i.e.         <ol> <li>The Dementia Hub and GPs and the Hub and social workers</li> <li>The Dementia Hub and other Voluntary Sector organisations in Merton</li> <li>The Holistic Assessment Rapid Investigation (HARI) service and the New Community Dementia Nurses</li> </ol> </li> </ol>
HEALTH AND SO	<ul> <li>Sufficient data capture on size and caseload in relation to dementia While ASCOF has a placeholder for the dementia indicator, local solutions will be required to ensure efficient data collection</li> <li>The data on dementia admissions with a primary or secondary admission of dementia was insufficient to compare the average length of stay (ALOS) between those with dementia and those without</li> </ul>	4. Consider improving information sharing across organisational boundaries and improving data collection on the size, protected characteristics <sup>22</sup> , caseload and the costs in relation to people with dementia and their carers to inform planning and enable the assessment of equitable access. The specific areas in Merton include:  a. Acute care data on people with a primary or a secondary diagnosis of dementia and ensuring that people discharged from

<sup>&</sup>lt;sup>21</sup> Memory Services National Accreditation Programme (MSNAP), Standards for Memory Services <a href="http://www.rcpsych.ac.uk/quality/quality/andaccreditation/memoryservices/memoryservicesaccreditation/msnapstandard">http://www.rcpsych.ac.uk/quality/quality/andaccreditation/memoryservices/memoryservicesaccreditation/msnapstandard</a>

S.aspx

22
The protected characteristics in the Equality Act 2010 are Age, Gender/sex, Gender Reassignment, Disability, Marriage

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
	- A key theme from the Commissioner and	hospital have their dementia diagnosis in
	Provider stakeholder engagement event was the need for improved information sharing across organisational boundaries	the discharge summary b. Dementia Hub data capture on service user ethnicity in both the Dementia Advisor (DAS) and Dementia Support Worker (DSW) and age of carers who use the DSW service. c. Adult Social Care service user data in the absence of ASCOF indicators d. Regarding information sharing consider developing systems locally for sharing information across different information capture systems particularly considering those who do not have access to RIO 23
ASSESSMENT AND DIAGNOSIS, EARLY INTERVENTION AND TREATMENTS	<ul> <li>There is variation in relation to dementia diagnosis. The average diagnosis rate in East Merton is 57%, in Raynes Park is 78% and in West Merton the average is 68%.</li> <li>The proportion of people with dementia (of all age groups) whose care plan has been reviewed in a face-to-face review with their GP in Merton is 83.6%<sup>24</sup></li> <li>There is a perceived limited availability of GPs as sources of information expressed through the qualitative research by both carers and people with dementia</li> <li>According to analysis of Primary Care data on indicators relating to dementia and key dementia risk factors there are some Merton GP practices with relatively<sup>25</sup> <ul> <li>Lower diagnosis rates</li> <li>Lower Face- to-face reviews of dementia patients</li> <li>Higher proportions of GP registered older people (people aged 65 and over)</li> <li>Higher hypertension and smoking prevalence (QOF)</li> <li>In addition, higher levels of deprivation. (See Table 7)</li> </ul> </li> <li>These practices have been deemed to be requiring more targeted support with improving dementia care and prevention and they are located in Cricket Green, Lavender Fields, Wimbledon Village and Ravensbury.</li> </ul>	<ul> <li>a. Reducing variation in dementia diagnosis rates between GP practices and localities as this could lead to health inequalities</li> <li>b. Improving the face-to-face reviews of people with dementia carried out in Primary care.</li> <li>c. Strengthening the role of primary care to ensure robust shared care monitoring arrangements for people with dementia and tackling the perceived limited availability of GPs</li> <li>d. Consider a plan of action for more targeted support to the areas identified through the Primary Care mapping, these are located in Cricket Green, Lavender Fields, Wimbledon Village and Ravensbury.</li> </ul>

<sup>&</sup>lt;sup>23</sup> An electronic service user Record system <sup>24</sup> (QOF ID: DEM002) 2013/14 <sup>25</sup> In relation to other Merton GP Practices

	THE DISTURE IN MEDICAL COADS	DECOMMATNID ATIONS
	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
EARLY INTERVENTION AND TREATMENTS	<ul> <li>The indicative number of people with early onset dementia in Merton in 2015 is 46 people<sup>26</sup>. While the cohort is small their needs are complex</li> <li>There are more men than women with early onset dementia in Merton (i.e. people aged 30-64). In the younger age bands i.e. people aged 65 to 74, the dementia prevalence is higher in men than women</li> </ul>	6. Consider developing a programme for the identification and early intervention of dementia in people of working age.  a. To achieve economies of scale, consider developing pathways at a South West London sector level  b. Bearing in mind that in early onset dementia the rate is higher in men, consider developing programmes around encouraging men to come forward with their symptoms and not attributing them to stress. The programme could incorporate help to sustain employment and be linked with NHS Health Checks <sup>27</sup>
DEMENTIA FRIENDLY COMMUNITIES	<ul> <li>The dementia prevalence is higher in BAME populations in Merton. It is estimated that 332 people (aged 65 and over) from BAME groups have dementia in Merton in 2015</li> <li>There is substantial anticipated growth of 56% in people aged 65 and over from BAME groups from 2015-2025</li> <li>There are limited "culturally appropriate" community activities for BAME groups</li> </ul>	7. Consider sharing learning and good practice around dementia care for BAME populations. Also consider:  a. Develop "culturally appropriate" community activities for BAME groups b. Consider developing South West London Partnerships for BAME service developments
, AND	- There was an expressed need for out of hours crisis support (particularly around challenging behaviour).	8. Consider improving the availability, flexibility and responsiveness of respite care for carers of people with dementia to enable people to stay in the community longer. As residential care represents the largest segment of the dementia care budget, better provision of community support both for people with dementia and carers is a cost-effective way to enable people to live at home for longer, thus reducing the significant costs of residential care
LIVING WELL WITH DEMENTIA	- Stigma remains an issue for people with dementia as expressed in the focus group	9. Consider tackling dementia stigma through increased education to all stakeholders (i.e. Health and Social Care, Commissioners and Providers and the Voluntary Sector). Also consider developing a joint work force development and training strategy
LIVING W	- An overarching theme in the Dementia Commissioner and Provider Stakeholder engagement event was the need for a strategic shift from identification and diagnosis to ensuring good quality post- diagnostic support	10. Developing a strategic shift from the emphasis of increasing identification and diagnosis rates to improving post-diagnostic support and enabling people to live well with dementia

<sup>&</sup>lt;sup>26</sup> POPPI <sup>27</sup> The NHS Health Checks programme is for adults in England aged 40-74 and checks circulatory and vascular health as well as assesses the risk of getting a disabling vascular disease.

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
	Adult Social Care users with Dementia	11. Consider:
LIVING WELL WITH DEMENTIA, SUPPORTING CARERS AND DEMENTIA FRIENDLY COMMUNITIES	- A crude direct comparison of the ethnic distribution of Merton borough in 2014 the ethnic distribution of all ASC service users with dementia in 2013/14 resident in Merton suggests that the Black and Asian ethnic groups with dementia are under represented in terms of ASC service access. In specific services:  In Nursing Care- the data is suggestive that the white ethnic group is considerably over represented, the black ethnic group is marginally under represented and the Asian ethnic group is considerably under represented In Direct Payments- the data is suggestive that the white ethnic group is markedly underrepresented, and Black and Asian people are marginally overrepresented In Residential Care and Home Care the data is suggestive that the white ethnic group is markedly over represented the black ethnic group is marginally under represented and the Asian ethnic group is markedly under represented. The data is suggests that there may be an issue regarding equitable access to ASC services for people with Dementia.  The Dementia Hub DAS and DSW users The Dementia Advisor Service (DAS) user data is suggestive that the 85 and over age group is under-represented and males aged between 65-74 are under-represented	a. Investigating further if there are access issues to Adult Social Care Services for the under-represented ethnic groups. b. Regarding the Dementia Hub consider increasing the reach on the Dementia Advisor Service (DAS) to people aged 85 and over and males aged between 65-74 and improving data capture on protected characteristics particularly ethnicity.
GOOD DEMENTIA CARE IN HOSPITAL AND LIAISON PSYCHIATRY	<ul> <li>There is no dedicated psychiatric liaison resource for older residents of Merton</li> <li>There is a Psychiatric Liaison Service that covers all age groups but the resource dedicated to older people at St Georges Hospital is only for Wandsworth residents; the resource for older people at Epsom and St Helier Hospital is only for Sutton residents leaving a gap of an older person's resource for Merton residents</li> </ul>	12. Consider a service development of a dedicated psychiatric liaison resource for older residents of Merton in the main acute trusts for Merton residents
GOOD DEN AND	<ul> <li>Acute Trusts had the option of discontinuing the Dementia CQUIN and St.</li> <li>Georges reported that it would be discontinuing the Dementia CQUIN. It is however redesigning older people's</li> </ul>	13. Consider ensuring the momentum in the main acute trusts for Merton residents in identifying assessing and referring people with dementia in light of changes to the CQUIN scheme

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
	services and incorporating a Frailty Model and Acute Senior User's Unit (ASHU)	
There is a need to further investigate discharge processes for those with Dementia admitted into hospital to ensure seamless care i.e. ensuring discharge letters include the dementia diagnosis and social service re-set up after brief hospitalisation (less than 72hours) to ensure this is in line with best practice (at the time of the research the latter point was raised as a theme)		14. Consider investigating further the discharge processes for those admitted into hospital with dementia. In order to ensure that they are in line with best practice and that people with dementia receive seamless care.
END OF LIFE CARE (EOLC)	<ul> <li>None of the participants (n=39) in the focus groups reported having had a conversation with health and social care professional on the subject of their preferred place of care at the end of their life</li> <li>There are misconceptions on how much advance care planning in End of Life Care (EoLC) a person with dementia can do particularly if they are self-funding</li> </ul>	15. Consider improving advanced care planning, conversations around preferred place of care and End of Life Care (EoLC) discussions between clinicians (Particularly in Primary Care) and dementia patients and their carers

### 2. Introduction to Dementia

#### **About Dementia**

Dementia is a progressive syndrome that is characterised by widespread impairment of mental function. Dementia is associated with complex needs particularly in the later stages where the person with dementia has higher levels of dependency and morbidity. People with dementia can present carers and social care staff with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions, hallucinations, and mobility difficulties that can lead to falls and fractures.

Dementia is not a specific disease. Instead, it is a general term that describes a group of symptoms such as loss of memory, judgment, language, complex motor skills, and other intellectual function caused by the permanent damage or death of the brain's nerve cells, or neurons. The clinical symptoms and the progression of dementia vary, depending on the type of disease causing it, and the location and number of damaged brain cells. Some types progress slowly over years, while others may result in sudden loss of intellectual function. Dementia is an important condition because it is common, complex and challenging to manage.

Dementia is one of the major causes of disability and dependency among older people. It can be overwhelming not only for the people who have it, but also for their caregivers and families. Dementia is an 'organic' disorder, meaning there is an associated physical deterioration of the brain tissue, which can be seen on a brain scan or, after death, at autopsy. Dementia is not a normal result of aging, but rather is the result of a disease<sup>28</sup>. Both prevalence (existing cases) and incidence (new cases) of dementia rise exponentially with advancing age; however, it is possible to have dementia when you are younger. Dementia diagnosed in younger people (those aged 65 and below) can be referred to as 'early onset dementia' (EOD), 'young-onset dementia', and 'working age dementia<sup>129</sup>. According to the Alzheimer's Society, about one person in every one thousand under the age of 65 develops dementia<sup>30</sup>. EOD as opposed to the prevalence of late onset dementia is relatively rare with a national prevalence of 2.2% but the prevalence among people with a learning disability is higher. It has been established that this form of the disease is inherited in approximately 80 per cent of cases<sup>31</sup>.

#### Causes and types of Dementia

Cerebral Vascular Disease (CVD) including strokes, Frontotemporal dementia (degeneration of the frontal lobe of the brain), Parkinson's disease, Huntington's disease, Creutzfeldt Jacob disease, can cause dementia and there is HIV/AIDS related dementia. Alzheimer's disease is the most common form of dementia and may make up 60–70% of cases<sup>32</sup>. Vascular dementia is the next most common. Lewy Body Dementia (abnormal aggregates of protein

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<sup>&</sup>lt;sup>28</sup>SCIE. Dementia Gateway, http://www.scie.org.uk/publications/dementia/index.asp

<sup>&</sup>lt;sup>29</sup> The Alzheimer's society Younger People with dementia Factsheet <a href="http://www.alzheimers.org.uk/site/scripts/documents">http://www.alzheimers.org.uk/site/scripts/documents</a> info.php?documentID=164

<sup>&</sup>lt;sup>30</sup> Alzheimer's Research UK, <a href="http://www.alzheimersresearchuk.org/dementia-types/10000/alzheimersdisease/">http://www.alzheimersresearchuk.org/dementia-types/10000/alzheimersdisease/</a>

<sup>&</sup>lt;sup>31</sup>Kandel, E R, Schwartz, J H, Jessell, T M, Principles of Neural Science 5 the Edition, New York: McGraw Hill Medical, 2013

<sup>&</sup>lt;sup>32</sup> World Health organisation Dementia Factsheet http://www.who.int/mediacentre/factsheets/fs362/en/

that develop inside nerve cells), can account for 10 % of all cases<sup>33</sup>. Mixed pathologies are more common than any 'pure' form of the disease, particularly, Alzheimer with vascular dementia, and Alzheimer's with Lewy Body dementia. The boundaries between different forms of dementia are indistinct and mixed forms often co-exist. The figure below shows the common causes of early onset dementia.

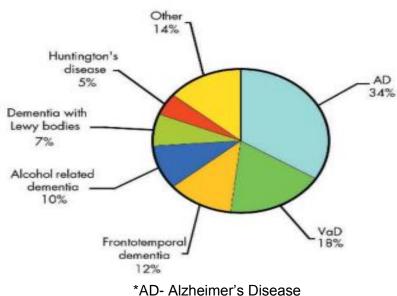


FIGURE 1: CAUSES OF EARLY ONSET DEMENTIA

\*VaD- Vascular Dementia Source: Harvey at al<sup>34</sup>

<sup>33</sup> http://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=113

<sup>&</sup>lt;sup>34</sup> Harvey RJ, Skelton-Robinson M, Rossmoor MN. The prevalence and causes of dementia in people under the age of 65 years. J Neurol Neurosurgery Psychiatry2003; 74:1206-9.

### 3. The Picture of Dementia in Merton

The table below shows the sources of the epidemiological data and a brief description of the source.

#### **Table 2: DATA SOURCES AND DESCRIPTION**

**(ANDPR)** Adjusted National Dementia Prevalence Rate— This estimate is a refinement of the National Dementia Prevalence (NDPR), recognising that patients in a Nursing or Care home are more likely to have dementia than those in the community. By using the Nursing Home Data, or figures provided by GPs, the NDPR is refined to give a more accurate estimate of the expected rate of dementia.

#### DPC

The National Dementia Prevalence Calculator (DPC)<sup>35</sup> enables health and care communities to gain a better understanding of their local estimated prevalence of dementia in the community, and among people living in local care homes. The DPC is elaborated on in Appendix G.

#### **EPACT.net**

Is an application that allows authorised users at Primary Care Organisations (PCOs) / Area Teams / Trusts and National users to electronically access prescription data.

#### **GLA SHLAA**

Greater London Authority (GLA) Strategic Housing Land Availability Assessment (SHLAA) provides population projections.

#### **HSCIC**

Health and Social Care Information Centre is the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care.

#### **PANSI**

**Projecting Adults Needs and Services Information** 

#### OOF

Quality and Outcomes Framework improves the quality of care patients are given by GPs by rewarding practices for the quality of care they provide to their patients.

#### ONS

The Department for Communities & Local Government and Office for National Statistics provide population projections from the household projections model using sub-national population figures from the Office for National Statistics (ONS)

#### CareFirst

Carefirst is Merton's Adult Social Care electronic customer database and holds the current and historic customer/carer record from initial referral, to allocation, assessment/review etc., and details any provision and cost of services provided including the details of the resources used.

<sup>&</sup>lt;sup>35</sup> National Dementia Prevalence Calculator <a href="https://www.primarycare.nhs.uk/">https://www.primarycare.nhs.uk/</a>

### 3.1. Key characteristics of the population of interest

The population of interest is people aged 30-64 in relation to Early onset Dementia, and people aged 65 and over in relation to later onset dementia. The characteristics considered relevant to dementia services planning are:

- Population growth
- Distribution of deprivation
- · Ethnic Composition
- Where older people in Merton are concentrated

### **Population Growth**

The figure below shows the projected percentage increase in Merton population in the next ten years (2015-2025) in those:

- Aged 30 to 65<sup>36</sup>
- · Aged 65 and over
- Aged 65 and over from BAME groups and;
- Population growth in all people of all ages

The diagram shows that there is substantially more growth in people aged 65 and over as well people aged 65 from BAME groups. As age is a significant risk factor to dementia and prevalence doubles every five years after the age of 65<sup>37</sup> this would suggest that as the older population grows so will the conditions that come with increasing age. There will also be an increase in older people from BAME groups in Merton and inevitably an increase in dementia prevalence in this population group.

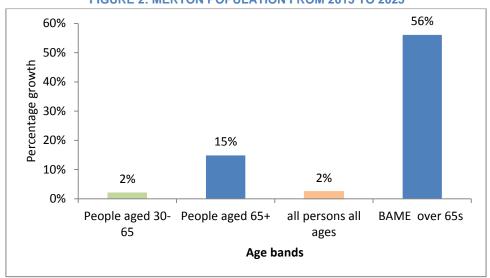


FIGURE 2: MERTON POPULATION FROM 2015 TO 2025

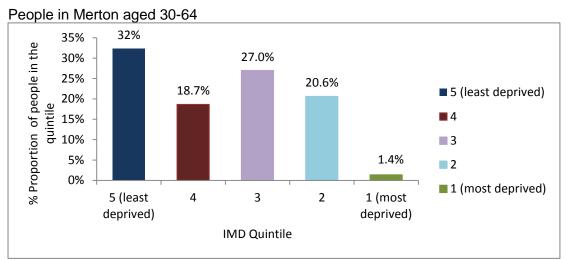
Source: GLA SHLAA

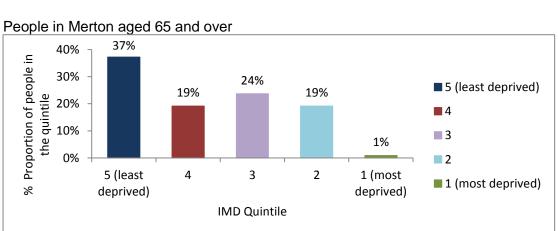
<sup>&</sup>lt;sup>37</sup> (Harvey et al) Harvey RJ, Skelton-Robinson M, Rossor MN. The prevalence and causes of dementia in people under the age of 65 years. Journal of Neurology, Neurosurgery and Psychiatry2003;74:1206–9

### **Distribution of deprivation in Merton**

When looking at the 30-64 age group and the cohort of people aged 65 and above we see a similar pattern of distribution of deprivation between these two groups. 22% of the population aged 30-64 are in the most deprived quintiles <sup>38</sup> (1 and 2) and in the population aged 65 and over 20% are in the most deprived quintiles (1 and 2). As deprivation is inextricably linked with poorer health outcomes deprivation is one of the characteristics considered later in terms of equitable access to services.

FIGURE 3: DEPRIVATION (IMD 2010) BY AGE GROUPS





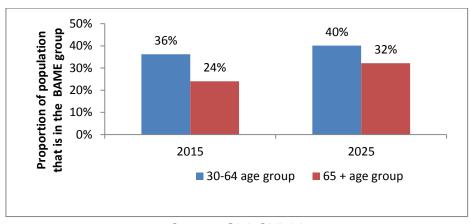
Source: Department for Communities & Local Government and Office for National Statistics (Mid-year estimates 2012)

<sup>&</sup>lt;sup>38</sup> The Indices of Multiple Deprivation (IMD) 2010, part of the English Indices of Deprivation is a model of measuring deprivation in an area. It is underpinned by separate dimensions of deprivation; these dimensions are weighted and an overall deprivation score is given. Office of National Statistics (ONS) Population – Lower Super Output Area level Mid-Year Population Estimate 2012 <a href="http://www.ons.gov.uk/ons/rel/sape/soa-mid-year-pop-est-engl-wales-exp/mid-2012/stb---super-output-area---mid-2012.html">http://www.ons.gov.uk/ons/rel/sape/soa-mid-year-pop-est-engl-wales-exp/mid-2012/stb---super-output-area---mid-2012.html</a>

### Population composition by ethnicity

Black, Asian and Minority Ethnic (BAME) populations make up 36%<sup>39</sup> of the people aged between 30 to 64 and 24% of the cohort of people aged 65 and over in 2015. The proportion of the population from a BAME background is estimated to grow in the next ten years. The figure below shows the proportion of the population in the 30-64 age group and the 65 and above age group in Merton in 2015 and in 2025.

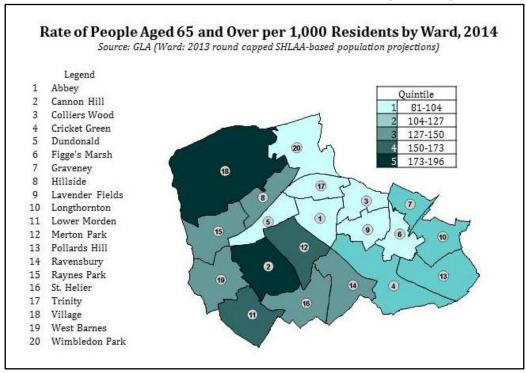
FIGURE 4: BAME IN 30-64 AND 65+ AGE GROUP IN 2015 AND PROJECTED IN 2025



Source: GLA SHLAA

### Where are older people concentrated?

FIGURE 5: MERTON WARD RATE OF OLDER PEOPLE (PER 1,000)



<sup>&</sup>lt;sup>39</sup> Source: 2013 GLA SHLAA Round Ethnicity <a href="http://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables">http://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables</a>

Using the rate of people aged 65 and over (per 1,000 residents by ward), the four wards with the highest concentration of older people are Wimbledon Village and Cannon Hill, Merton Park and Lower Morden all of which are in the West of Merton. Older people (i.e. those aged 65 and over) are also generally more concentrated in the west of Merton than the east. The figure above is a heat map showing how the different wards in Merton vary in terms of the distribution of older people.

### 3.2. Merton Expected Dementia Prevalence

The figure below shows Merton dementia prevalence and comparators. As at February 2015, there are 1926 people in Merton with dementia according to the DPC out of a total registered population of 217,858. This gives a prevalence of 0.9% for Merton CCG, which is higher than the national prevalence (England 0.7%), and London (0.7%). The figure shows the prevalence of dementia in Merton and comparators with 95% Confidence Intervals. Merton dementia prevalence is statistically significantly lower than three of the south West London comparators (Sutton, Richmond and Croydon) and statistically significantly higher than Wandsworth. Of the ONS comparators, Merton is statistically significantly lower than Barnet and Harrow, similar to Redbridge and statistically significantly higher than Hounslow. This shows that dementia prevalence varies substantially across boroughs.

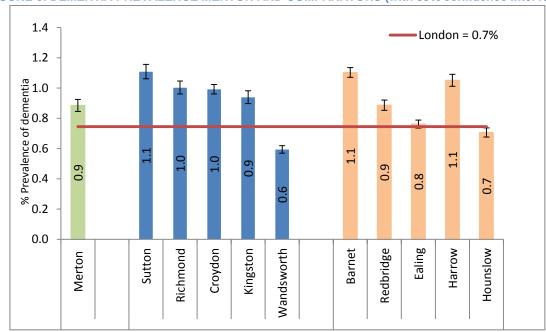


FIGURE 6: DEMENTIA PREVALENCE MERTON AND COMPARATORS (with 95% confidence intervals\*)

England = (0.7%)

Source: Dementia Prevalence Calculator (DPC) as at March 2015

<sup>\* 95%</sup> Confidence Intervals (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC <a href="https://indicators.ic.nhs.uk/webview/">https://indicators.ic.nhs.uk/webview/</a>

### What is the indicative prevalence of Early Onset Dementia?

The indicative number of people with early onset dementia in Merton in 2015 is 46 people<sup>40</sup>. As a proportion of all cases of dementia in Merton in 2015, early onset dementia represents 2.4%. As a proportion of all Merton registered patients, the prevalence of early onset dementia in Merton in 0.02%. Appendix I shows the indicative number of cases by sex and shows that there are more men than women with Early Onset Dementia.

### What is dementia prevalence in BAME populations of Merton?

Estimates of BAME prevalence in older people (people aged 65 and above) published in 2013<sup>41</sup> were used to model the prevalence of dementia in BAME older people in Merton. This is shown in the table below.

TABLE 3: ESTIMATED PREVALENCE OF LATE ONSET DEMENTIA IN THE MERTON BAME POPULATION IN 2015

Age	%Prevalence of all dementias in BAME communities <sup>42</sup>	Merton BAME Population within that age band (GLA projections 2015)	Indicative number of people from BAME communities in Merton with dementia in each age band
65-69	1%	2007	20
70-79	4%	2865	115
80+	17%	1159	197
TOTAL		6054	332

This gives an indicative value of 332 people (aged 65 and over) from BAME groups with dementia in Merton. The prevalence for BAME late onset dementia is 0.15% as a proportion of all GP registered Merton residents. The prevalence of dementia in BAME people aged 65 and over is 5.5%. This is a higher rate of prevalence to the dementia (all ages, all ethnicities) in Merton of 0.9%. Although this is looking at dementia in the population aged 65 and above only, an inference can be made (with caution) that dementia prevalence is higher in BAME groups. This is in line with research such as Bhattacharyya<sup>43</sup> and Turner<sup>44</sup> that states that 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 since these groups have higher prevalence of vascular diseases.

<sup>&</sup>lt;sup>40</sup> PANS

<sup>&</sup>lt;sup>41</sup> The UK Race Equality Foundation briefing paper on dementia and BAME communities Black and Minority Ethnic Communities and Dementia: Where are we now? David Truswell, Race Equality Foundation, Better Health Briefing Paper November 2013, (Page 3)

<sup>&</sup>lt;sup>42</sup> Black and Minority Ethnic Communities and Dementia: Where are we now? David Truswell, Race Equality Foundation, Better Health Briefing Paper November 2013, (Page 3)

<sup>&</sup>lt;sup>43</sup> Bhattacharyya, S & Benbow, S M (2012) Mental health services for black and minority ethnic elders in the United Kingdom: a systematic review of innovative practice with service provision and policy implications, International Psychogeriatrics

<sup>&</sup>lt;sup>44</sup> Turner, D, Salway, S, Chowbey, P and Mir, G (2012) Mini Case Study Book Real world examples of using evidence to improve health services for minority ethnic people

#### What is the case-mix of dementia in Merton?

The pie chart below shows expected levels of severity in people that have dementia in Merton. It shows that 55% of the people have mild dementia, 33% have moderate and 12% have severe dementia. The data shows that there are more mild cases, followed by moderate then severe.

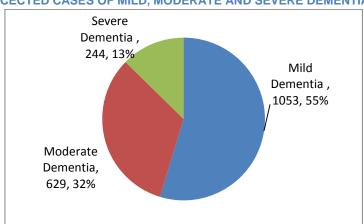


Figure 7: EXCECTED CASES OF MILD, MODERATE AND SEVERE DEMENTIA IN MERTON

Source: DPC (as at February 2015)

### What are the estimated cases by Dementia type?

The table below shows the expected number of cases of different types of Dementia in Merton obtained by applying the prevalence rates by Knapp and Prince<sup>45</sup> to Merton dementia prevalence. It should be noted that this is population prevalence therefore some of the people may or may not have a diagnosis. Another caveat is that these estimates are based on a model published in 2007. The biggest cohort is those with Alzheimer's disease then vascular dementia, which has been shown to be modifiable by improving vascular health. The modelled number of cases of different types of dementia in Merton is shown below.

TABLE 4: ESTMATED NUMBER OF CASES OF DIFFERENT TYPES OF DEMENTIA IN MERTON 46

Types of dementia	Number of cases
Alzheimer's disease 62%	1194
Vascular dementia 17%	327
Mixed dementia 10%	193
Dementia with Lewy bodies 4%	77
Fronto-temporal dementia 2%	39
Parkinson's dementia 2%	39
Other dementias 3%	58
0 ANDD (DD0) (1/2	

Source: ANDP (DPC) and (Knapp and Prince 2007)

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<sup>&</sup>lt;sup>45</sup> Knapp, M. & M. Prince. 2007. Dementia UK – A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (LSE and King's College, London) http://alzheimers.org.uk/site/scripts/download\_info.php?fileID=2

<sup>&</sup>lt;sup>46</sup> Adjusted National Dementia Prevalence Numerator ANDP , 1926, (as at February 2015) , National Dementia Prevalence Calculator

### What are the living arrangements for people with dementia?

The DPC estimates that 83% of people with dementia in Merton are in the community and 17% are in local care homes. This is shown in the pie chart below. As the majority of people with dementia are in the community, this shows that unpaid/informal carers play a very important role in Dementia care in Merton.

PWD in Care Care, 336, 17% PWD in the Community 1590,83%

FIGURE 8: LIVING ARRANGEMENTS OF PEOPLE WITH DEMENTIA

Source: DPC (as at February 2015)

### What is the Distribution by Age of Early and Late Onset Dementia?

The figures below show the distribution of late onset Dementia in Merton in 2015 by age group according to POPPI projections<sup>47</sup>. The graph shown that the highest proportion of people with dementia is those aged 85 and over. This is important later for assessing equity of access to services in terms of age.

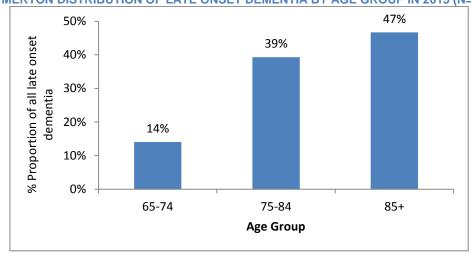


FIGURE 9: MERTON DISTRIBUTION OF LATE ONSET DEMENTIA BY AGE GROUP IN 2015 (N= 1749) 48

Source: POPPI

N.B. POPPI estimation of Dementia Prevalence is difference from the DPC estimation of dementia prevalence due to different methodologies. The DPC factors in residential and nursing homes whereas POPPI applies a prevalence rate to ONS population projections.

<sup>&</sup>lt;sup>48</sup> POPPI uses ONS Population Projections

The graph below shows the distribution of Late Onset Dementia in Merton by age group and gender obtained through applying POPPI dementia prevalence rates by age group to Merton 2015 population projections<sup>49</sup>. The graph shows that in the 65-74 and the 75-84 age groups, more men than women have dementia and in the 85 plus age group, more women than men have dementia. This is important when assessing access to services later.

60% 52% 50% 40% 40% % Proportion 38% 40% 30% 20% 20% 10% 10% 0% 75-84 85+ 65-74 Age Group ■ Females ■ Males

FIGURE 10: DISTRIBUTION OF LATE ONSET DEMENTIA BY AGE GROUP AND GENDER (N=1818)<sup>50</sup>

Source: POPPI Dementia Prevalence Rates and GLA SHLAA Merton population 2015

### 3.5. What is the anticipated incidence/new cases?

Incidence is a measure of the number of new cases of a disease that develop in a population of individuals at risk during a specified time. There is ample research on dementia prevalence but a dearth of research on dementia incidence. The Medical Research Council (MRC) and Cognitive Function and Ageing Study (CFAS) published estimates of the incidence of Dementia in England and Wales<sup>51</sup>. From the CFAS study, the incidence of dementia in different age groups was given as tabulated below:

TABLE 5: DEMENTIA INCIDENCE RATE PER 1,000 PERSON YEARS WITH 95% CONFIDENCE INTERVALS IN ENGLAND AND WALES

Age group	Men & Women (Confidence Intervals)
65-69	6.7 (3.8-12.4)
70-74	10.3 (6.2-19.9)
75-79	14.5 (9.6-20.7)
80-84	26.5 (18.3-37.7)
85+	68.5 (52.5-88.1)

<sup>10</sup> 

<sup>&</sup>lt;sup>49</sup> 2013 Round of Demographic Projections Local authority population projections - SHLAA Capped Household Size-based ethnic group projections, August 2014 <a href="http://data.london.gov.uk/datastore/package/glademographic-projections">http://data.london.gov.uk/datastore/package/glademographic-projections</a>

demographic-projections

This number is different from the number in the previous chart because POPPI uses ONS population projections and in this figure POPPI dementia prevalence rates by age group were applied to GLA SHLAA population projections

Matthews F, Brayne C, and Investigators MRC CFAS (2005) The Incidence of Dementia in England and Wales: Findings from the Five Identical Sites of the MRC CFA Study. PLoS Med 2(8): e193 http://medicine.plosjournals.org/perlserv/?request=get-document&doi=10.1371/journal.pmed.0020193

Applying these estimates to Merton 2015 census population will give the indicative new cases of late onset dementia. If we apply these incidence rates to Merton future population projections, we can also get indicative projections of late - onset dementia for the next 10 years. Inevitably, these values are only indicative as they are based on population projections; they assume that the incidence rate will remain constant. The figure below shows the anticipated new cases by age bands. From the projections below, we see that the percentage growth in the next fifteen years is 45.1% in new cases of late onset dementia, from (521 cases) in 2015 to (756 cases) in 2030. The percentage growth is substantial and unsurprisingly the age band with the highest number is people aged 85 and over.

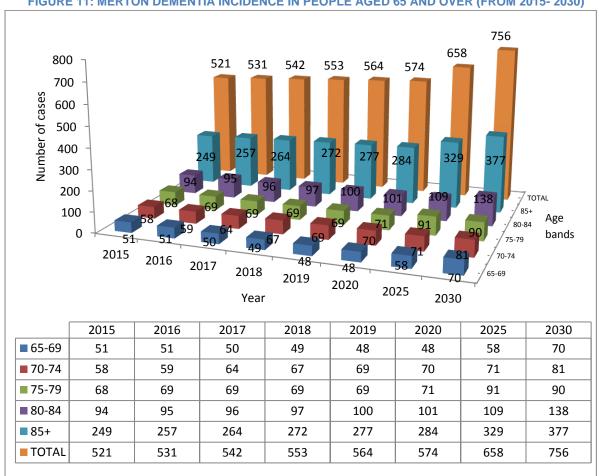


FIGURE 11: MERTON DEMENTIA INCIDENCE IN PEOPLE AGED 65 AND OVER (FROM 2015- 2030)

Source: GLA SHLAA Merton Population and Incidence rates applied from CFAS study

### What are the future projections for early onset dementia?

The figure below shows the total number of people aged 30-64 in Merton predicted by PANSI to have early onset in Merton from 2015 to 2030. The number of people with early onset dementia is small and the growth over the next fifteen years is 28.2%. The growth rate in this cohort is as expected smaller than the growth rate in the population of people aged 65 and over.

Figure 12: PEOPLE AGED 30-64 PREDICTED TO HAVE DEMENTIA IN MERTON 70 Number of people aged 30-64 59 predicted to have dementia 56 60 51 46 50 40 30 20 10 0 2015 2020 2025 2030 Year

Source: Projecting Adult Needs and Service Information System (PANSI)

### 3.6. Dementia in Primary care

What is the overall diagnosis rate<sup>52</sup> of dementia as at March 2015?

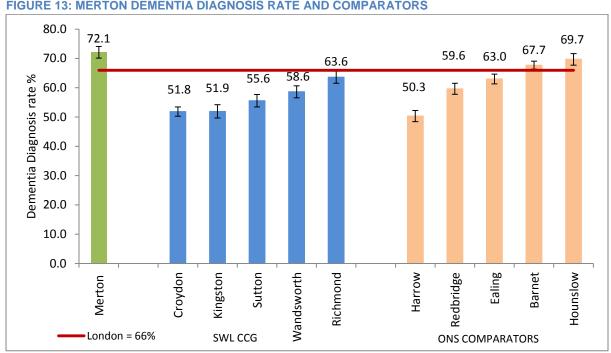


FIGURE 13: MERTON DEMENTIA DIAGNOSIS RATE AND COMPARATORS

England = 60.78%

Source: DPC (as at March 2015) and MCCG

The diagnosis rate shows the number of people with dementia detected in the population. QOF requires GP practices to keep a register of people diagnosed with dementia and this is compared to the expected dementia in the population to determine the diagnosis rate. According to the DPC and MCCG, the Merton diagnosis rate is 72% as at March 2015 meaning that 28% of people with dementia remain undetected or without a formal diagnosis;

<sup>&</sup>lt;sup>52</sup> Same as the Observed over Expected Ratio

this is known as the dementia gap<sup>53</sup>. The figure above shows the dementia diagnosis rate in Merton and comparators with 95% confidence intervals. The graph shows that Merton's diagnosis rate is statistically significantly higher than all SWL comparators as well as London and England. Merton is statistically significantly higher than four of the ONS comparators (Harrow, Redbridge, Ealing and Barnet) and similar to Hounslow.

### What are the diagnosis rates by locality?

The figure below shows the diagnosis rate of individual GP practices in the three Merton localities that is East Merton, Raynes Park and West Merton. The diagram shows that there is marked variation between GP practices and between localities in the dementia diagnosis rates. This is suggestive of health inequalities in relation to diagnosis and is an area for further investigation locally. The average diagnosis rate in East Merton is 57%, in Raynes Park is 78% and in West Merton the average is 68%. It should be noted that there is a practice with a diagnosis rate greater that 100% meaning that more people are being diagnosed with dementia than expected.

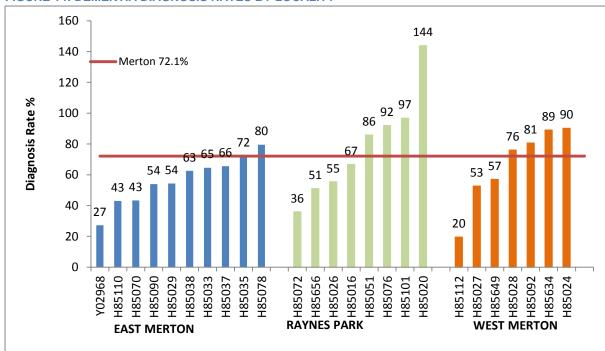


FIGURE 14: DEMENTIA DIAGNOSIS RATES BY LOCALITY

Source: DPC (as at March 2015) and MCCG

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<sup>&</sup>lt;sup>53</sup> **The 'Dementia Gap'** is the percentage of patients on the practice list with dementia who are undiagnosed. This is calculated by subtracting the QOF dementia register from the aNDPR number, and expressing that figure as a percentage of the ANDPR. It is possible to have a negative dementia gap if the practice has more patients on the dementia register than would be expected from the aNDPR. The maximum Dementia Gap is 100%.

### Face-to-face dementia reviews in GP practices

To help ensure high standards of primary health care and treatment delivered to NHS patients diagnosed with dementia QOF<sup>54</sup> incentivises GPs not only to maintain a register of people with dementia but also to review them. The figure below shows the proportion of people with dementia (of all age groups) whose care plan had been reviewed in a face-to-face review with their GP in the preceding 12 months in Merton and comparator boroughs. The figure shows that when compared to SWL comparators Merton is similar to four (Sutton, Richmond, Croydon and Kingston) and statistically significantly lower than Wandsworth. When compared to the ONS cluster and London, Merton is similar to the all the comparators.

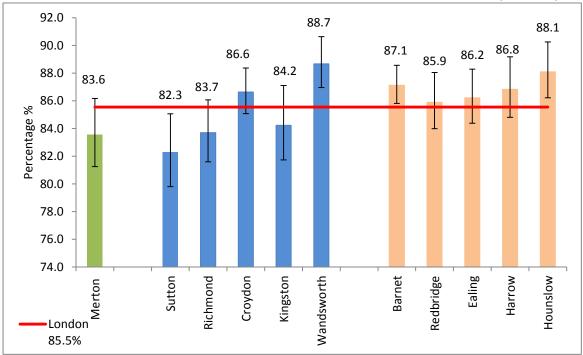


FIGURE 15: FACE-TO-FACE CARE REVIEW IN MERTON AND COMPARATORS (2013/14<sup>55</sup>)

Source: HSCIC released March 2015

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<sup>&</sup>lt;sup>54</sup> (QOF ID: DEM002) The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months. The **NUMERATOR** is patients on the dementia register who have had their care review recorded in the 12 months before the reference date. The **DENOMINATOR** is - All patients on the dementia register excluding those who have been exception reported.

<sup>&</sup>lt;sup>55</sup> Indicator Care review among patients with dementia: Statistic Percent (%) Age Group All ages Period Financial year 2013/14 Scale Version 14\_V1 Released March 2015 Notes Face to face review in the previous 12 months. Source HSCIC Published in March 2015

### Face-to-face dementia reviews by Merton GP practice and Locality

The figure below shows the proportion of people with dementia (of all age groups) whose care plan had been reviewed in a face-to-face review with their GP in the preceding 12 months in Merton GPs and by Locality. Similar to the diagnosis rate, there is marked variation between practices and localities.

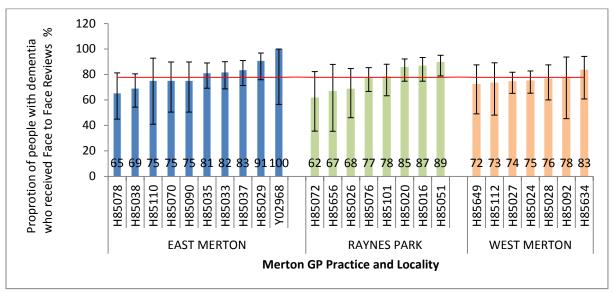


FIGURE 16: FACE-TO-FACE DEMENTIA REVIEWS BY MERTON GP PRACTICE

Source: QOF and DPC

### 3.6.1. Primary Care mapping of GP practices for targeted support

The latest available data on primary care QOF and other indicators relating to dementia and key dementia risk factors was obtained and tabulated (Appendix K) for Merton GP practices. The risk factors are elaborated in detail in Chapter 5. The GP indicators of interest were as follows:

TABLE 6: INDICATORS USED TO IDENTIFY AREAS FOR MORE SUPPORT

INDICATOR		POLARITY <sup>56</sup>
•	Diagnosis rates from the Dementia Prevalence Calculator (DPC) as at March 2015	(Higher is better) as higher diagnosis rates imply that more people with dementia are being identified and accessing support
•	<b>Face-to-face reviews</b> of people with dementia 2013/14 (QOF) <sup>57</sup>	(Higher is better) this is a proxy for good quality dementia care. QOF incentivises GPs to review dementia patients to help ensure high standards of primary health care and treatment delivered to NHS patients diagnosed with dementia.
•	Proportion of people aged 65 and over registered with the GP practice in 2014 (HSCIC)	This is to give context of the proportion of older people registered at each practice. As age is a major risk factor to dementia the assumption is that the more older people registered at a GP practice, the higher the number of people expected to have dementia
•	Hypertension prevalence 2013/14 (QOF) <sup>58</sup>	<b>(Lower is better)</b> Higher rates indicate more people as increased risk of vascular dementia as hypertension is a vascular disease which is a risk factor to dementia,
•	Estimated smoking prevalence 2013/14 (QOF) <sup>59</sup>	<b>(Lower is better)</b> Higher rates indicate more people as increased risk of vascular dementia as smoking is a risk factor to vascular disease and dementia.
•	Proportion of new hypertension patients, aged 30-74, with cardiovascular risk assessment >=20% treated with statins 2013/14 (QOF) <sup>60</sup>	(Higher is better). This is a proxy for primary prevention of Cardiovascular disease therefore the assumption is the more people treated with statins the more primary prevention of CVD which is a risk factor to dementia
•	The IMD Quintile for each GP practice 2015. This was calculated by attributing each registered patient to the IMD score of the LSOA in which they usually reside then the weighted average was used to obtain the score for each practice (elaborated in Appendix K)	(Higher number is better). Quintile 1 is the most deprived and 5 is the least deprived. Higher levels of deprivation are inextricably linked with poorer health outcomes therefore the GP practices with higher levels of deprivation could have people at higher risk of poorer health outcomes.

<sup>&</sup>lt;sup>56</sup> The desired direction of travel for the indicator

<sup>&</sup>lt;sup>57</sup> (QOF ID: DEM002) The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months. The **NUMERATOR** is patients on the dementia register who have had their care review recorded in the 12 months before the reference date. The **DENOMINATOR** is - All patients on the dementia register excluding those who have been exception reported.

<sup>&</sup>lt;sup>58</sup>Hypertension QOF prevalence (all ages) the percentage of patients with established hypertension, as recorded on practice disease registers (proportion of total list size).

<sup>&</sup>lt;sup>59</sup> GP Patient Survey smoking prevalence. Percentage of all respondents to the question "Which of the following best describes your smoking habits?" who answered "Occasional smoker" or "Regular smoker".

<sup>&</sup>lt;sup>60</sup> CVD-PP001. In those patients with a new diagnosis of hypertension aged 30 or over and who have not attained the age of 75, recorded between the preceding 1 April to 31 March (excluding those with pre-existing CHD, diabetes, stroke and/or TIA), who have a recorded CVD risk assessment score (using an assessment tool agreed with the NHS Commissioning Board of >20% in the preceding 12 months percentage who are currently treated with statins NICE 2011 menu ID: NM26

All 24 practices in Merton were ordered from best performing to worst for each indicator and the lowest third (9/24) were identified for each indicator. Note that for each indicator, the practices in the lowest third vary. This is tabulated below:

TABLE 7: TABLE OF THE LOWER THIRD OF GP PRACTICES IN INDICATORS FOR DEMENTIA CARE AND DEMENTIA RISK FACTORS

	Diagnosis Rates <sup>61</sup>		Face to face reviews <sup>62</sup>		Proportion of registered patients aged 65 and above <sup>63</sup>		Hypertension QOF prevalence 13/14 (proportion %) <sup>64</sup>		Estimated smoking prevalence (QOF) 13/14 (Proportion %) <sup>65</sup>		Deprivation  IMD  Quintile <sup>66</sup>		CVD-PP001: New hypertension patients, aged 30-74, treated with statins	
1.	H85029	54%	H85024	75%	H85027	19%	H85076	16%	Y02968	24.5%	H85090	2	H85656	-
2.	H85090	54%	H85027	74%	H85016	17%	H85078	16%	H85649	21.9%	H85078	2	H85072	-
3.	H85027	53%	H85112	73%	H85076	17%	H85029	14%	H85038	21.7%	H85024	2	H85038	29%
4.	H85656	51%	H85649	72%	H85078	14%	H85038	14%	H85078	20.7%	Y02968	2	Y02968	33%
5.	H85070	43%	H85038	69%	H85038	14%	H85035	13%	H85634	20.4%	H85029	2	H85027	33%
6.	H85110	43%	H85026	68%	H85037	14%	H85016	13%	H85033	20.3%	H85038	2	H85051	46%
7.	H85072	36%	H85656	67%	H85110	13%	H85024	12%	H85024	20.1%	H85033	2	H85070	50%
8.	Y02968	27%	H85078	65%	H85020	13%	H85090	12%	H85110	19.7%	H85035	2	H85092	50%
9.	H85112	20%	H85072	62%	H85101	13%	H85033	12%	H85090	19.3%	H85110	3	H85024	50%

A matrix was then created showing how often each practice appeared on the lists of higher risk areas or areas requiring greater support to improve dementia care. These practices are shown in the table below. These practices had relatively<sup>67</sup>:

- Lower diagnosis rates
- Lower Face- to-face reviews of dementia patients
- Higher proportions of GP registered older people (people aged 65 and over)
- Higher hypertension and smoking prevalence (QOF)
- Higher deprivation

These practices are located in Cricket Green, Lavender Fields, Wimbledon Village and Ravensbury and were deemed areas requiring more support with improving dementia care and prevention.

<sup>&</sup>lt;sup>61</sup> Dementia Prevalence Calculator (DPC as at March 2015)

<sup>&</sup>lt;sup>62</sup> QOF indicator DEM002: Dementia Face to face reviews 13/14 Indicator Care review among patients with dementia: Statistic Percent (%) Age Group All ages Period Financial year 2013/14 Scale Version 14\_V1 Released March 2015 Notes Face to face review in the previous 12 months. Source HSCIC Published in March 2015

<sup>&</sup>lt;sup>63</sup> Health and Social Care Information Centre, Numbers of Patients Registered at a GP Practice - April 2013 <a href="http://www.hscic.gov.uk/article/2021/Website-Search?productid=11737">http://www.hscic.gov.uk/article/2021/Website-Search?productid=11737</a>

<sup>&</sup>lt;sup>64</sup> National GP Profiles http://fingertips.phe.org.uk/profile/general-practice

<sup>65</sup> National GP Profiles http://fingertips.phe.org.uk/profile/general-practice

<sup>&</sup>lt;sup>66</sup> English Indices of Deprivation <u>www.gov.uk/government/collections/english-indices-of-deprivation</u> <u>www.hscic.gov.uk/catalogue/PUB18762/gp-reg-patients-lsoa-alt-tall.csv</u>

<sup>&</sup>lt;sup>67</sup> To other practices in Merton

TABLE 8: MATRIX SHOWING SEVEN PRACTICES THAT APPEAR ON FOUR OR MORE LISTS OF HIGHER **RISK AREAS FOR TARGETING** 

Practice Code	Number of times the practice is in the lowest third	Lower Diagnosis Rates	Lower Face to face reviews	Higher Hypertension QOF prevalence 13/14 (proportion %)	Higher Estimated smoking prevalence (QOF) 13/14 (Proportion %)	Higher levels of Deprivation	Lower rates of CVD-PP001: new hypertension patients, age 30-74, treated with statins
H85038	5		<b>✓</b>	✓	✓	✓	✓
H85024	5		✓	✓	✓	✓	✓
H85078	4		✓	✓	✓	✓	
H85090	4	✓		✓	✓	✓	
Y02968	4	✓			✓	<b>√</b>	<b>√</b>
H85027	3	✓	✓				<b>√</b>
H85110	3	✓			✓	✓	

### What is the trend in prescribing for dementia drugs?

Average Daily Quantities (ADQ) are a measure of prescribing volume based on prescribing behaviour in England and represent the assumed average maintenance dose per day for a drug used for its main indication in adults. ADQs are not recommended doses but are analytical units produced in order to compare more accurately the prescribing activity of primary care practitioners. Specific Therapeutic Group Age-sex weightings Related Prescribing Units (STAR-PU) are differences in the age and sex profiles of patients who are prescribed drugs in specific therapeutic groups. The figure below shows the common dementia drugs Average Daily Quantities (ADQ) per weighted population in Merton and comparator boroughs. The figure shows that Merton's value is higher than all the SWL comparators and all but two (Redbridge and Barnet) of the ONS comparators and a higher ADQ is considered better. This is not surprising as Merton has higher diagnosis rates than a number of its comparators therefore more people are being identified and having dementia drugs prescribed.

0.9 1.0 0.9 Dementia Drugs ADQ/STAR PU 0.9 8.0 0.7 0.5 0.7 0.6 0.5 0.5 0.6 0.4 0.5 0.4 0.3 0.3 0.4 0.3 0.2 0.1 0.0 Ealing Croydon Sutton Richmond Kingston Wandsworth Harrow Hounslow Redbridge Merton London = 0.57

FIGURE 17: DEMENTIA DRUGS AVERAGE DAILY QUANTITIES (ADQ)

Source: ePACT.net<sup>68</sup> (Q3: October – December 2014) MCCG Medicines Management

 $<sup>^{68}</sup>$  ePACT.net is an application which allows authorised users at Primary Care Organisations (PCOs) / Area Teams / Trusts and National users to electronically access prescription data. http://www.nhsbsa.nhs.uk/3230.aspx

### 3.7. Dementia in Secondary care

Data collected on the Average Length of Stay (ALOS) of people with a primary or secondary dementia diagnosis to see if there was any disparity between the groups. ALOS data provides general information about the efficiency of care delivery in hospital, and is an important quality indicator<sup>69</sup>. However, this has been omitted because the number of admissions with a primary or secondary diagnosis of dementia was too small to deem the analysis reliable. Rarely people are admitted with a diagnosis of dementia but are coded under the condition or symptoms they present with and this is why the number of hospital admissions with a diagnosis of dementia was small.

#### The Dementia CQUIN in Merton

The dementia CQUIN aims to improve dementia and delirium care and there are three elements to the CQUIN, which are:

- Finding ,Investigating and Referring (FAIR)
- Clinical leadership and;
- Supporting carers.

Both the main acute trusts frequented by Merton residents met their dementia CQUIN targets in 2014/15.

## 3.8. Dementia in the Community What are the trends in demand for the Community Mental Health Team (CMHT)?

The figures below show an upward trajectory in the referrals for dementia patients as well as the number of dementia patients seen by the CMHT over four years showing an increase in demand for the CMHT. From 2011-2015 there has been a 49.3% growth in the number of referrals for dementia to the CMHT and a 42.5% growth in number of patients seen by the CMHT. Inevitably, as more people are being identified in primary care a key consideration in the future of dementia care is ensuring that there is sufficient capacity to meet with the increase in demand.

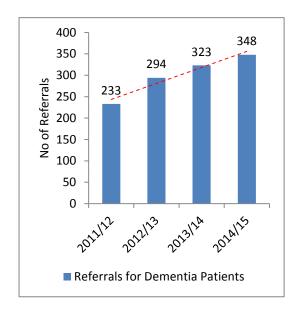
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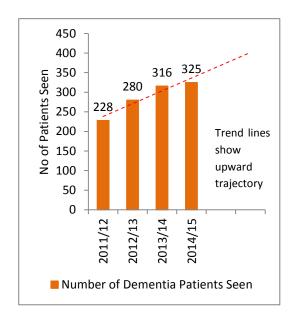
<sup>&</sup>lt;sup>69</sup> National Healthcare Quality Report, 2010 http://www.ahrg.gov/research/findings/nhgrdr/nhgr10/Chap7.html

FIGURE 18: YEAR ON YEAR TREND IN DEMAND ON THE CMHT

Referrals For Dementia Patients

Number Of Dementia Patients Seen

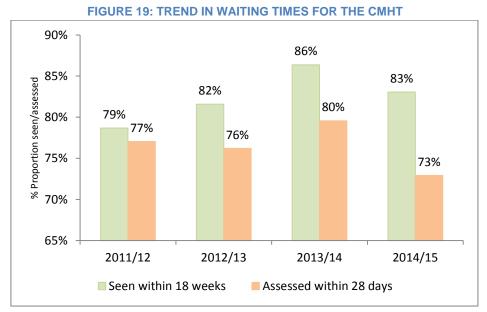




Source: South West London and St George's Mental Health NHS Trust

Source: South West London and St George's Mental Health NHS Trust

The figure below shows the four-year trend in waiting times for the Merton CMHT for dementia patients. The graph shows that the CMHT has been managing to maintain waiting times above 70% for people seen within the 18 weeks (from referrals to treatment) and the target of those assessed within 28 days despite the increase in demand on the service.



Source: South West London and St George's Mental Health NHS Trust

### 3.9. Adult Social Care Services used by people with dementia

Pseudonymised data from Care First on 425 Adult Social Care (ASC) users with an open classification/health condition or primary client group of dementia who received services and had a Merton postcode during 2013/14 was analysed. The characteristics of interest in relation to service access were age, ethnicity and deprivation.

### Age

Unsurprisingly there were more service users in the older age bands, 80% of the service users are aged 80 and over and 2% are aged below 65. Given that as a proportion of all cases of dementia in Merton in 2015, early onset dementia represents 2.4%, the fact that the service users with dementia aged below 65 are 2% suggests that ASC is accessible to a good number of those with early onset dementia. The table below shows the distribution of ASC services users with dementia by age bands.

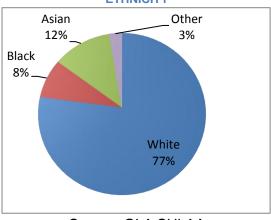
33% Proprotion of all dementia 30% 26% 25% 21% 20% 15% 10% 10% 5% 3% 2% 5% 0% <65 65-69 70-74 75-79 80-84 85-89 90+ Age bands

FIGURE 20: ASC SERVICE USERS WITH DEMENTIA BY AGE BANDS (2013/14)

Source: CareFirst

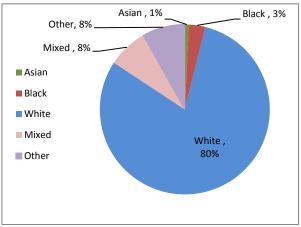
### **Distribution by Ethnicity**

FIGURE 21: MERTON POPULATION (AGED 65 AND OVER) IN 2014 DISTRIBUTION BY **ETHNICITY** 



Source: GLA SHLAA

FIGURE 22: ADULT SOCIAL CARE USERS WITH **DEMENTIA 2013/14 BY ETHNICITY** 



Source: CareFirst

The figures above show the population distribution by ethnicity of people aged 65 and over in Merton in 2014 and the distribution of ASC service users in 2013/14 by ethnicity. A crude direct comparison suggests that the Black and Asian ethnic groups are under-represented in terms of ASC service access. The caveats are that the data from Care first includes a

category "mixed" while in the overall distribution of Merton the "Mixed" category is incorporated into the category "other". However even if the category of mixed was distributed evenly to the Black and Asian ethnic groups (of the adult social care users) they would still be under-represented.

### **Deprivation**

The figure below shows the distribution of Adult Social Care service users by IMD Quintile<sup>70</sup>. The distribution shows that 42% of ASC service users are in the more deprived quintiles (Quintile 1 and 2). The shape and type of distribution<sup>71</sup> suggests that there are more people in the more deprived quintiles accessing the service.

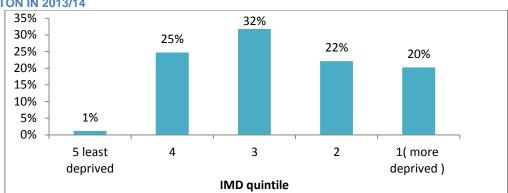


FIGURE 23: DISTRIBUTION BY DEPRIVATION OF ALL ADULT SOCIAL CARE SERVICE USERS RESIDENT IN MERTON IN 2013/14

Source: Care First and Service User Post Code Mapped against IMD Quintile

Appendix J shows the distribution of services users by deprivation and ethnic group. When considering the distribution of deprivation in different ethnic groups accessing ASC the data suggests that:

- The Asian, Mixed and Other ethnic groups are normally distributed<sup>72</sup> by the deprivation quintiles meaning that people in those ethnic groups from different levels of deprivation (quintiles 1-5) are accessing the service appropriately.
- More black people from affluent quintiles are accessing the service<sup>73</sup>
- More deprived people from the white ethnic group are accessing the service<sup>74</sup>

<sup>&</sup>lt;sup>70</sup> The Indices of Multiple Deprivation (IMD) 2010, part of the English Indices of Deprivation is a model of measuring deprivation in an area. Separate dimensions of deprivation underpin it; these dimensions are weighted and an overall deprivation score is given. Quintiles are ranked by deprivation with Quintile 1 containing the 20% most deprived data zones and Quintile 5 containing the 20% least deprived data zones

<sup>&</sup>lt;sup>71</sup>(Skew-1.4) Skewness quantifies how symmetrical a distribution is. A symmetrical (normal) distribution has a skewness of zero. An asymmetrical distribution with a long tail to the right (higher values) has a positive skew. An asymmetrical distribution with a long tail to the left (lower values) has a negative skew. The low values in this case are IMD Quintiles 1 and 2 (more deprived), the Higher values are IMD Quintile 4 and 5 (less deprived).

The distributions have a skew of zero; therefore, the distribution is a normal distribution. Skewness is a measure of symmetry, or more precisely, the lack of symmetry. A distribution, or data set, is symmetric if it looks the same to the left and right of the centre point

<sup>&</sup>lt;sup>73</sup> Distribution of black ethnic group service users by IMD quintile has a skew of 0.8

<sup>&</sup>lt;sup>74</sup> Distribution of white ethnic group service users by IMD quintile of -1.6

### Which are the most frequently used ASC services by people with Dementia?

The figure below shows the top five most frequently used services in 2013/14 by people with dementia in Merton. The graph shows the number of service contacts/spells. Some people access more than one service and some people access a service more than once. This graph shows that the majority of people with dementia accessing adult Social care in Merton use the Home care service followed by residential care and direct payments.

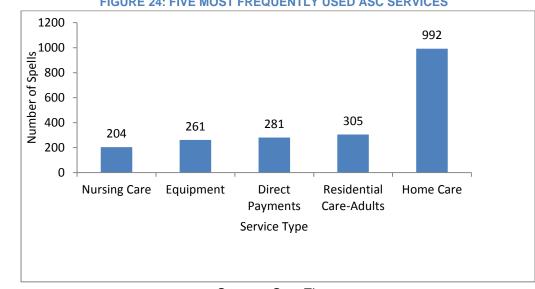


FIGURE 24: FIVE MOST FREQUENTLY USED ASC SERVICES

Source: CareFirst

The figure below shows that the majority of users (57%) only have one service contact and that the proportion of those who have multiple contacts is smaller.

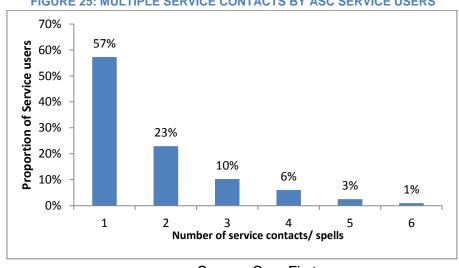


FIGURE 25: MULTIPLE SERVICE CONTACTS BY ASC SERVICE USERS

Source: Care First

What is the distribution by ethnic group of the service users (when considering the top five frequently used services)?

% Proportion of Service User by Ethnic Group 100% White 80% Other 60% Mixed Black 40% Asian 20% 0% Nursing Equipment Direct Residtl Home Care Merton Care **Payments** Carepopulation Adults (65+) by ethnicity 2014 White 90% 73% 58% 85% 85% 77% Other 0% 4% 2% 3% 3% 3% Mixed 1% 1% 0% 1% 0% 0 Black 6% 10% 14% 7% 6% 8% Asian 3% 11% 27% 4% 6% 12%

FIGURE 26: DISTIRBUTION OF SERVICE USERS BY ETHNIC GROUP AND SERVICE TYPE

Source: CareFirst and GLA SHLAA

The graph above shows the distribution by ethnic group of the top five most frequently use ASC services by people with dementia and Merton's population distribution by ethnicity of people aged 65 and over in 2014. Using the population distribution of Merton by ethnicity as a comparator, this is suggestive that there are some ethnic groups under represented and over represented in some services i.e.:

- Nursing Care- the data is suggestive that the white ethnic group is considerably over represented, the black ethnic group is marginally under represented and the Asian ethnic group is considerably under represented
- **Direct Payments** the data is suggestive that the white ethnic group is markedly under- represented, and Black and Asian people are marginally over-represented
- Residential Care and Home Care the data is suggestive that the white ethnic group is markedly over represented the black ethnic group is marginally under represented and the Asian ethnic group is markedly under represented. Therefore, there is an issue regarding equitable access to ASC services for people with Dementia.

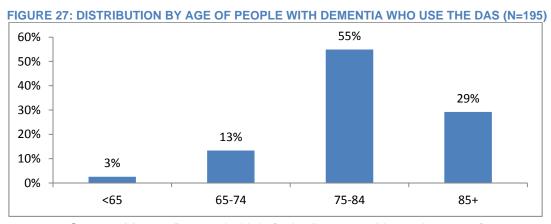
#### 3.10. Merton Dementia Hub Service Users

There are many services provided at the Merton Dementia Hub (detailed in Chapter 8) however, two services were reviewed for the purpose of the needs assessment. Data on people with dementia who used the Dementia Adviser Service (DAS) and carers of people with dementia who used Dementia Support Worker Service (DSW) between 1 April 2014 and 9 November 2015 was analysed. The data on the carers of people who used the DAS was not included because the sample sizes were small. The key characteristics of interest were age, gender and ethnicity to assess equitable access. Referral sources were also reviewed. Postcode data could not be obtained therefore deprivation was not incorporated into the analysis.

### **Dementia Adviser Service (DAS)**

### Age

The figure below shows the distribution of people with dementia who use the DAS by age (excluding those on the information system whose age was coded as unknown). Given that as a proportion of all cases of dementia in Merton in 2015, early onset dementia represents 2.4%, the fact that the service users with dementia aged below 65 are 3% suggests that ASC is accessible to a good number of those with early onset dementia.



Source: Merton Dementia Hub (1 April 2014- 9 November 2015)

When the figure above is compared to the POPPI Merton distribution of Late Onset Dementia by age group in 2015 (Figure 9), the data is suggestive that the 75-84 age group is over-represented (POPPI- 39%) and the 85+ age group is markedly under-represented (POPPI- 47%). Therefore, the DAS service should increase its reach to people aged 85 and over to improve equitable access. According to POPPI, projections the largest proportion (47%) of people with Late Onset Dementia is people aged 85 and over therefore these people should be accessing the Dementia Hub according to how the people with dementia are distributed in Merton. A possibility for the under-representation of the 85 and over age group is that more people with severe dementia are in this age group and would not benefit from the services provided at the Hub. There is a need to locally to better understand the reasons behind the under representation of the 85 and over age group.

#### Gender

The figure below shows the distribution of people with dementia who use the DAS by age and gender excluding those with the age or gender coded as unknown (n=8).

(N=195)54% 55% 60% 50% % Proportion 40% 29% 30% 30% 20% 15% 11% 10% 0% <65 65-74 75-84 85+ **Age Groups** ■ Female ■ Male

FIGURE 28: DISTRIBUTION OF PEOPLE WITH DEMENTIA USING THE DAS BY AGE AND GENDER
(N-195)

Source: Dementia Hub (1 April 2014- 9 November 2015)

When the figure above is compared to Figure 10<sup>75</sup>, which shows the distribution of Late Onset Dementia in Merton in 2015 by age group and gender, the data suggests that:

- Females aged between 65-74 are over-represented (POPPI- 10%)
- Males aged between 65-74 are under-represented (POPPI-20%)
- Both males and females in the 75-84 age group are over-represented (POPPI Females- 38%, Males 40%) and;
- Both males and females in the 85 plus age group are under-represented (POPPI Females- 52%, Males 40%).

Therefore, the DAS service should increase its reach to males aged between 65-74, all people aged 85 and over.

### **Ethnicity**

There was no comparison made of the distribution by ethnicity of people with dementia who used the DAS with the Merton population distribution as a considerable proportion of people (26%) were coded as ethnicity unknown, not disclosed, incomplete or undisclosed.

### **Dementia Support Worker (DSW) Service**

Data was analysed on carers of people who use the DSW and the following conclusions were drawn:

• When considering age, the proportion of carers with their age marked as unknown was 44% therefore few inferences could be made

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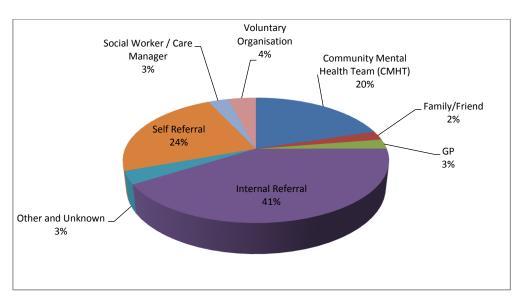
<sup>&</sup>lt;sup>75</sup> Distribution of Late Onset Dementia in Merton in 2015 by age group and gender (Source: POPPI Dementia Prevalence Rates and GLA SHLAA Merton population 2015)s

•When considering gender from the available data (N= 252), women made up 72% while men made up 28% and this is in line with the national trend of more female carers than males<sup>76</sup>.

### Referral Sources for both the DAS and DSW services

The figures below show the referral sources for the DAS and DSW and the most notable observation is the very low proportion of referrals to both services from Social Workers and GPs and other voluntary sector organisations suggesting that stronger links need to be developed between these services.

FIGURE 29: REFERRAL SOURCES OF CARERS WHO USE THE DEMENTIA SUPPORT WORKER SERVICE (N=457)

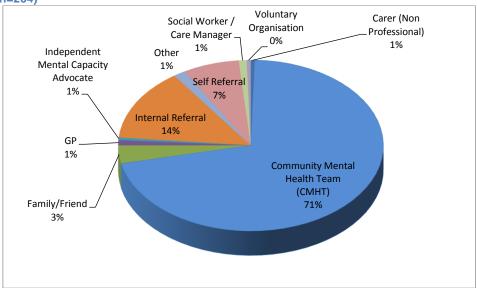


Source: Dementia Hub (1 April 2014- 9 November 2015)

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<sup>&</sup>lt;sup>76</sup>Carers UK policy Briefing May 2014 <a href="https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy\_file&id=4762">https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy\_file&id=4762</a>.

FIGURE 30: SOURCE OF REFERALS OF PEOPLE WITH DEMENTIA WHO USE THE DEMENTIA ADVISOR SERVICE (n=204)



Source: Dementia Hub (1 April 2014- 9 November 2015

# 4. What is the indicative cost to the health economy of dementia in Merton?

The Alzheimer's Society commissioned the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London to produce a report on dementia in the UK<sup>77</sup>. The research provided an evaluation of the overall financial cost of dementia among other things. The report provided the table below showing the cost (NHS, Social Services, Informal care and accommodation) of people with dementia at different levels of severity. Included in the model were costs of informal care in the form of lost income for those carers who have to give up employment or cut back their work hours to care. Residential care represents the largest segment of the dementia care budget therefore better provision of community support both for people with dementia and carers is a cost-effective way to enable people to live at home for longer and reduce the costs of residential care<sup>78</sup>.

FIGURE 31: COST PER INDIVIDUAL PER YEAR WITH MILD, MODERATE AND SEVERE DEMENTIA

	Mild	Moderate	Severe
NHS	£2,508	£2,430	£2,639
Social Services	£4,935	£6,224	£7,738
Informal Care	£9,246	£17,223	£27,096
Accommodation	0 <del>2</del>	0 <del>2</del>	<del>2</del> 0
Total	£16,689	£25,877	£37,473

Source: Knapp and Prince 2007<sup>79</sup>

As these are figures from 2005/06 adjusting them for inflation and applying them to the expected number of people with dementia provides a crude measure of cost tabulated below. The table shows that the cost to the health economy of dementia in Merton is in excess of £54million pounds per year.

http://alzheimers.org.uk/site/scripts/download\_info.php?fileID=2

<sup>&</sup>lt;sup>77</sup> Knapp, M. & M. Prince. 2007. Dementia UK – A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (LSE and King's College, London)

<sup>&</sup>lt;sup>78</sup> Spotlight on Dementia Care, A Health Foundation improvement report, October 2011, http://www.health.org.uk/public/cms/75/76/4181/2703/Spotlight Dementia%20Care.pdf?realName=55ojeV.

Table 9: INDICATIVE COSTS OF DEMENTIA IN MERTON PER YEAR

	Mild Dementia	Moderate Dementia	Severe Dementia
Number of estimated cases in Merton	1,053	629	244
2015 costs (based on Knapp and Prince costs adjusted for inflation <sup>80</sup> )	£21,329.40	£33,072.14	£47,892.43
Overall cost for each type of dementia	£22,459,858	£20,802,376	£11,685,753
Overall estimated costs for Dementia in Merton		£54,947,987	

Source: Knapp and Prince Costs applied to Merton Dementia Prevalence (DPC)

Appendix H shows an alternative model where average cost of late onset dementia per person is applied to Merton POPPI projections giving an estimate of more than £45million as costs for those with late onset dementia alone.

### **Merton CCG GP Prescribing of Dementia Drugs**

The year-to-year costs of GP Prescribing for dementia drugs<sup>81</sup> have been decreasing. Although the number of people with dementia is increasing and the number of people being diagnosed with dementia is increasing the overall cost of dementia drugs is decreasing because more generic less costly brands of drugs are increasingly available.

<sup>80</sup> UK Inflation Calculator <a href="http://www.whatsthecost.com/cpi.aspx">http://www.whatsthecost.com/cpi.aspx</a>

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Common dementia drugs Rivastigmine, Galantamine, Memantine Hydrochloride and Donepezil Hydrochloride

### 5. Risk Factors to developing Dementia

Risk factors are conditions that increase an individual's likelihood of developing a disease. Risk factors can be modifiable, meaning that a person can take measures to change them. Non-modifiable risk factors, on the other hand are those that cannot be changed. Identification of modifiable risk factors is crucial in the prevention of dementia because it is a condition that has limited treatment options and the causes are still unknown. Dementia has often been thought to be incurable and inevitable however, in recent years epidemiological research has provided a substantial amount of evidence of modifiable risk and protective factors that can be addressed to prevent or delay onset<sup>82</sup>. There is new evidence that the adult brain maintains plasticity and response to external stimuli.

### 5.1. Modifiable risk factors and actions to mitigate risks

The key modifiable risk factors to dementia are:

- Vascular disease
- **Obesity and Diabetes**
- Depression
- Smoking
- Excessive alcohol consumption
- Physical inactivity<sup>83</sup>
- Cognitive inactivity or lower educational attainment and;
- Other risk factors i.e. sleep quality

### TABLE 10: MODIFIABLE RISK FACTORS AND /ACTIONS TO MITIGATE THE RISKS

#### Vascular disease<sup>84</sup> 1.

- Vascular disease such as hypertension, Atrial Fibrillation, and High Blood Pressure and hypercholesterolemia have been linked with cognitive decline and
- Earlier onset of dementia is linked to the rapid, irregular heart rhythm of atrial fibrillation. A study found that people who have atrial fibrillation develop dementia at younger ages than those without AF showing the relationship between heart health and health of the brain.
- Raised cholesterol is a known risk factor for cerebrovascular accidents, which in turn are associated with increased risk for vascular dementia.

#### 2. **Obesity and Diabetes**

Obesity (raised body mass index) in mid life is linked to increased likelihood of dementia in later life <sup>85</sup>. Obesity is a risk factor for type 2 diabetes, which in turn is a risk factor for cerebrovascular disease and the subsequent development of dementia.

 $<sup>^{82}</sup>$  Dementia prevention: current epidemiological evidence and future perspective. Mangialasche et al. Alzheimer's Research & Therapy 2012, 4:6, http://alzres.com/content/4/1/6

<sup>&</sup>lt;sup>83</sup> Barnes DE, Yaffe K. <u>The projected effect of risk factor reduction on Alzheimer's disease prevalence</u>. The Lancet Neurology, Early Online Publication, July 19 2011

<sup>&</sup>lt;sup>84</sup> Conditions that affects the circulatory system

<sup>&</sup>lt;sup>85</sup> Nutrition and the risk of Alzheimer's disease. Hu N; Yu JT; Tan L; Wang YL; Sun L; Tan L BioMed Research International, 2013, vol./is. 2013/(524820), 2314-6141 (2013)

### Mitigating actions to vascular disease, obesity and diabetes

- Lifestyle measures that maintain or improve vascular health such as consumption of healthy diets, moderate use of alcohol and regular physical exercise in general are effective for reducing dementia risk<sup>86</sup>.
- Screening and management of mid-life high blood pressure, cholesterol and diabetes.
- Reducing the risk for the onset of Atrial Fibrillation by maintaining a heart-healthy through regular physical activity, eating a healthy diet, low in saturated fats, transfats, and cholesterol and maintaining a healthy weight

### 3. Depression

- It is known that rates of depression in those with dementia are raised and depression can be an early manifestation of dementia<sup>87</sup>. A meta-analysis study found that people with a history of depressive illness had an increased risk of developing dementia in the future.
- Another study found that depressive illness occurring as much as 25 years before the onset of cognitive impairment increased the risk of dementia<sup>88</sup>.

### Mitigating actions to depression

- Screening management and treatment of depression are public health measures that can be taken to minimise risks of dementia.

### 4. Smoking

Smoking increases the risk of vascular disease.

### 5. Excessive alcohol consumption

- Excessive alcohol consumption is a well-known risk factor for dementia89.
- Moderate rates of alcohol consumption are associated with lower rates of cardiovascular disease, cerebrovascular disease and dementia than are abstinence or heavy consumption<sup>90</sup>.

### Mitigating actions smoking and excess alcohol consumption

 Evidence based interventions include avoiding smoking and excessive alcohol consumption.

### 6. Physical inactivity

- Physical inactivity reduces heart and vascular system health and increases risk factors to dementia such as vascular disease.

### **Mitigating actions**

There is some evidence that regular exercise (at least twice a week and of 20-30 minutes duration and which causes breathlessness and sweating) in midlife can reduce the likelihood of dementia in later life by about one half (odds ratio [OR] 0.48 [95% CI 0.25–0.91]<sup>91</sup>.

<sup>&</sup>lt;sup>86</sup> Nutrition and the risk of Alzheimer's disease. Hu N; Yu JT; Tan L; Wang YL; Sun L; Tan L BioMed Research International, 2013, vol./is. 2013/(524820), 2314-6141 (2013)

<sup>&</sup>lt;sup>87</sup> Jorm, A.F. (2000) Is depression a risk factor for dementia or cognitive decline? A review. Gerontology, 46, 219–227

<sup>&</sup>lt;sup>88</sup> Green, R.C., Cupples, L.A., Kurz, A., et al. (2003) Depression as a risk factor for Alzheimer disease: the MIRAGE Study. Archives of Neurology, 60, 753–759.

<sup>&</sup>lt;sup>89</sup> Saunders, P.A., Copeland, J.R., Dewey, M.E., et al. (1991) Heavy drinking as a risk factor for depression and dementia in elderly men. Findings from the Liverpool longitudinal community study. The British Journal of Psychiatry, 159, 213–216 <sup>90</sup> Letenneur, L. (2004) Risk of dementia and alcohol and wine consumption: a review of recent results. Biological Research,

<sup>&</sup>lt;sup>91</sup> Rovio, S., Kareholt, I., Helkala, E.L., et al. (2005) Leisure-time physical activity at midlife and the risk of dementia and Alzheimer's disease. The Lancet Neurology, 4, 705–711

Observational studies suggest that being physically active improves vascular function and reduces the risk of dementia.

#### 7. Cognitive inactivity or lower educational attainment

- A systematic review concluded that it is possible that low educational attainment is associated with increased risk for dementia<sup>92</sup>. This has led to speculation about whether cognitive stimulation may be a protective factor.
- Another study found that a group of people engaging in common mentally stimulating activities subsequently had a decreased likelihood of developing dementia<sup>19</sup>. There is also evidence from randomised controlled trials that cognitive stimulation can have positive benefits, which last for up to two years<sup>93</sup>

### Mitigating actions

Encouraging people to engage in cognitively stimulating activities is good practice in primary care. Staying connected socially and interacting regularly with others, challenging one's brain by trying something new, playing games or learning a new language all are protective steps that can be taken to reduce the risk of dementia.

### 6. Other risk factors i.e. sleep quality

Observational data indicate that sleep quality may also be a modifiable risk factor for dementia prevention<sup>94</sup>.

### Mitigating actions

Ensuring regular good quality sleep.

#### 5.2. Non- Modifiable Risk Factors

The key non-modifiable risk factors for dementia include age, having learning disabilities, genotype/genetics and brain damage and head injury. These are elaborated on below:

### TABLE 11 NON-MODIFIABLE RISK FACTORS OF DEMENTIA

1. Age

While it is possible to develop dementia early in life, the chances of doing so increase dramatically with age. One in fifty people between the ages of 65 and 70 have a form of dementia, compared to one in five people over the age of 80.

### 2. Learning disabilities

People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia. Research shows that people diagnosed with amnestic Mild Cognitive Impairment (MCI) have an increased risk of developing dementia, but only about 1 in 6 eventually do 95.

### Genotype/genetics

The role of genetics in the development of dementia is still not fully understood however, in early onset Alzheimer's disease, this tends to cluster within families, sometimes with several generations affected, in which case it is called familial disease 16. In some of

<sup>&</sup>lt;sup>92</sup> Valenzuela, M.J. & Sachdev, P. (2005) Brain reserve and dementia: a systematic review. Psychological

<sup>&</sup>lt;sup>93</sup> Ball, K., Berch, D.B., Helmers, K.F., et al. (2002) Effects of cognitive training interventions with older adults: a randomized controlled trial. The Journal of the American Medical Association, 288, 2271–2281.

 $<sup>^4</sup>$  Non-pharmacologic treatment and prevention strategies for dementia. Yaffe K; Hoang T Lifelong Learning in Neurology, April 2013, vol./is. 19/2 Dementia(372-81), 1080-2371;1538-6899 (2013 Apr)

<sup>&</sup>lt;sup>15</sup> 7.Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. Alzheimers Dement. 2012

these cases, early onset Alzheimer's is caused by mutations in one of three genes. These three genes are the amyloid precursor protein gene (APP) and two presentilingenes (PSEN-1 and PSEN-2)<sup>96</sup>.

### 4. Brain damage and Head Injury

Dementia can results from brain damage. Studies demonstrate that head injury sufficient to cause loss of consciousness approximately doubles the risk of dementia. The intervention that can contribute to preventing dementia is protecting one's head by wearing a helmet when engaging in sporting activities

### **Dementia and ethnicity**

Little is known about the relative prevalence of dementia in BAME populations. There is however a growing body of evidence that the BAME community in the UK has a higher prevalence of vascular dementia than other communities <sup>97,98</sup>. Prevalence of dementia in Black African-Caribbean and South Asian UK populations is greater than the white UK population as these groups are also more likely to experience high blood pressure <sup>99</sup>. The proportion of BAME groups among the elderly are increasing and consequently BAME populations will bear an increased share of the economic and social burden associated with diseases that predominantly affect the elderly, such as dementia. A Centre for Policy on Ageing Report <sup>100</sup> applied well-established dementia prevalence rates to census data on BAME communities in England and Wales. The findings were nearly a seven-fold increase in 40 years in BAME prevalence of dementia compared to a two-fold increase in the numbers of people with dementia across the whole UK population in the same time.

### Learning disabilities

People with a learning disability are at greater risk of developing dementia at a younger age. Estimating prevalence rates of dementia in people with learning disabilities is problematic because of a number of methodological issues, which include the diagnostic difficulties associated with dementia in a population, which has pre-existing cognitive and functional impairments and the complexity of establishing accurate population samples of people with intellectual disabilities. There are therefore no indicative values for people with learning disabilities in Merton who will develop dementia. (See Appendix D for general prevalence of learning disabilities in Merton)

http://www.alzheimers.org.uk/site/scripts/download info.php?downloadID=1097

 $\underline{http://www.raceequality foundation.org.uk/resources/downloads/black-and-minority-ethnic-communities-and-dementia-where-are-we-now \\$ 

<sup>&</sup>lt;sup>96</sup> Alzheimer's Society factsheet: Genetics of Dementia

<sup>&</sup>lt;sup>97</sup> Black and Minority Ethnic Communities and Dementia: Where are we now? David Truswell, Race Equality Foundation, Better Health Briefing Paper November 2013

<sup>&</sup>lt;sup>98</sup> Turner, D, Salway, S, Chowbey, P and Mir, G (2012) Mini Case Study Book Real world examples of using evidence to improve health services for minority ethnic people

http://clahrc-sy.nihr.ac.uk/images/health%20inequalities/resources/EEiC mini case study book.pdf

<sup>&</sup>lt;sup>99</sup> Bhattacharyya, S, Benbow, S M & Kar, N (2012) 'Unmet Service Needs of Ethnic Elders with Dementia in United Kingdom', Indian Journal of Gerontology, 26(1), pp.242-258.

<sup>&</sup>lt;sup>100</sup> The future ageing of the ethnic minority population of England and Wales: Older BME People and Financial Inclusion Report, Centre for Policy on Ageing, 2010

 $<sup>\</sup>frac{http://www.runnymedetrust.org/uploads/publications/pdfs/TheFutureAgeingOfTheEthnicMinorityPopulation-ForWebJuly2010.pdf}{}$ 

## 6. Dementia Best Practice

The table below shows the sources of information reviewed to develop the best practice chapter.

TABLE 12: BEST PRACTICE GUIDANCE REVIEWED TO DEVELOP PRIMARY THEMES

ORGANISATION	DOCUMENT TITLE
National Institute for	Support for commissioning dementia care NICE and Social Care Institute for
Health and Clinical	Excellence (SCIE) commissioning guides [CMG48] Published date: April
Excellence (NICE)	2013https://www.nice.org.uk/guidance/cmg48/
	Supporting people with dementia and their carers in health and social care (CG42),
	Nov 2006 https://www.nice.org.uk/guidance/cg42
	Donepezil, galantamine, rivastigmine and Memantine for the treatment of
	Alzheimer's disease NICE technology appraisal guidance [TA217] Published date:
	March 2011 https://www.nice.org.uk/guidance/ta217
National Audit Office	Improving Dementia services in England- an interim report
	http://www.nao.org.uk/report/improving-dementia-services-in-england-an-
	interim-report/
Royal College of GPs	Dementia Revealed: What Primary Care Needs to Know
	http://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-
	<u>toolkit.pdf</u>
Royal College of	Memory Services National Accreditation Programme (MSNAP), Standards for
Psychiatrists	Memory Services
	http://www.rcpsych.ac.uk/pdf/MSNAP%20Standards%20Fourth%20Edition%20201
	<u>4r.pdf</u>
Alzheimer's Society	The dementia guide: Living well after a diagnosis (2013)
	http://www.alzheimers.org.uk/site/scripts/documents info.php?documentID=224
	<u>0</u>
	Building dementia-friendly communities: A priority for everyone, The Alzheimer's
	society, August 2013
	http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1916
Department of Health	The use of antipsychotic medication for people with dementia: Time for action, An
	independent report commissioned and funded by the Department of Health,
	November 2009
	https://www.rcpsych.ac.uk/pdf/Antipsychotic%20Bannerjee%20Report.pdf
	The National Dementia Strategy 2009
	https://www.gov.uk/government/publications/living-well-with-dementia-a-
0 1 6 11	national-dementia-strategy
Centre for Mental	Liaison psychiatry in the modern NHS, 2012 <u>www.centreformentalhealth.org.uk</u>
Health	Guidance for commissioners of liaison mental health services to acute dementia
Joint Commissioning Panel	
for Mental Health	and People with Learning Disabilities <a href="http://www.jcpmh.info/wp-content/uploads/jcpmh-liaison-guide.pdf">http://www.jcpmh.info/wp-content/uploads/jcpmh-liaison-guide.pdf</a>
The Royal College of	Guidance on the assessment, diagnosis, treatment and support of people with
Psychiatrists and The	learning disabilities who develop dementia CR155
British Psychological	http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr196.a
Society	Spx
Public Health England	Making Reasonable Adjustments to Dementia Services for People with Learning
(supported by	Disabilities, Public Health England 2013
Department of Health)	http://www.improvinghealthandlives.org.uk/uploads/news/vid 19037 RA%20De
- spartment of ficultify	mentia1908Final%20LD%20edit%20docxPHE-2013179.pdf
Social Care Institute of	Maximising the potential for dementia reablement
Excellence SCIE	http://www.scie.org.uk/publications/guides/guide49/dementia.aspSocial
St John's Cognitive	Alzheimer's: Six pillars of prevention
Health	http://www.cognitivehealthjh.org/perch/resources/pillars-of-brain-health.pdf

There is a plethora of best practice guidelines and policy documents that outline good quality services and principles of good dementia care. The guidance documents are crosscutting and have been summarised in relation to the following primary themes for simplicity:

- Prevention
- Health and Social Care deliver and commissioning
- **Identification, Assessment and Diagnosis**
- **Early Intervention and Treatments**
- Living Well with Dementia, Supporting Carers and Dementia Friendly Communities
- **Good Dementia Care in Hospital and Liaison Psychiatry**
- **Reablement and Dementia**
- **End of Life Care (EoLC)**
- People with Learning Disabilities who develop Dementia

#### 6.1. Prevention

The National Dementia Strategy 2009<sup>101</sup> advocates for 'Improving public and professional awareness and understanding of dementia' as a key contributing factor to the prevention of dementia. The strategy also states that the current evidence base suggests that up to 50% of dementia cases may have a vascular component. The biggest message in prevention of dementia is what is good for your heart is good for your head. The six pillars of Alzheimer's prevention<sup>102</sup> are regular exercise, healthy diet, mental stimulation, quality sleep, stress management and an active social life. The best practice principle for dementia prevention is strengthening each of the six pillars in daily life, this in turn contributes to a healthier brain



TABLE 13: SIX PILLARS IN DAILY LIFE TO PREVENT DEMENTIA

<sup>&</sup>lt;sup>101</sup> The National Dementia Strategy 2009 <a href="https://www.gov.uk/government/publications/living-well-with-">https://www.gov.uk/government/publications/living-well-with-</a> dementia-a-national-dementia-strategy

Alzheimer's: Six pillars of prevention <a href="http://www.cognitivehealthjh.org/perch/resources/pillars-of-brain-">http://www.cognitivehealthjh.org/perch/resources/pillars-of-brain-</a>

health.pdf

### 6.2. Health and Social Care Deliver and Commissioning

An integrated/ whole-systems approach to commissioning should be adopted meaning; developing integrated health and social care plans where possible as well as involving the public, people with dementia, their carers and families when commissioning services 103, 104.

NICE dementia quality standards also advocate an integrated approach to the provision of services as a central way of ensuring the delivery of high quality care to people with dementia. The table below shows the ten statements of the nice dementia quality standards that summarise the best practice principles to health and social care commissioning and delivery of dementia care.

### Table 14: THE TEN STATEMENTS OF THE NICE DEMENTIA QUALITY STANDARDS 105

- People with dementia receive care from staff appropriately trained in dementia care
- People with suspected dementia are referred to a Memory Assessment Service specialising in the diagnosis and initial management of dementia
- Newly diagnosed people with dementia and/or their carers receive information (written or verbal) about their condition, treatment and locally available support options
- People with dementia have an assessment and an on-going personalised care plan, agreed across health and social care, with a named care coordinator
- While they have capacity people with dementia have the opportunity to discuss and make decisions about the use of advance statements and preferred priorities of care
- Carers of people with dementia are offered an assessment of needs, if accepted, receive tailored interventions identified by a care plan to address those needs
- People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors
- People with dementia or people with suspected dementia using acute and general hospital inpatient services have access to a liaison service that specialise in the diagnosis and management of dementia and older people's mental health
- People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs
- Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia

#### The Care Act 2014

The aims of the Care Act include:

• Ensuring the care and support system is clearer, fairer-more consistent and transparent

• Promoting wellbeing-physical, mental and emotional wellbeing for all individuals

Enabling people to prevent, reduce or delay needs for care and support

NICE commissioning guidance (CMG48) Support for Commissioning Dementia Published April 2013 <a href="https://www.nice.org.uk/guidance/cmg48">https://www.nice.org.uk/guidance/cmg48</a>

NICE and Social Care Institute for Excellence (SCIE) commissioning guides [CMG48] Published date: April 2013 https://www.nice.org.uk/guidance/cmg48/

<sup>105</sup> NICE dementia Quality Standards <a href="https://www.nice.org.uk/guidance/qs1/chapter/quality-statement-10-respite-services-for-carers">https://www.nice.org.uk/guidance/qs1/chapter/quality-statement-10-respite-services-for-carers</a>

- Putting individuals in control of their lives so they can pursue opportunities and realise their potential
- Embedding and extending personalisation

The Act also provides a new national eligibility model, that aims to decrease disparity from place to place in the care, and support individuals receive. Additionally this minimum threshold for eligibility sets a guarantee of the minimum needs, which local authorities must meet in every area. The implications of the care act are that commissioners and providers will have to be cognisant of new safeguarding duties, a duty to integrate, cooperate and work in partnership between partners and Local authorities. As of April 2015, there are new rights for carers. More people with dementia will have access to an independent advocate to help make decisions about their care. Local Authorities will also have to provide more information to support people's wellbeing. The table below shows other Local Authority requirements under the Care Act 2014:

#### Table 15: LOCAL AUTHORITY REQUIREMENTS UNDER THE CARE ACT 2014

Local Authorities will be required to:

- Carry out an assessment of anyone who appears to require care and support, regardless of their likely eligibility for state-funded care
- Focus the assessment on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve
- Involve the person in the assessment and, where appropriate, their carer or someone else they nominate
- Provide access to an independent advocate to support the person's involvement in the assessment if required
- Consider other things besides care services that can contribute to the desired outcomes (e.g. preventive services, community support) and
- Use the new national minimum threshold to judge eligibility for publicly funded care and support.

### 6.3. Identification, Assessment and Diagnosis

If dementia is diagnosed early, more can be done to delay progression of the disease. The National Dementia Strategy aims for good-quality early diagnosis and intervention for all<sup>106</sup>. Commissioners should ensure sufficient memory services, which are based on best practice<sup>107</sup>. Examples of best practice include the Memory Services National Accreditation Programme (Appendix C). MSNAP standards can be used as a comprehensive process of review, through which services are supported to identify and address areas for improvement.

The overarching principles are those of equitable access to people with dementia and person-centred care. The standards currently centre on 'function', rather than any particular model of service delivery.

Diagnosis of dementia should be made only after a comprehensive assessment, which includes history taking, cognitive and mental state examination, physical examination and

The National Dementia Strategy 2009 <a href="https://www.gov.uk/government/publications/living-well-with-">https://www.gov.uk/government/publications/living-well-with-</a>

dementia-a-national-dementia-strategy
<sup>107</sup> Improving Dementia services in England- an interim report <a href="http://www.nao.org.uk/report/improving-dementia-services-in-england-an-interim-report/">http://www.nao.org.uk/report/improving-dementia-services-in-england-an-interim-report/</a>

other appropriate investigations<sup>108</sup>. Regarding the diagnosing of dementia in primary care an educational tool aimed at GPs and practice nurses<sup>109</sup> states that there is no single 'dementia test' and that cognitive decline, specifically memory loss alone, is not sufficient to diagnose dementia. There needs to be an impact on daily functioning. There must be evidence of decline over time (months or years rather than days or weeks) to make a diagnosis of dementia. Delirium and depression are the two commonest conditions in the differential diagnosis and there is often a challenge in differentiating delirium and dementia.

### 6.4. Early Intervention and Treatments

Access to treatment should be equitable, with no discrimination and people with dementia should be fully involved in making important decisions, providing valid consent in all aspects of their investigation, diagnosis and treatment. Commissioners should plan to increase access to behaviour and social interventions for people with dementia, which can reduce inappropriate use of antipsychotic drugs<sup>110</sup>. Good practice on pharmacological interventions includes that people with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme provided by a range of health and social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia. Antipsychotics should not be a first-line, the first line of management should be detailed assessment to identify any treatable cause of the behavioural and psychological symptoms of dementia (BPSD) such as delirium, pain, depression and good practice guidelines call for a reduction in the use of antipsychotic medication 111,112.

### 6.5. Living Well, Supporting Carers and Dementia Friendly Communities

The key objectives of the National Dementia Strategy include having a system where people with dementia:

- Know where to go for help
- Have a good understanding of what services they can expect
- · Get help early for problems with memory
- Get high quality and equitable care wherever they live and;
- Are involved in decisions about their care. Appendix A shows the seventeen objectives of the National Dementia Strategy.

Commissioning guidance recommend the commissioning of a range of respite services for carers of people with dementia, ensuring that carers assessment are routinely offered at the time of diagnosis and further ensuring that there is sufficient local capacity in services that

<sup>&</sup>lt;sup>108</sup> NICE: Supporting people with dementia and their carers in health and social care (CG42)

Dementia Revealed What Primary Care Needs to Know, Royal college of GPs version 2 http://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf

Support for commissioning dementia care NICE and Social Care Institute for Excellence (SCIE) commissioning guides [CMG48] Published date: April 2013<a href="https://www.nice.org.uk/guidance/cmg48/">https://www.nice.org.uk/guidance/cmg48/</a>

The use of antipsychotic medication for people with dementia: Time for action, An independent report commissioned and funded by the Department of Health, November 2009

https://www.rcpsych.ac.uk/pdf/Antipsychotic%20Bannerjee%20Report.pdf

NICE/SCIE. Dementia – Supporting People with dementia and Their Carers in Health and Social Care. London: NICE/SCIE, 2006.

can provide emotional, psychological and social support to carers<sup>113</sup>. A dementia friendly community is one "in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them"<sup>114</sup>.

Activities that make a community dementia friendly are encouraging people with dementia to be involved in their communities, challenging stigma, ensuring post-diagnostic support, responsive transport, physical environments, businesses, and services that are respectful and responsive to people with dementia. Additionally, adopting an approach based on inclusion that builds on what people can still do and the contributions they can still make. The figure below shows the range of services necessary to contribute to people with dementia living well with their condition.

#### Table 16: ESSENTIAL SERVICES NECESSARY FOR PEOPLE TO LIVE WELL WITH DEMENTIA

### Post diagnosis support

- Living with memory problems training/courses for people with dementia
- Support groups for people with dementia and their informal carers
- Counselling and emotional support and Independent advocacy
- Help to sustain employment for younger people with dementia
- Information on welfare benefits and concessions
- Assistance to help plan for the future e.g. powers of attorney, advance statements and wills
- Consideration of sheltered housing and extra care housing,
- Introduction of assistive technology

### **Community services**

- Practical assistance and other help in the home
- Help with housing issues
- Day services/day opportunities
- Short breaks/respite care
- Crisis response/rapid response assistance
- Intensive support and rehabilitation
- Household aids and adaptations, and assistive technology.

### **Continuing care:**

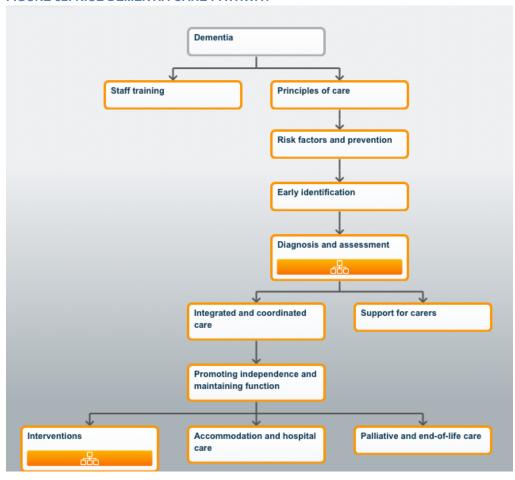
- Extra care housing
- Care homes
- Hospital care
- Palliative care
- · Social and cultural stimulation
- · Assistance with Challenging behaviour, and
- Continuing support for informal carers including bereavement support.

The figure below shows the NICE Dementia Pathway which brings together all NICE guidance, quality standards and materials and illustrates the essential elements to a dementia best practice pathway:

Supporting people with dementia and their carers in health and social care (CG42), Nov 2006 <a href="https://www.nice.org.uk/guidance/cg42">https://www.nice.org.uk/guidance/cg42</a>

Building dementia-friendly communities: A priority for everyone, The Alzheimer's society, August 2013

FIGURE 32: NICE DEMENTIA CARE PATHWAY<sup>115</sup>



### 6.6. Good Dementia Care in Hospital and Liaison Psychiatry

Hospitals have an important role to play in helping to identify patients with dementia. Government initiatives such as the Dementia Commissioning for Quality and Innovation (CQUIN) payments as an incentive to improve dementia care in hospitals have lead to improved identification of patients with dementia in acute hospitals. NICE guidelines state that people with suspected or known dementia using inpatient services should be assessed by a liaison service that specialises in the treatment of dementia and older people's mental health. NICE also states that care should be planned jointly by the trust's hospital staff, liaison teams, relevant social care staff, the person with suspected or known dementia and carers. The Royal College of Nursing RCN (now Nursing and Midwifery Council, NMC) made a commitment to the care of people with dementia in general hospitals and published five principles known as SPACE principles detailed in the figure below:

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<sup>&</sup>lt;sup>115</sup> NICE Dementia Pathway <a href="http://pathways.nice.org.uk/pathways/dementia">http://pathways.nice.org.uk/pathways/dementia</a>

#### Table 17: RCN SPACE PRINCIPLES OF CARE FOR PEOPLE WITH DEMENTIA IN HOSPITAL

- Staff needs to be informed, skilled and have enough time to care.
- Partners in care-family carers and friends are seen as partners in care, unless indicated otherwise by the person living with dementia.
- A dementia assessment will be offered to all those at risk, to support early identification and appropriate care
- Care plans will be person-centred, responsive to individual needs and support nutrition, dignity, comfort, continence, rehabilitation, activity and palliative care.
- Environments will be dementia friendly and support independence and well-being

Liaison psychiatry provides psychiatric treatment to patients attending general hospitals, whether they attend outpatient clinics, or are admitted to inpatient wards and deals with the interface between physical and psychological health. Liaison psychiatry is a critical service that should be integral to all acute hospitals. There is no guidance on a specific service model and there is great variation nationally on types of models adopted depending on need and population morbidity. The Joint Commissioning Panel for Mental Health (JCPMH)<sup>116</sup> emphasises that liaison psychiatry services should fulfil the minimum requirements. These include:

- Raising awareness of the importance of mental health
- Enabling general hospital staff to acquire basic skills of mental health assessment and treatment through education and training
- Assisting with the management of serious and complicated cases of mental disorder
- Championing the cause of older people with mental disorders in the general hospital

### 6.7. Reablement and Dementia

There is a dearth of research evidence on supporting people living with dementia through reablement. The SCIE however, recommends that people should not be excluded from reablement based on a dementia diagnosis but should be assessed based on their needs and strengths without prejudice about their potential to be 'reabled' 117. A reablement goal for most people living with dementia needs to be 'preserving and encouraging a more functional state' rather than achieving complete 'independence'. Outcomes might more appropriately focus on reducing social isolation, building routine, supporting the carer and learning to live well with dementia as opposed to significant reductions in the support required.

SCIE recommends that during planning support for people with dementia (including goalsetting), it is particularly important to see past their diagnosis and gain an in-depth understanding of the person for example their interests, past jobs or hobbies, their family context and the things that motivate them. Training on supporting people with dementia through reablement would usefully focus on recognising the signs and symptoms of dementia, tips for dealing with the potential complexities of helping someone with dementia

<sup>&</sup>lt;sup>116</sup> Guidance for commissioners of liaison mental health services to acute dementia and People with Learning Disabilities <a href="http://www.jcpmh.info/wp-content/uploads/jcpmh-liaison-guide.pdf">http://www.jcpmh.info/wp-content/uploads/jcpmh-liaison-guide.pdf</a>

<sup>117</sup> Maximising the potential for dementia reablement http://www.scie.org.uk/publications/guides/guide49/dementia.aspSocial

to dress, wash and bathe safely, the importance of maintaining familiar routines, the importance of offering help sensitively and dealing with challenging behaviour.

### 6.8. End of Life Care (EoLC)

A key commissioning priority should be supporting primary care to identify people with dementia and add them to palliative care registers when they approach the end of their lives<sup>118</sup>. The Alzheimer's society states that EoLC should be a key part of the dementia care plan<sup>119</sup>. Having EoLC covered in the care plan means the person with dementia will be able to specify where they would like to die and to ensure that they are treated with dignity. This topic needs to be broached sensitively and gradually after an individual has had an opportunity to come to terms with their diagnosis.

### 6.9. People with Learning Disabilities who develop Dementia

The overarching principle of best practice for people with learning disabilities it the principal of "reasonable adjustments". These adjustments entail training staff about what people with learning disabilities are likely to need. This is in line with the Disability Discrimination Act (DDA)<sup>120</sup>.

<sup>&</sup>lt;sup>118</sup> Support for commissioning dementia care NICE and Social Care Institute for Excellence (SCIE) commissioning guides [CMG48] Published date: April 2013 <a href="https://www.nice.org.uk/guidance/cmg48/">https://www.nice.org.uk/guidance/cmg48/</a>

<sup>&</sup>lt;sup>119</sup> End of Life Care. The Alzheimer's society

http://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=428 Accessed 15 April 2015

120 Disability Discrimination Act http://www.nidirect.gov.uk/the-disability-discrimination-act-dda

### 7. The Merton Dementia Strategy and local services

The Merton Dementia Strategy 2010-2015 and local implementation plan<sup>121</sup>.

The strategy was published following a baseline review of Dementia services incorporating the views of people with dementia and their carers. The overarching aims of the strategy included:

- Ensuring better knowledge about dementia
- Ensuring early diagnosis support and treatment for people with dementia, their families and carers and;
- Developing services to meet changing needs.

The gap analysis and priorities for investment identified as part of the baseline review are detailed in the table below:

### **Table 18: SUMMARY OF GAP ANALYSIS AND PRIORITIES**

- Provide comprehensive specialised accessible information and support for carers for all people with dementia.
- Increase the flexibility and responsiveness of respite care for people with dementia.
- Offer easily accessible and clearly sign posted memory assessment counselling, information, and advice services.
- Take account of the expansion of payments to carers, personal and self-directed support.
- Co-ordinate and increase the capacity and skills of hospital and CMHT teams that assess and support older people with dementia.
- Develop a range of low-level community based services that provide opportunities for social interactions.
- Develop services for people from Black and Minority Ethnic (BAME) groups.
- Develop an integrated intermediate care service to provide short-term intervention, promote independence and maximise functional skills.
- Develop services for younger people with dementia.
- Improve data sources that inform planning for people with dementia and improve data recording.
- Develop a joint work force development and training strategy.

The local implementation plan was refreshed annually between 2010-2015 and the objectives of the implementation plan included raising awareness of dementia, good quality early diagnosis support and treatment, good quality information, structured peer support, improving care in general hospitals and ensuring an informed and effective workforce in dementia care.

Some of the progress made since the strategy was published in 2010 includes:

- Closer joint working across health and social care because of the Better Care Fund
- A contract that was put in place in 2013 with the Alzheimer's Society for the Dementia Hub, which provides information and support for people with Dementia, their carers and families. Dementia Diagnosis rates have improved; the 67% target was reached in 2015
- The main acute trusts used by Merton residents Epsom and St Helier and St. Georges Hospital met their Dementia CQUIN targets in 2012/13

<sup>121</sup> Dementia – A Joint Commissioning Strategy for Merton 2010-2015, London borough of Merton, NHS Sutton and Merton and the Third Sector.

• A number of actions and work streams in the local dementia implementation plan are underway and the above only captures some of the progress made to date.

## Local services in Merton to support dementia care 122

The biggest issue for mental health services for people over the age of 65 is dementia. There is a range of services available in Merton for people with dementia and their carers provided by statutory and non-statutory providers.

#### NHS

The NHS provides medical diagnosis, treatment and management of dementia through primary care (GPs), secondary, tertiary and specialised services through the South West London and St. George's Mental Health NHS Trust. The Mental Health Trust also provides community support through a Community Mental Health Team (CMHT), which assesses and treats people with both dementia and functional mental illnesses such as depression, schizophrenia or bipolar disorder. The service operates:

- An intensive home treatment (IHTT) service to support people in their own homes over a crisis, as an alternative to hospital admission
- A Challenging Behaviour Service which works with nursing homes to help them review and deliver care to residents with challenging behaviour using cognitive approaches, and minimizing the need for psychotropic medication or admission to hospital
- There currently is no discrete Memory assessment service (MAS). The CMHT runs memory clinics at the Dementia Hub and at the Nelson Health Centre.

### **London Borough of Merton Adult Social Care (ASC)**

ASC provides a variety of services for people with mild to moderate dementia, who need additional social support and contact. Respite for carers is provided through non-specialist day centres. Other services provided by the council include:

Extracted from the Merton Mental Health Needs Assessment (MMHA) 2013-14. London Borough

of Merton Public Health

Table 19: BRIEF OVERVIEW OF ADULT SOCIAL CARE SERVICES FOR PEOPLE WITH DEMENTIA

SERVICE	BRIEF SERVICE OVERVIEW
Association of Crossroads	Provides practical support and respite care to carers
MASCOT Telecare	Mascot Telecare helps people to live safely, securely and independently in their own homes. Services include a personal alarm service that connects service users to help when they need it, bed or chair occupancy sensors, fall detectors, and property exit sensors
Direct Payments	Individuals can choose to receive payments from the council (called 'direct payments') to buy the services they need to meet their needs
Homecare	Provided through the Commissioning Brokerage Team (from various private agency providers). Home carers assist with a range of tasks to help people remain independent in their own homes. Support at home may be provided using Merton Council's in-house service or the services of a private agency
Equipment	Equipment is provided through the Merton Occupational Therapy (OT) Team
Meals-on-Wheels	The meals on wheels service is provided in partnership with a catering company and is available seven days a week for people who are unable to prepare or cook a hot meal for themselves. The meals meet dietary, religious and ethnic needs
Residential and Nursing Home permanent and respite placements	Residential and Nursing Home permanent and respite placements with Eltandia. There are also three other homes in the borough (Carter House, Woodlands, and Link House) that provide care for clients with mild dementia
Day Care – mainly in Woodlands and Eastways in borough day centres	Woodlands Day Centre is a service for older and vulnerable adults from the local community. Eastways day centre offers activities for clients during weekdays and working hours
Transport Services	Transport Passenger operations have a number of accessible vehicles to transport passengers in and out of the borough and to and from Day Centres

### **Merton Dementia Hub, Mitcham**

The Merton Dementia Hub is situated in Mitcham with additional outreach services held across the borough by the Alzheimer's Society. The Alzheimer's Society works in partnership with the Merton older peoples CMHT (Community Mental health Trust) Memory Clinic and provides a range of activities for people with dementia and their carers. The emphasis of the Dementia Hub is on early diagnosis improving prognosis promoting a dementia friendly borough, providing a weekly 'one stop shop' facility through a dedicated team. The services provided by the Alzheimer's Society include:

Table 20: SERVICES AT THE DEMENTIA HUB

SERVICE	BRIEF OVERVIEW		
Dementia Support Services (including living with Dementia and early diagnosis support)	Both Dementia Adviser Service (DAS) and Dementia Support Workers (DSWs) develop support plans with people and the DSWs continue with those who need more support to achieve their identified outcomes. Telephone and email support and home visits if required are also provided. The Dementia Advisor works predominantly with people with dementia and the Dementia Support Worker works predominantly with carers of people with dementia.		
Peer Support Service	This includes support groups for carers, people with dementia, and family members. They can also participate in a range of activities or just talk about dementia		
Information Services	The support includes details of local support and services. The information worker raises awareness and promotes the benefits of early diagnosis amongst professionals and the local community. This includes presentations to community groups and information provision in community settings such as libraries, supermarkets, local shops and places of worship.		
Workshops	<ul> <li>Carers Support and Information Programme (CrISP) entails providing training to carers through support and Information to help understand the condition, developing coping strategies and enable them to know sources of support.</li> <li>Singing for the Brain is a stimulating group activity, for people in the early to moderate stages of dementia and their carers, which can help with general well-being and confidence.</li> <li>Life After Diagnosis (LAD) support for people with a new diagnosis of dementia</li> </ul>		

### **Carers Support Merton: Provides support for Carers**

Carers Support Merton is a voluntary sector organisation that was set up in 1992 for the sole purpose of providing free and independent information, advice, support, advocacy and respite to carers in Merton. Their services include:

- Carers' Benefits and Income Maximisation
- Carers' Rights Training
- Advocacy
- Respite Activities
- Emotional Support to deal with anxiety, Stress and Low Mood
- Carers Cafes
- Social and Advice/Support Groups
- Health checks for Carers and drop In events

### 8. The Merton Dementia Service user and stakeholder voice

### The data collection methodology included:

- In-depth, semi-structured one-to-one interviews with some key providers (n=5). The
  key providers included the CMHT Psychiatrist, Adult Social Services Director, the
  Dementia Hub Service lead, and the CMHT service lead and the Merton CCG
  Dementia GP champion.
- A Stakeholder engagement event held at the Merton Dementia Hub with Commissioners and Providers.
- Two focus groups with Carers of people with dementia, one held at the civic centre and one held at the dementia Hub.
- A focus group held with people with dementia held at the Merton Dementia Hub. The total number of participants in the focus groups was 39.

#### Limitations

- The majority of people who attended the focus group for people with dementia were in the early to middle stages of dementia therefore their needs were not complex for them to have navigated across the dementia pathway or across a number of services. It was necessary and inevitable to have people in the early and middle stages of dementia in order to have a constructive discussion.
- There were no people with early onset Dementia in the focus but given that the estimated number of people with EOD in Merton (46) and that the focus groups occurred during working hours, this is not surprising.
- There was small representation of people of a BAME background (3/39), therefore the experiences of BAME people were captured to a limited extent.

### 8.1. Findings from the Stakeholder engagement event

The workshop was held on the 12<sup>th</sup> of March 2015 for Commissioners and Providers of dementia services in Merton at the Dementia Hub. The themes that emerged from the stakeholder engagement event were:

- i. The need for a change in strategic focus
- ii. Service gaps in Merton
- iii. Considerations for the future Dementia Strategy 2015-2020

### Theme 1: The need for a change in strategic focus

An overarching theme in the Commissioner and Provider stakeholder event was that significant progress had been made particularly around increasing diagnosis rates, closing the diagnosis gap and coping with the increase in service demand however, there was now a need to change the strategic focus to ensuring that the post –diagnostic support was of good quality. Areas for improvement given this proposed new direction of strategic focus were:

- Ensuring sufficient capacity of the CMHT
- Increasing capacity in Improving Access to Psychological Therapies (IAPT)
- Increasing capacity in Occupational Therapy
- **Developing stronger links between services**: There remains scope for improvement in relation to information sharing across organisational boundaries for

example when dementia patients are discharged from hospital their discharge letter may in some cases not state that they have dementia. There are difficulties in compatibility or sharing between different data systems for example some services use RIO and others use different systems. There is a need to continue to promote the services available at the Hub in order to increase referrals to the Dementia Hub from LBM Adult Social Care and from GPs. The Merton Dementia Action Alliance has been established, but needs a concerted effort now in order to grow it right across the borough bringing on board a diverse range of members.

### Theme 2: Service gaps in Merton

#### **Dementia CQUIN**

Acute Trusts had the option of discontinuing the Dementia CQUIN and St. Georges reported that it would be discontinuing the Dementia CQUIN. It is however redesigning older people's services and incorporating a Frailty Model and Acute Senior User's Unit (ASHU). This presents a local challenge to maintain the momentum of identifying people with dementia in Acute Trusts and ensuring they are appropriately referred on to the relevant service (which is the aim of the Dementia CQUIN).

### Social Service re-set up after hospitalisation

This is a barrier for people who have already been assessed by Social Services and are in receipt of a care package receiving seamless care particularly after a short stay in hospital. The Social Service re-set up after hospitalisation is different for Sutton and Merton patients in that in Sutton a care package can be resumed after 72 hours in hospital with out restarting the application process whereas in Merton the application process needs to be restarted

### Older person's psychiatric liaison resource in hospital

There is no older person's psychiatric liaison resource at both St. Georges and at Epsom and St Helier for Merton residents. There is a Psychiatric liaison service that covers all age groups and the resource dedicated to older people at St Georges hospital is only for Wandsworth residents, the resource for older people at Epsom and St Helier is only for Sutton residents leaving a clear gap for Merton older residents

### "Culturally appropriate" community activities for BAME

There are limited "culturally appropriate" community activities for BAME groups this was an expressed need by both commissioners and providers.

### Theme 3: Considerations for the future Dementia Strategy 2015-2020

### The Care Act 2014

A key future consideration is the Care Act 2014, which places a series of new duties and responsibilities on local authorities about care and support for adults. The personalisation agenda, which entails enabling individuals to have complete choice and control through receiving their own budget and deciding how they wish to spend it will have an impact on existing activities for people with dementia. Post-diagnostic supports needs to remain intact in light of influences from the personalisation agenda.

### Building and developing effective links with new service developments

Ensuring effective links with new service developments such as the Community Dementia Nurse Specialists (DNSs), Better Care Fund (BCF), Holistic Assessment and Rapid Intervention(HARI).

### 8.2. Findings from the focus groups with carers of people with dementia

There was generally positive feedback about the range of dementia services in Merton. The key themes that emerged from the stakeholder engagement event were:

- i. A need for more respite care and crisis response options
- ii. Misinformation on options for those who are self-funding
- iii. A perception of limited availability of General Practitioners
- iv. Carer Privacy
- v. Improved post diagnostic support, sources, and methods of communication
- vi. Difficulty of conversations about End of Life Care

### Theme 1: A need for more respite care and crisis response options

Carers felt that services tended to take a reactive response to support and that it took a crisis to get recognition or the right level of respite care. More than fifty percent of the participants reported that it took a crisis such as the person with dementia wandering off for the right level of support to be provided. They also expressed a need for greater flexibility of respite care provision

"It's either I ring 999 and mum get's sectioned which I absolutely fear or there is nothing else"

### Theme 2: Misinformation on options for those who are self-funding

There was a clear outlook that people with dementia who are self-funding have limited support particularly once they had had their community care assessment and were deemed not to meet the financial eligibility criteria because they owned property or had savings. It was expressed numerously that once someone was classified as self-funding then they "were on their own" and received little support in navigating the dementia pathway or understanding services available. It emerged that there were misconceptions that people who are self-funding are not able to carry out advanced care planning in relation to preferred place of care. These misconceptions were present among carers of people who were self-funding.

"Once they see that you are above the threshold-you're on your own"

"Everyone knows that you have to sell your house if you want to make any arrangements for End of Life Care"

### Theme 3: A perception of limited availability of General Practitioners

When discussing the topic area of who one calls for advice and information around the theme of living well with dementia of all 39 participants (carers and people with dementia) only one individual said their first port of call or the first person that comes to mind as a source on information on living well with dementia was their GP. This was followed by a discussion in which it was conveyed that it is difficult to get an appointment with one's GP and that the time is not enough to enable one to get advice. Both carers and people with dementia expressed the perception of GPs having limited availability.

### **Theme 4: Carer Privacy**

Contrary to the drive for person- centred care and involving the person with dementia in decisions about their care, carers expressed a need for time for a conversation between the carer and health and social care professional without the person who has dementia present. This was in order to allow for open discussions and accurate reporting of symptoms and to enable the professional to make an accurate assessment of the true level of need. Carers described having difficulty describing openly to health and social care professionals the extent of the memory problems or cognitive impairment of the person with dementia (a spouse or parent in most cases) as the person with dementia maybe in denial.

Theme 5: Improved post diagnostic support, sources, and methods of communication Carers expressed that it took a long time to understand the different services available in Merton and it was only possible after concerted and proactive effort. Although there is plenty of information in the form of booklets and leaflets available, understanding the range of services remains a challenge.

### Theme 6: Difficulty of conversations about End of Life Care

While considerable progress has been made with raising the profile of best practice and Merton has an EOLC strategy, no respondents stated that they had had this conversation about EoLC. The subject proved to be difficult and contentious as carers felt discussions around EOLC upset the people they care for and gave rise to challenging behaviour. The topic of death remains a taboo and conversations around dying and preferred place of care remain difficult for both the health and social care professionals.

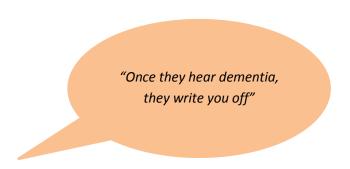
### 8.3. Findings of the focus groups with people with dementia

The key themes that emerged were:

- v. Stigma around Dementia is still a real concern
- vi. EoLC remains a sensitive, contentions and challenging area
- vii. Improved shared care monitoring arrangements with Primary care
- viii. Having no single individual to ring with any concerns of dementia

### Theme 1: Stigma around dementia is still a real concern

People with dementia felt that there was undoubtedly more awareness on the subject of dementia and more people with dementia, but that stigma associated with dementia was still highly prevalent and presented a challenge to people seeking help once they started experiencing problems with memory loss. Stigma was felt to impede early diagnosis and impede good quality care. There was a perception that health and social care professions (among other professionals) still see dementia as a condition were very little can be done.



#### Theme 2: EoLC remains a sensitive, contentions and challenging area

None of the 39 participants in all the focus groups (people with dementia and carers of people with dementia) reported having had conversations around preferred place of care. This theme emerged too in the two focus groups with carers. This could be potentially because the focus group with people with dementia was with people in the early stages of dementia and therefore they may not have reached a stage deemed clinically appropriate to have conversations around End of life Care. NICE guideline detailed in the best practice chapter highlight that End of life care planning and advanced care planning is an important part to the dementia care plan and should ideally be carried out while have enough cognitive functioning to decide their preferred place of care.

# Theme 3: Improved shared care monitoring arrangements with Primary care

There was expressed need for more contact with GPs and there was varied feedback on the people with dementia's experience with their GPs. The common strand on the varied accounts of experiences with their GPs (on how they got their diagnosis to how their get their regular prescriptions) included the perceived limited availability of GPs. There were some participants with a lot of praise for their GPs but getting an appointment was seen as a potential barrier to getting timely advice and information as well as post- diagnostic support.

#### Theme 4: No single individual to ring about concerns of dementia

It was an expressed that it would make navigating the dementia pathway easier if there was one person to call with all concerns or for advice. As there is an extensive range of information and information sources and services people with dementia engage with, some reported that they find it difficult to know who to contact when their needs changed for example, and that having a single individual to ring for help, and support would be particularly helpful. Whilst this may not be feasible given the range of needs that people with dementia have, this was a frequently expressed need and therefore incorporated into the needs assessment.

# 9. The Merton Picture, Gaps and Recommendations Summary

#### Where Merton is Doing Well

#### - Dementia continues to be an area of high profile

Dementia has long been a priority in Merton and continues to be an area of high profile and robust stakeholder engagement. There has been a local Dementia strategy 2010-2015<sup>123</sup> and an implementation plan in place and considerable progress has been made against the milestones. Examples include getting a contract for the Dementia Hub in place and, improved joint working. There was positive feedback on services on all the dementia services in Merton from all the stakeholder engagement (Commissioners, Providers, carers of people with dementia and people with dementia).

## - Increasing diagnosis rates

Merton has made substantial progress in identifying and diagnosing those with dementia. The Merton diagnosis rate was 72% as at March 2015 meaning that 28% of people with dementia remain undetected. The national target of 67% was exceeded.

## - Coping with a substantial increase in demand

The Community Mental Health Team (CMHT) has coped to date with increases in demand and caseload. From 2011-2015 there has been a 49.3% growth in the number of referrals for dementia to the CMHT and a 42.5% growth in number of patients seen by the CMHT. The service has maintained consistent performance in terms of waiting time targets (18 weeks Referral to Treatment (RTT) and assessed within 28 days).

# - There is a wide range of information sources for dementia advice and support.

The dementia Hub is admired, highly regarded as a success story and the first one of its type in the country<sup>124.</sup> The dementia Hub was nominated for two awards at the Local Government Chronicle awards in January 2015. The Dementia Hub was nominated for an HSJ Award and the staff at the Hub won the Alzheimer's Society National People's Award in the Pushing boundaries category. The availability of a wide range of services was a theme from all the focus groups as well as the Commissioner and Provider stakeholder event.

<sup>&</sup>lt;sup>123</sup> Dementia – A Joint Commissioning Strategy for Merton 2010-2015

Health Watch Merton, Alzheimer's Society open the new Dementia Hub in Mitcham http://www.healthwatchmerton.co.uk/news/alzheimer%E2%80%99s-society-open-new-dementia-hub-mitcham

# **Gaps and Recommendations**

TABLE 21: THE MERTON PICTURE, GAPS AND RECOMMENDATIONS SUMMARY

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS		
PREVENTION	<ul> <li>The biggest cohort is those with Alzheimer's disease (62%) then vascular dementia (17%), which is modifiable by improving vascular health</li> <li>The prevalence of dementia in BAME people aged 65 and over is 5.5%. This is a higher prevalence to the dementia (all ages, all ethnicities) in Merton of 0.9%. Targeted interventions towards BAME groups was a gap identified in the baseline review of the 2010 Local Dementia Strategy but little progress has been reported in this area</li> </ul>	1. Consider implementing prevention of vascular risk factors with a focus on atrial fibrillation  a. Consider targeted interventions at the BAME population as they have a higher prevalence of vascular disease and are more at risk of vascular risk factors  b. Interventions could align with physical health services such as diet and nutritional advice and consider joint working practices between stroke services and dementia services		
SOCIAL CARE DELIVER AND COMMISSIONING	<ul> <li>More people are being identified in primary care, the diagnosis rate is was 72% as at March 2015 and exceeded the national target of 67%</li> <li>From 2011-2015 there has been a 49.3% growth in the number of referrals for dementia to the CMHT and a 42.5% growth in number of patients seen by the CMHT</li> <li>People with Dementia and carers are not always aware of the different services and sources of information in Merton</li> <li>The proportion of referral from GPs and Social Workers to the Dementia Adviser and Dementia Support Worker at the Dementia Hub is smaller than 4% in both services.</li> <li>The provider landscape is changing due to the Better Care Fund (BCF), new MDT Locality teams, the Holistic Assessment Rapid Investigation (HARI) service, the Adult Social Care (ASC) Redesign and the new Community Dementia Nurses</li> </ul>	<ol> <li>Consider ensuring that there is sufficient capacity to meet with the increase in demand particularly in the Memory Assessment re-design that is underway in Merton, and all post-diagnostic support services. Also ensure that any service developments (in the Memory clinics) are in line with Memory Services National Accreditation Programme (MSNAP)<sup>125</sup> recommendations</li> <li>Consider effectively promoting the services at the Dementia Hub, raising the profile and developing strong links between existing services i.e.         <ol> <li>The Dementia Hub and GPs and the Hub and social workers</li> <li>The Dementia Hub and other Voluntary Sector organisations in Merton</li> <li>The Holistic Assessment Rapid Investigation (HARI) service and the New Community Dementia Nurses</li> </ol> </li> </ol>		
HEALTH AND SO	<ul> <li>Sufficient data capture on size and caseload in relation to dementia While ASCOF has a placeholder for the dementia indicator, local solutions will be required to ensure efficient data collection</li> <li>The data on dementia admissions with a primary or secondary admission of dementia was insufficient to compare the average length of stay (ALOS) between those with dementia and those without</li> </ul>	4. Consider improving information sharing across organisational boundaries and improving data collection on the size, protected characteristics 126, caseload and the costs in relation to people with dementia and their carers to inform planning and enable the assessment of equitable access. The specific areas in Merton include:  a. Acute care data on people with a primary or a secondary diagnosis of dementia and ensuring that people discharged from		

Memory Services National Accreditation Programme (MSNAP), Standards for Memory Services <a href="http://www.rcpsych.ac.uk/quality/quality/andaccreditation/memoryservices/memoryservicesaccreditation/msnapstandard">http://www.rcpsych.ac.uk/quality/quality/andaccreditation/memoryservices/memoryservicesaccreditation/msnapstandard</a> s.aspx

s.aspx

126 The protected characteristics in the Equality Act 2010 are Age, Gender/sex, Gender Reassignment, Disability, Marriage and civil partnership, Race, and Religion / belief

	THE DISTURE IN ACCUSA	DECOMMENDATIONS
	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
	- A key theme from the Commissioner and Provider stakeholder engagement event was the need for improved information sharing across organisational boundaries  - There is variation in relation to dementia	hospital have their dementia diagnosis in the discharge summary  b. Dementia Hub data capture on service user ethnicity in both the Dementia Advisor (DAS) and Dementia Support Worker (DSW) and age of carers who use the DSW service.  c. Adult Social Care service user data in the absence of ASCOF indicators  d. Regarding information sharing consider developing systems locally for sharing information across different information capture systems particularly considering those who do not have access to RIO 127
ASSESSMENT AND DIAGNOSIS, EARLY INTERVENTION AND TREATMENTS	diagnosis. The average diagnosis rate in East Merton is 57%, in Raynes Park is 78% and in West Merton the average is 68%.  The proportion of people with dementia (of all age groups) whose care plan has been reviewed in a face-to-face review with their GP in Merton is 83.6% 128  There is a perceived limited availability of GPs as sources of information expressed through the qualitative research by both carers and people with dementia  According to analysis of Primary Care data on indicators relating to dementia and key dementia risk factors there are some Merton GP practices with relatively 129  Lower diagnosis rates  Lower Face- to-face reviews of dementia patients  Higher proportions of GP registered older people (people aged 65 and over)  Higher hypertension and smoking prevalence (QOF)  In addition, higher levels of deprivation. (See Table 7)  These practices have been deemed to be requiring more targeted support with improving dementia care and prevention and they are located in Cricket Green, Lavender Fields, Wimbledon Village and Ravensbury.	a. Reducing variation in dementia diagnosis rates between GP practices and localities as this could lead to health inequalities b. Improving the face-to-face reviews of people with dementia carried out in Primary care.  c. Strengthening the role of primary care to ensure robust shared care monitoring arrangements for people with dementia and tackling the perceived limited availability of GPs  d. Consider a plan of action for more targeted support to the areas identified through the Primary Care mapping, these are located in Cricket Green, Lavender Fields, Wimbledon Village and Ravensbury.

An electronic service user Record system (QOF ID: DEM002) 2013/14 large In relation to other Merton GP Practices

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
EARLY INTERVENTION AND TREATMENTS	<ul> <li>The indicative number of people with early onset dementia in Merton in 2015 is 46 people 130. While the cohort is small their needs are complex</li> <li>There are more men than women with early onset dementia in Merton (i.e. people aged 30-64). In the younger age bands i.e. people aged 65 to 74, the dementia prevalence is higher in men than women</li> </ul>	6. Consider developing a programme for the identification and early intervention of dementia in people of working age.  a. To achieve economies of scale, consider developing pathways at a South West London sector level  b. Bearing in mind that in early onset dementia the rate is higher in men, consider developing programmes around encouraging men to come forward with their symptoms and not attributing them to stress. The programme could incorporate help to sustain employment and be linked with NHS Health Checks <sup>131</sup>
NDLY COMMUNITIES	<ul> <li>The dementia prevalence is higher in BAME populations in Merton. It is estimated that 332 people (aged 65 and over) from BAME groups have dementia in Merton in 2015</li> <li>There is substantial anticipated growth of 56% in people aged 65 and over from BAME groups from 2015-2025</li> <li>There are limited "culturally appropriate" community activities for BAME groups</li> </ul>	7. Consider sharing learning and good practice around dementia care for BAME populations. Also consider:  a. Develop "culturally appropriate" community activities for BAME groups b. Consider developing South West London Partnerships for BAME service developments
LIVING WELL WITH DEMENTIA, AND DEMENTIA FRIENDLY COMMUNITIES	- There was an expressed need for out of hours crisis support (particularly around challenging behaviour).	8. Consider improving the availability, flexibility and responsiveness of respite care for carers of people with dementia to enable people to stay in the community longer. As residential care represents the largest segment of the dementia care budget, better provision of community support both for people with dementia and carers is a cost-effective way to enable people to live at home for longer, thus reducing the significant costs of residential care
	- Stigma remains an issue for people with dementia as expressed in the focus group	9. Consider tackling dementia stigma through increased education to all stakeholders (i.e. Health and Social Care, Commissioners and Providers and the Voluntary Sector). Also consider developing a joint work force development and training strategy
TIVING W	<ul> <li>An overarching theme in the Dementia Commissioner and Provider Stakeholder engagement event was the need for a strategic shift from identification and diagnosis to ensuring good quality post- diagnostic support</li> </ul>	10. Developing a strategic shift from the emphasis of increasing identification and diagnosis rates to improving post-diagnostic support and enabling people to live well with dementia

POPPI 131 The NHS Health Checks programme is for adults in England aged 40-74 and checks circulatory and vascular health as well as assesses the risk of getting a disabling vascular disease.

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
	Adult Social Care users with Dementia	11. Consider:
LIVING WELL WITH DEMENTIA, SUPPORTING CARERS AND DEMENTIA FRIENDLY COMMUNITIES	- A crude direct comparison of the ethnic distribution of Merton borough in 2014 the ethnic distribution of all ASC service users with dementia in 2013/14 resident in Merton suggests that the Black and Asian ethnic groups with dementia are under represented in terms of ASC service access. In specific services:  In Nursing Care- the data is suggestive that the white ethnic group is considerably over represented, the black ethnic group is marginally under represented and the Asian ethnic group is considerably under represented In Direct Payments- the data is suggestive that the white ethnic group is markedly underrepresented, and Black and Asian people are marginally overrepresented In Residential Care and Home Care the data is suggestive that the white ethnic group is markedly over represented the black ethnic group is marginally under represented and the Asian ethnic group is markedly under represented. The data is suggests that there may be an issue regarding equitable access to ASC services for people with Dementia.  The Dementia Hub DAS and DSW users The Dementia Advisor Service (DAS) user data is suggestive that the 85 and over age group is under-represented and males aged between 65-74 are under-represented	a. Investigating further if there are access issues to Adult Social Care Services for the under-represented ethnic groups. b. Regarding the Dementia Hub consider increasing the reach on the Dementia Advisor Service (DAS) to people aged 85 and over and males aged between 65-74 and improving data capture on protected characteristics particularly ethnicity.
GOOD DEMENTIA CARE IN HOSPITAL AND LIAISON PSYCHIATRY	<ul> <li>There is no dedicated psychiatric liaison resource for older residents of Merton</li> <li>There is a Psychiatric Liaison Service that covers all age groups but the resource dedicated to older people at St Georges Hospital is only for Wandsworth residents; the resource for older people at Epsom and St Helier Hospital is only for Sutton residents leaving a gap of an older person's resource for Merton residents</li> </ul>	12. Consider a service development of a dedicated psychiatric liaison resource for older residents of Merton in the main acute trusts for Merton residents
GOOD DEM AND L	<ul> <li>Acute Trusts had the option of discontinuing the Dementia CQUIN and St. Georges reported that it would be discontinuing the Dementia CQUIN. It is however redesigning older people's</li> </ul>	13. Consider ensuring the momentum in the main acute trusts for Merton residents in identifying assessing and referring people with dementia in light of changes to the CQUIN scheme

	THE PICTURE IN MERTON & GAPS	RECOMMENDATIONS
	services and incorporating a Frailty Model and Acute Senior User's Unit (ASHU)	
GOOD DEMENTIA CARE IN HOSPITAL	- There is a need to further investigate discharge processes for those with Dementia admitted into hospital to ensure seamless care i.e. ensuring discharge letters include the dementia diagnosis and social service re-set up after brief hospitalisation (less than 72hours) to ensure this is in line with best practice (at the time of the research the latter point was raised as a theme)	14. Consider investigating further the discharge processes for those admitted into hospital with dementia. In order to ensure that they are in line with best practice and that people with dementia receive seamless care.
END OF LIFE CARE (EOLC)	<ul> <li>None of the participants (n=39) in the focus groups reported having had a conversation with health and social care professional on the subject of their preferred place of care at the end of their life</li> <li>There are misconceptions on how much advance care planning in End of Life Care (EoLC) a person with dementia can do particularly if they are self-funding</li> </ul>	15. Consider improving advanced care planning, conversations around preferred place of care and End of Life Care (EoLC) discussions between clinicians (Particularly in Primary Care) and dementia patients and their carers

# 10. List of Appendices:

APPENDIX A:	The Seventeen Strategic Objectives of the National Dementia Strategy			
APPENDIX B:	NICE Best Practice Principles			
APPENDIX C:	MSNAP Standards			
APPENDIX D:	The Prevalence of Learning Disabilities in Merton			
APPENDIX E:	Participants of the Focus Group with Carers demographic data			
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APPENDIX G:	Definitions from the Dementia Prevalence Calculator			
APPENDIX H:	The Demographic Data on the Participants of the Focus Groups with people with dementia			
APPENDIX I:	Data Sources and Descriptions (DPC elaborated)			
APPENDIX J:	Indicative Costs for Late Onset Dementia			
APPENDIX K:	Is there a relationship between deprivation and dementia underdiagnoses?			

## Appendix A: The Seventeen Objectives of The National Dementia Strategy

In 2009, the Department of Health (DH) published their national strategy<sup>132</sup>. It outlined 17 strategic objectives as shown below.

- Improving public and professional awareness and understanding of dementia
- •Good-quality early diagnosis and intervention for all
- •Good-quality information for those with diagnosed dementia and their carers
- Enabling easy access to care, support and advice following diagnosis
- •Development of structured peer support and learning networks
- •Improved community personal support services
- Implementing the Carers' Strategy
- Improved quality of care for people with dementia in general hospitals
- •Improved intermediate care for people with dementia
- •Considering the potential for housing support, housing-related services and telecare to
- •support people with dementia and their carers
- •Living well with dementia in care homes
- •Improved end of life care for people with dementia
- •An informed and effective workforce for people with dementia
- A joint commissioning strategy for dementia
- •Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers
- •A clear picture of research evidence and needs
- Effective national and regional support for implementation of the Strategy

<sup>132</sup> The National Dementia Strategy 2009 <a href="https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy">https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy</a>

# Appendix B: NICE Best Practice Principles 133

#### Table 22: NICE BEST PRACTICE PRINCIPLES ELABORATED

- People with dementia should not be excluded from any services because of their diagnosis, age or coexisting learning disabilities.
- Health and social care professionals should always seek valid consent from people with dementia.
- Health and social care managers should ensure that the rights of carers to receive an assessment of needs as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 are upheld.
- Health and social care managers should coordinate and integrate working across all agencies involved in the treatment and care of people with dementia and their carers.
- Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia.
- Memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia.
- People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop challenging behaviour should be offered an assessment at an early opportunity.
- Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training that is consistent with their roles and responsibilities.
- Acute and general hospital trusts should plan and provide services that address the specific personal and social care needs and the mental and physical health of people with dementia who use acute hospital facilities for any reason.

-

<sup>&</sup>lt;sup>133</sup>Support for commissioning dementia care NICE and Social Care Institute for Excellence (SCIE) commissioning guides [CMG48] Published date: April2013 https://www.nice.org.uk/guidance/cmg48/

# Appendix C: (MSNAP) Standards 134

The Memory Services National Accreditation Programme Standards cover the processes of assessment, diagnosis, pharmacological treatment and psychosocial therapies.

#### SERVICE PLANNING AND COMMISSIONING

- Health and Social Care Commissioners have formally commissioned memory services
- Health and Social Care Commissioners have in place a detailed analysis of the demographic and ethnic profile
  of their population, to assess needs and plan for current and future provision of services for the assessment
  and diagnosis of memory problems
- Health and Social Care Commissioners have undertaken a joint needs assessment and a review of the current service provision of services for the assessment and diagnosis of memory problems
- Health and Social Care Commissioners, in consultation with local partners, people with memory problems/dementia and carers, have a local integrated care pathway based on best practice, which includes referral to national or regional specialist centres and exit from the service, where appropriate
- People with memory problems/dementia and their carers are involved in service planning, developing and monitoring the service

#### **QUALITY ASSURANCE, RESEARCH AND SERVICE DEVELOPMENT**

- The memory service demonstrates that there is a commitment to on going quality improvement and research
- The memory service conducts audit and/or service evaluation on compliance with relevant guidelines, at least once every two years
- The memory service conducts audit and/or service evaluation on referrals to the memory service, at least once every two years
- The memory service conducts audit and/or service evaluation on adherence to guidelines around consent and assessing capacity, at least once every two years
- People with memory problems/dementia and their carers are asked about their experiences of using the service at least once a year, and their feedback has been used to improve the service
- The service provides people with dementia and their carers with information about opportunities to participate in local, national and international research, such as National Institute for Health Research (NIHR) portfolio studies or equivalent local bodies
- The service ensures that all people with dementia and their carers are offered the opportunity to register their interest in participating in research

#### **COMPLAINTS AND UNTOWARD INCIDENTS**

- All complaints and untoward incidents are dealt with in accordance with appropriate Trust rules and guidelines
- There are policies and procedures for managing complaints
- Information is provided for people with memory problems/dementia and their carers about how to make a complaint about any aspect of the service
- There is evidence of audit, action and feedback from complaints and suggestions

#### **SUPPORTING VULNERABLE PEOPLE**

• The memory service has systems and procedures to ensure the safety of vulnerable adults, in accordance with appropriate Trust rules and guidelines and relevant statutory guidance

• The service is compliant with statutory guidance on the safeguarding of vulnerable adults and children

<sup>&</sup>lt;sup>134</sup> Memory Services National Accreditation Programme (MSNAP), Standards for Memory Services http://www.rcpsych.ac.uk/pdf/MSNAP%20Standards%20Fourth%20Edition%202014r.pdf

## Appendix D: The Prevalence of Learning Disabilities in Merton

## **Learning disabilities and Dementia in Merton**

- People with a learning disability are at greater risk of developing dementia at a younger age. Studies have shown that one in ten people with a learning disability develop early onset Alzheimer's disease between the ages of 50 to 65<sup>135</sup>.
- According to a registered charity called Young Dementia UK<sup>136</sup> the numbers of people under 65 living with a learning disability and young onset dementia are growing. Whilst the health and social care sectors have some distinct pathways of care and support for learning disabilities in isolation, and likewise for dementia, how to support a person living with both is not historically well understood.
- The challenges that usually accompany the diagnostic process for a younger person who suspects that they may have dementia are greater for a person with a learning disability.

Early symptoms of dementia are often dismissed as they are masked by 'behaviours' which are associated with having a learning disability rather than developing dementia, and this is compounded by the idea that the person is likely to be 'too young' to develop dementia. Helping a person with a learning disability to understand a diagnosis of dementia is an immensely challenging task for the professionals who make that diagnosis, and the people who are supporting the person with a learning disability. Assuming an accurate diagnosis of dementia is made; deterioration can be rapid, often affecting other aspects of the person's life, such as mobility.

Young Dementia UK<sup>76</sup> claims that many learning disability services are not equipped to support a person with a learning disability and dementia. Additionally, this combined with the way in which many local authorities prefer to place people with dementia into specialist dementia units means that for a person in their 40's or 50's with a learning disability and dementia the only option for their future care is to move into a nursing home with people in their 70's, 80's and 90's.

Furthermore, Young Dementia UK claims that while many care homes specialise in dementia, few have the understanding needed to support a person who is also living with a learning disability, and often the person ends up with very little say in where they live. For some people with a learning disability who have potentially lived in the same support service for many years, sometimes more than half their lifetime, a move into a dementia specialist care home can lead to a very poor quality of life and may even hasten death.

The life expectancy for people with learning disabilities has improved markedly from 18.5 years in the 1930s to 66 years in the 1990s<sup>137</sup>. Given these improvements, the overall population with learning disabilities is steadily increasing and it has been predicted that the proportion of people with learning disabilities aged over 65 will have doubled by 2020, with

http://www.bps.org.uk/system/files/Public%20files/rep77\_dementia\_and\_id.pdf

<sup>&</sup>lt;sup>135</sup> http://www.youngdementiauk.org/living-learning-disability-and-young-onset-dementia

http://www.youngdementiauk.org/living-learning-disability-and-young-onset-dementia

over a third of all people with learning disabilities being over 50 years of age by that time 138. People with learning disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier age<sup>139</sup>. According to the British Psychological Society (BPS) guidance on dementia and learning disabilities, estimating prevalence rates of dementia can be problematic because of a number of methodological issues that include the diagnostic difficulties associated with dementia in a population that has pre-existing cognitive and functional impairments and the complexity of establishing accurate population samples of people with intellectual disabilities. There are no indicative values for people with learning disabilities in Merton. The figure below shows the prevalence of learning disabilities in Merton in people aged 25 and over.

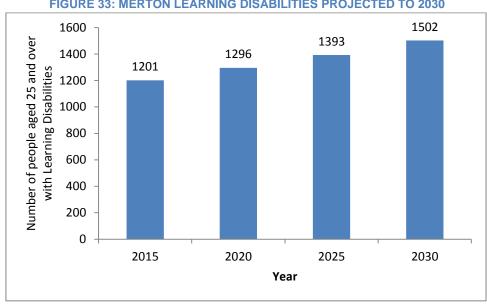


FIGURE 33: MERTON LEARNING DISABILITIES PROJECTED TO 2030

Source: PANSI and POPPI

<sup>&</sup>lt;sup>138</sup> Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability services. Mental Retardation, 38, 276-88.

<sup>139</sup> The British Psychological Society (BPS) Dementia and People with Intellectual Disabilities Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop http://www.bps.org.uk/system/files/Public%20files/rep77 dementia and id.pdf

# Appendix E: Participants of the Focus Group with Carers demographic data (n= 28)

Number, (percentage to the nearest whole number)

Religion	Ethnicity of Carer	Employment status	Relationship to person with
None-1(4%) Buddhist Catholic-4 (14%) Christian-18 (64%) Hindu Jewish Muslim- 2 (7%) Other- 2 (7%) Not stated -1(4%)	White British- 23 (82%) Asian British- 1(4%) Indian Pakistani Bangladeshi Any other Asian background Black Caribbean Black African Black British -1(4%) Any other Black background Prefer not to say Chinese Other-2 (7%) Not stated- 1(4%)	I am employed for wages - 3 (11%) I am Self-employed I am out of work but not currently looking for work I am a homemaker I am a student I am retired – 20 (71%) I am unable to work- 2 (7%) Other- 3 (11%)	dementia  My spouse- 8 (29%)  My Mother- 11 (39%)  My Father- 4 (14%)  My Sister - 1(4%)  My Brother  Other-4 (14%)
How old are you?  18-29 30-39 40-49 50-55 – 4(14%) 56-59-6(21%) 60-69- 8(29%) 70-79- 10 (36%) 80+ Not stated	Gender  Male -6 (22%) Female -21 (75%) Prefer not to say -0% Not stated- 1(4%)	Parental (or other carer responsibility)  I have No Children–4(14%) I have children <sup>140</sup> that I care for - 11 (39%) I have grandchildren that I care for 3 (10%) I have elderly parent(s) that I care for-3 (10%) Not stated – 7 (25%)	At what stage of dementia is the person you care for?  Early - 12 (43%) Middle— 10 (36%) Late - 5(18%) Not stated-1 (4%)
What is the age of the person you care for 18-29 30-39 40-49 56-59- 2 (7%) 60-69- 4 (14%) 70-79 -12 (43%) 80 and over – 10 (36%) Not stated	Where do you live in Merton?  East Merton- 12 (43%) West Merton – 7 (25%) Raynes Park -6(21%) Not stated - 3 (10%)		

<sup>140</sup> Children are not necessarily below the age of 18

# Appendix F: Participants in the Focus Groups With People With Dementia (n=11)

# Demographic data

Religion	Ethnicity	How old are you?	Gender	
Catholic Christian-7 (64%) Hindu Jewish Muslim-1(9%) Other-1(9%) Not stated-1(9%)	Other- 2 (18%) Not stated-1 (9%)  50-55 56-59-1 (9%) 60-69-1 (9%) 70-79-8 (73%)		Male 5 (45%) Female6 (55%) Prefer not to say Not stated	
What is the age of the person who cares for you?  56-59-5 (45%) 60-69-3 (27%) 70-79 - 80 and over Not stated-3 (27%)	At what stage of dementia are you?  Early – 9 (82%) Middle-1(9%) Late – 0 Not stated-1(9%)		What is you marital status?  Single - 2 (8%) I am married 4 I have a domestic Partner-1(9%) I am widowed 4 (36%) Other	

Number, (percentage to the nearest whole number)

#### Appendix G: Definitions from the Dementia Prevalence Calculator

Prevalence is the overall number of people with a condition at a single point in time.

# What is the Dementia Prevalence Calculator (DPC)?

Using Dementia UK (2007) figures for prevalence of dementia, the calculator:

- Applies these figures to a General Practice's registered patient population, by age and by Gender;
- In order to estimate local prevalence, the tool distinguishes between the patient population in the community, and those patients living in care homes;
- It considers prevalence at different phases of the disease (mild, moderate, severe), and by age group;
- It compares numbers on dementia registers with numbers of patients registered for comorbid conditions, such as cardiovascular disease, in order to inform case finding;
- It aggregates general practice data at the level of Clinical Commissioning Group
- Using prevalence data and the most recent Quality Outcomes Framework data (QOF DEM1), to allow the user to benchmark, and set trajectories for improvement in diagnosis rates;
- Based on local trajectories for improvement, CCGS may determine a quantified ambition
- For improvement in its average diagnosis rate, year-on-year

#### **DPC** definitions:

- **Prevalence-** The expected or predicted number of people with dementia.
- **True or actual prevalence** The number of people in the population who actually have dementia
- **Local prevalence-** the expected number of people with dementia in the local area, adjusted through the DPC Tool, weighted by number of care home places.
- Prevalence rate or prevalence proportion: The expected or predicted prevalence as a percentage of population. This is point prevalence, i.e. the percentage of population with dementia at a point in time.
- Diagnosis -The number of people detected in the population that have dementia.
   Diagnosis is the same as detection. (The number of people diagnosed with dementia is captured via the Department of Health Primary Care Quality and Outcomes Framework (DEM1).
- **Diagnosis rate** Diagnosis as a percentage of prevalence. This is the same as the detection rate.
- Diagnosis gap Prevalence rate minus diagnosis

Dementia diagnos	sis rate
Statistic:	Ratio
Time period:	Position as March 2015
Age group:	All ages
Description:	The estimated dementia diagnosis rate calculated as the ratio of the number of people on a Quality and Outcomes Framework GP practice dementia register to the estimated number of people with dementia (from the NHS England Dementia Prevalence Calculator) by Clinical Commissioning Group of GP registration, October 2014
Data source:	Numerator: The Quality and Outcomes Framework. Copyright © re-used with the permission of the Health and Social Care Information Centre. All rights reserved. Denominator: NHS England Dementia Prevalence Calculator The NHS England Primary Care Web Tool, Dementia Module.
Coding scheme use	d:
Numerator:	The numbers of people on the dementia register in the Quality and Outcomes Framework (QOF).
Denominator:	Estimated prevalence number. Dementia prevalence rates published in Dementia UK report (2007), adjusted for general practice register patient numbers, and numbers of general practice patients in care homes (Adjusted National Dementia Prevalence, NHS England Dementia Prevalence Calculator v3, 2013).
Methodology:	Numerator divided by denominator expressed as a ratio. The denominator is calculated by applying estimated dementia prevalence rates to GP practice registered list sizes and adjusted for age and gender. A further adjustment is made based on the numbers of patients within the practice list, living in residential care settings, recognising the higher prevalence of dementia in these settings. CCG values are equal to the sum of practice values within the CCG.
Source locations:	http://www.hscic.gov.uk/catalogue/PUB15751
www.primarycare.r	nhs.uk

# Appendix H: Indicative Costs For Late Onset Dementia (Those Aged 65 And Over)

The number of people aged 65 and over expected to have dementia in 2015 as projected by POPPI is multiplied with the average cost of late onset dementia per person £25, 472<sup>141</sup> This is shown in the table below and gives indicative costs in excess of £45 million pounds. This gives higher costs than the first model as this is the costs excluding those with early onset dementia.

FIGURE 34: INDICATIVE COSTS OF LATE ONSET DEMENTIA IN MERTON

Cost per person with late onset dementia	£25,472
POPPI number of people in Merton (aged 65+) with dementia in 2015	1782
Indicative costs of Late Onset Dementia in Merton	£45,391,104

Source: Knapp and Prince Costs (for 65+) applied to POPPI Merton dementia prevalence in those aged 65+

Knapp, M. & M. Prince. 2007. Dementia UK – A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (LSE and King's College, London) http://alzheimers.org.uk/site/scripts/download\_info.php?fileID=2

# Appendix I: Early Onset Dementia in Merton by sex and Growth from 2015-2030

The figure below shows the indicative number of cases of Early inset Dementia in Merton in 2015 by sex and shows that there are more men than women.

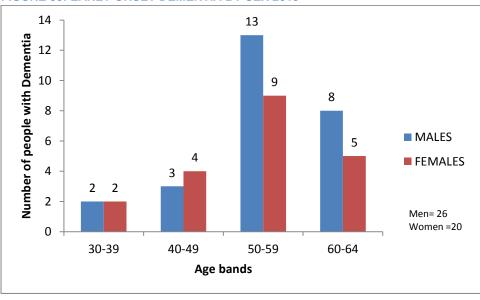


FIGURE 35: EARLY ONSET DEMENTIA BY SEX 2015

Source: PANSI

The growth rate in early onset dementia in the next fifteen years (2015-2030) is 34% in men, 25% in women

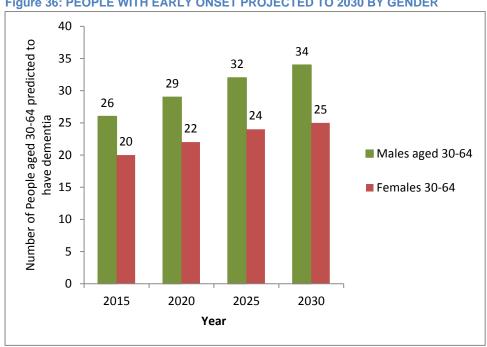


Figure 36: PEOPLE WITH EARLY ONSET PROJECTED TO 2030 BY GENDER

Source: PANSI

# Appendix J: Distribution of ASC service Users by deprivation Quintile

FIGURE 37: MERTON ASC SERVICE USERS BY DEPRIVATION QUINTILE 2013/14

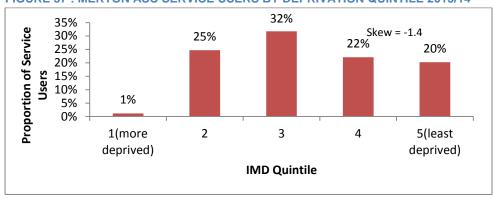


FIGURE 38: DISTRIBUTION OF ASC USERS BY IMD QUINTILES

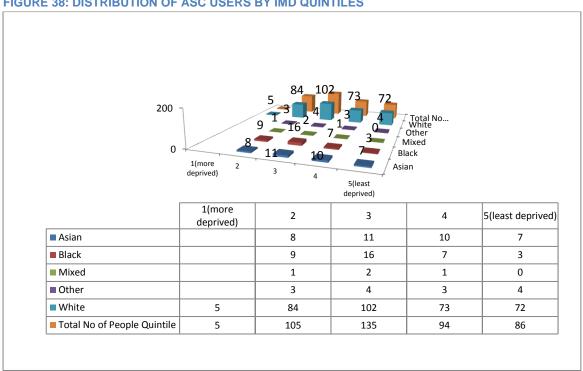


TABLE 23: ASC SERVICE USERS BY IMD QUINTILE

	Asian	Black	Mixed	Other	White	Total No of People in Quintile
1(more deprived)					5	5
2	8	9	1	3	84	105
3	11	16	2	4	102	135
4	10	7	1	3	73	94
5(least deprived)	7	3	0	4	72	86
SKEW	0	0.8	0	0	-1.6	-1.4

# APPENDIX K: PRIMARY CARE MAPPING OF AREAS OF HIGHER RISK

TABLE 24: QOF INDICATORS USED TO IDENTIFY PRIMARY CARE AREAS FOR TARGETING

QOF indicator	Description	Value type
DEM002: Dementia care has been reviewed last 12mths	The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months	% Proportion
Hypertension: QOF prevalence (all ages)	Estimated prevalence of hypertension (all ages)	% Proportion
GP patient survey: smoking prevalence	Percentage of all respondents to the question "Which of the following best describes your smoking habits?" who answered "Occasional smoker" or "Regular smoker".	% Proportion
CVD-PP001: new hypertension patients, age 30-74, with CV risk assessment >=20% treated w. statins	In those patients with a new diagnosis of hypertension aged 30 or over and who have not attained the age of 75, recorded between the preceding 1 April to 31 March (excluding those with pre-existing CHD, diabetes, stroke and/or TIA), who have a recorded CVD risk assessment score (using an assessment tool agreed with the NHS CB) of ≥20% in the preceding 12 months: the percentage who are currently treated with statins, NICE 2011 menu ID: NM26	% Proportion
CVD-PP001: new hypertension patients, age 30-74, with CV risk assessment >=20% treated w. statins	In those patients with a new diagnosis of hypertension aged 30 or over and who have not attained the age of 75, recorded between the preceding 1 April to 31 March (excluding those with pre-existing CHD, diabetes, stroke and/or TIA), who have a recorded CVD risk assessment score (using an assessment tool agreed with the NHS CB) of ≥20% in the preceding 12 months: the percentage who are currently treated with statins, NICE 2011 menu ID: NM26. Proxy for primary prevention of CVD	% Proportion
IMD Quintile	The average deprivation score for the registered population by GP Practice, calculated by attributing each registered patient to the IMD score of the LSOA in which they usually reside. The IMD scores calculated per GP Practice demonstrate a level of need of the population served by the GP Practice, which is a better indication of need than merely the location of the GP Practice.	Quintile 1-5 (1 most deprived, 5 least deprived)

# MERTON GP PRACTICES INDICATORS FOR DEMENTIA CARE AND DEMENTIA RISK FACTORS

Practice Code	Face to face reviews, (proportio n %)	Diagnosis rate%, (proportion %)	Proportion of people >65, (proportion %)	Hypertension QOF prevalence 13/14 (proportion %)	Estimated smoking prevalence (QOF) 13/14 (Proportion %)	CVD-PP001: new hypertension patients, age 30-74, with CV risk assessment >=20% treated w. statins	IMD Quintile	
Y02968	100%	27%	6%	9%	24.5%	33.3%	3	
H85110	75%	43%	13%	12%	19.7%	100.0%	2	
H85070	75%	43%	9%	10%	12.9%	50.0%	2	
H85090	75%	54%	10%	12%	19.3%	66.7%	2	
H85029	91%	54%	11%	14%	17.5%	60.0%	3	
H85038	69%	63%	14%	14%	21.7%	28.6%	3	
H85033	82%	65%	12%	12%	20.3%	63.6%	3	
H85037	83%	66%	14%	11%	18.8%	90.9%		
H85035	81%	72%	12%	13%	16.8%	100.0%	3	
H85078	65%	80%	14%	16%	20.7%	62.5%	2	
H85072	62%	36%	PRACTICE MERGED					
H85656	67%	51%	9%	9%	14.9%	-1.0%	5	

Practice Code	Face to face reviews, (proportio n %)	Diagnosis rate%, (proportion %)	Proportion of people >65, (proportion %)	Hypertension QOF prevalence 13/14 (proportion %)	Estimated smoking prevalence (QOF) 13/14 (Proportion %)	CVD-PP001: new hypertension patients, age 30-74, with CV risk assessment >=20% treated w. statins	IMD Quintile
H85026	68%	55%	9%	7%	8.9%	60.0%	5
H85016	87%	67%	17%	13%	17.7%	60.0%	
H85051	89%	86%	7%	8%	13.8%	46.2%	5
H85076		92%	17%	16%	16.5%	71.4%	
H85101	78%	97%	13%	11%	14.9%	61.1%	5
H85020	85%	144%	13%	9%	10.2%	71.4%	5
H85112	73%	20%	9%	8%	7.2%	100.0%	5
H85027	74%	53%	19%	10%	9.0%	33.3%	4
H85649	72%	57%	7%	10%	21.9%	71.4%	4
H85028	76%	76%	10%	8%	13.3%	100.0%	4
H85092	78%	81%	9%	8%	14.8%	50.0%	3
H85634	83%	89%	6%	6%	20.4%	61.5%	3
H85024	75%	90%	10%	12%	20.1%	50.0%	2

# MATRIX SHOWING GP PRACTICES THE FREQUENCY AT WHICH PRACTICES APPEAR ON THE LOST FOR HIGHER RISK AREAS FOR TARGETING

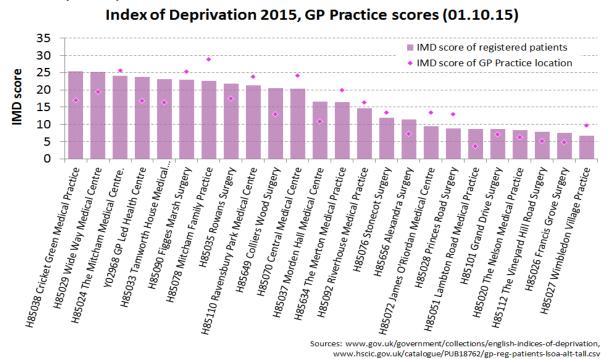
Practice Code	Number of times in lowest third	Lower Diagnosis Rates	Lower Face to face reviews	Higher Proportion of people >65	Higher Hypertension QOF prevalence 13/14 (proportion %)	Higher Estimated smoking prevalence (QOF) 13/14(proportion %)	IMD Quintile 1 (more deprived), 5 (least deprived)	CVD-PP001: new hypertension patients, age 30-74, with CV risk assessment >=20% treated w. statins (den.incl.exc.) (Proportion %)
H85038	6		✓	<b>✓</b>	✓	✓	✓	✓
H85024	5		✓		✓	✓	✓	✓
H85078	5		✓	✓	✓	✓	✓	
H85090	4	✓			✓	✓	✓	
H85027	4	✓	✓	✓				✓
H85110	4	✓				✓	✓	
Y02968	4	✓				✓	✓	✓
H85029	3	✓			✓		✓	
H85656	3	✓	✓					✓
H85072	3	✓	✓					✓
H85033	3				✓	✓	✓	
H85070	2	✓						✓
H85112	2	✓	✓					
H85649	2		✓			✓		
H85016	2			✓	✓			
H85076	2			✓	✓			
H85035	2				✓		✓	
H85026	1		$\checkmark$					

Practice Code	Number of times in lowest third	Lower Diagnosis Rates	Lower Face to face reviews	Higher Proportion of people >65	Higher Hypertension QOF prevalence 13/14 (proportion %)	Higher Estimated smoking prevalence (QOF) 13/14(proportion %)	IMD Quintile 1 (more deprived), 5 (least deprived)	CVD-PP001: new hypertension patients, age 30-74, with CV risk assessment >=20% treated w. statins (den.incl.exc.) (Proportion %)
H85020	1			✓				
H85037	1			✓				
H85101	1			✓				
H85634	1					✓		_
H85051	1							✓

## How the IMD Quintile was calculated for each practice:

Applying the ID2015 scores to the GP registered NHS Merton CCG population (as of 01.10.15), weighted average score = 15.14

The figure below shows the average deprivation score for the registered population by GP Practice, calculated by attributing each registered patient to the IMD score of the LSOA in which they usually reside.



The IMD scores calculated per GP Practice in the figure above may help demonstrate a level of need of the population served by the GP Practice, which is a better indication of need than merely the location of the GP Practice itself (represented in the figure above by the small diamond). Approximately half the GP Practices are located in LSOAs less deprived than the areas from which the registered population is drawn.