

# Dementia

---

*A Joint Strategic Needs Assessment (JSNA) Report for  
Hammersmith and Fulham    Kensington and Chelsea    Westminster*

July 2015

[www.jsna.info](http://www.jsna.info)

## **This report**

This needs assessment on dementia is designed to inform commissioning intentions for Hammersmith and Fulham, Kensington and Chelsea, and Westminster, that takes account of national and local policy, the North West London strategic approach to dementia and guidance.

Information has been collected from a variety of sources including audit, relevant policy and research as well as local data provided by stakeholders, providers, service users and carers. This evidence has been analysed to identify gaps and solutions and forms the basis of the recommendations outlined in Chapter 1.

## **Authors and contributors**

This report was written by Paula Arnell, Colin Brodie, Dan Lewer, Jessica Nyman, Andrew Rixom, and Neha Shah.

## **Acknowledgements**

We would like to thank the Dementia JSNA Task and Finish Group for their contributions to the needs assessment and developing the recommendations:

- Karen Bradshaw
- Lisa Cavanagh
- James Hebblethwaite
- Clare Lyons-Collins
- Juliet Ogbechie
- Sarah Richardson
- Malcolm Rose
- Margarita Russell
- Heather Tarrant
- Trish Welton
- Viv Whittingham
- Julie Willoughby

The following agencies have provided information and feedback during the development of this JSNA and the authors would like to thank all those who contributed for their input: Adult Social Care, Adults Joint Commissioning Team, Age UK, Central London Clinical Commissioning Groups, Hammersmith and Fulham Clinical Commissioning Group, Healthwatch, Imperial Healthcare NHS Trust, Mental Health Joint Commissioning Team, Open Age, Public Health Shared Services, West London Clinical Commissioning Group.

## CONTENTS

<b>1</b>	<b>Executive Summary .....</b>	<b>6</b>
1.1	Purpose of the JSNA.....	6
1.2	Key themes of the JSNA .....	7
1.3	Recommendations .....	8
<b>2</b>	<b>Background .....</b>	<b>13</b>
2.1	National strategy and policy drivers .....	13
2.2	National guidelines and standards .....	17
2.3	Relation to commissioning.....	18
<b>3</b>	<b>About Dementia .....</b>	<b>19</b>
3.1	What is dementia? .....	19
3.2	Types of Dementia .....	21
	Early-onset dementia.....	21
3.3	Risk factors for dementia.....	22
3.4	Impact of dementia.....	24
	Living with dementia .....	24
	Impact on carers .....	24
	The cost of dementia .....	25
	Co morbidities.....	26
3.5	National prevalence of dementia .....	28
	Uncertainty about prevalence .....	28
3.6	Incidence of dementia .....	29
3.7	Dementia and mortality.....	30
3.8	Ethnicity and dementia.....	32
3.9	Dementia and people with learning disabilities .....	32
<b>4</b>	<b>Dementia in our local population.....</b>	<b>35</b>
4.1	Estimated prevalence of dementia.....	35
4.2	Diagnosed prevalence of dementia .....	36
4.3	Estimated incidence of dementia .....	39
4.4	Unpaid Care .....	40
4.5	Local Audit .....	41
	Number, gender and age group of audited cases .....	41
	Time in contact with service .....	41
	Ethnicity .....	41
	Accommodation .....	42
	Level of support .....	42
	Carer availability .....	43
	Dementia type .....	43
	Care Homes.....	44
<b>5</b>	<b>Dementia services and asset mapping .....</b>	<b>47</b>
5.1	Local service cohesion .....	52
	Memory services: .....	52
	Complexity of services: .....	53
	Collaborative work:.....	53
	Communications:.....	53
	Liaison psychiatry: .....	53
5.2	Use of services – the national picture.....	55
	Hospitals .....	55
	Other health services .....	57
	Adult Social Care .....	57

<b>6</b>	<b>Views of people with dementia and their carers .....</b>	<b>59</b>
6.1	National Context .....	59
6.2	The Local Context.....	62
	Day centre.....	62
	Diagnosis.....	62
	Memory Cafés.....	62
	Care homes and hospitals.....	63
	Care and support .....	63
	Areas for improvement .....	63
	Carer satisfaction from the ASC Carers Survey.....	63
	Carer's issues from survey .....	65
	What helped most or what could change: .....	65
<b>7</b>	<b>Review of evidence and models of care .....</b>	<b>66</b>
7.1	Evidence of what works .....	66
	Prevention of dementia .....	66
	Future developments in prevention of dementia .....	66
	Management and care of people with dementia .....	67
	Living well with dementia .....	68
	Dementia friendly communities .....	69
	Peer support and befriending services .....	70
	Assistive technology (AT) .....	72
	Support for carers of people with dementia .....	74
	Respite Care.....	75
7.2	Models of care .....	76
	Integrated Care Models .....	76
	8 Pillars Model .....	76
	Gnosall primary-care based memory clinic .....	76
	Dual frailty ward and delirium recovery programme .....	77
<b>8</b>	<b>References .....</b>	<b>79</b>
<b>9</b>	<b>Appendices .....</b>	<b>84</b>
9.1	Appendix A: RAG Rating of local assets (read across two pages) .....	84
9.2	Appendix B: NICE Priorities for Implementation .....	93
9.3	Appendix C: Local audits of dementia .....	95
	Number, gender and age group of audited cases .....	95
	Time in contact with service .....	96
	Ethnicity and dementia.....	96
	Dementia type .....	97
	Accommodation .....	97
	Accommodation and service use comparison .....	98
9.4	Appendix D: Dementia Care Qualitative Analysis Summary .....	100
	Objective of report .....	100
	How diagnoses are made.....	100
	Factors affecting diagnosis rates .....	100
	Service cohesion .....	100
	Communication .....	101
	Escalation of care.....	101
	Interface between medical and psychiatric care .....	101
	Quality of care .....	102
	Attitudes and environment .....	103
	Support for carers.....	103
	Quality of life .....	103
	Demographics.....	103
9.5	Appendix E: Six Paths to a Good Life with Dementia.....	104

## Figures

<b>Figure 1:</b> National Dementia Strategy objectives.....	13
<b>Figure 2:</b> Quality Standards .....	14
<b>Figure 3:</b> Number of people in the UK with dementia subtypes, thousands (Kings College London & London School of Economics, 2007) .....	21
<b>Figure 4:</b> Estimated breakdown of costs of dementia for the UK, 2013 (Kings College London & London School of Economics, 2014) .....	26
<b>Figure 5:</b> Survival Curves for people with dementia (red) and without dementia (blue) by age at diagnosis, with 95% confidence limits .....	31
<b>Figure 6:</b> Comparison of dementia prevalence rates for people with learning disabilities and general population (Dodd et al., 2015) .....	33
<b>Figure 7:</b> Estimated numbers with dementia aged 65 years and older by borough.....	35
<b>Figure 8:</b> Estimated numbers with dementia aged 85 years and older by borough.....	36
<b>Figure 9:</b> Cases of dementia known to GPs (QoF prevalence), by CCG.....	37
<b>Figure 10:</b> Expected number of new case of dementia in the population each year by borough .....	39
<b>Figure 11:</b> Clinicians perspectives 2.....	40
<b>Figure 12:</b> Proportion of dementia clients living in a Care Home in Framework I audit .....	42
<b>Figure 13:</b> Care home location of ASC clients in care homes known to have dementia.....	44
<b>Figure 14:</b> Number of permanent admissions to care homes in 65+ age group per 100,000 aged 65+ from ASC Outcomes Framework .....	46
<b>Figure 15:</b> Dementia Service Pathways .....	47
<b>Figure 16:</b> Range of support provided locally (key below) .....	48
<b>Figure 17:</b> Clinicians perspectives 3.....	54
<b>Figure 18:</b> Assessments of people with dementia in hospital.....	56
<b>Figure 19:</b> Proportion of carers assessed who are caring for someone with dementia .....	64
<b>Figure 20:</b> Carers quality of life score (out of 12) – for all carers and those caring for someone with dementia .....	64
<b>Figure 21:</b> Carers satisfaction score (extremely and very satisfied) – for all carers and those caring for someone with dementia .....	64
<b>Figure 22:</b> Clinicians’ perspectives 4.....	72
<b>Figure 23:</b> Delirium Recovery Programme (DRP): Pilot study of Cognitive Enablement at Home following hospital admission .....	77
<b>Figure 24:</b> Clinicians perspectives 5.....	78
<b>Figure 25:</b> Location of Adult Social Care clients recorded as having dementia (From Adult Social Care) .....	97
<b>Figure 26:</b> Location and numbers of Adult Social Care clients in Care homes in the rest of London (from Adult Social Care) .....	98

## Tables

<b>Table 1:</b> Themes of Dementia JSNA.....	7
<b>Table 2:</b> Recommendations.....	8
<b>Table 4:</b> Risk and preventative factors for dementia .....	23
<b>Table 5:</b> Estimated local cost of dementia care in the three Boroughs .....	26
<b>Table 6:</b> Consensus estimates of the population prevalence of late onset dementia (Kings College London & London School of Economics, 2007) (used in current models).....	28
<b>Table 7:</b> Incidence rate per 1,000 person years with 95% confidence intervals (Matthews and Brayne, 2005) .....	29
<b>Table 8:</b> Median number of years survival in study following a diagnosis of dementia (red line) and for those that do not get dementia (blue line) with inter quartile range (25% dying and 75% dying. The values for “all” are taken from the ONS life tables .....	30
<b>Table 9:</b> National incidence rate applied to GLA borough population projections. Note this is population incidence (rather than the number presenting to services) .....	39
<b>Table 10:</b> Total care home placements for all reason by the three boroughs in 2013 (ASC), with rates per 1,000 aged 75+ (GLA estimates) compared with in-borough capacity.....	45
<b>Table 11:</b> Number (%) of cases by age group and gender in Service audit .....	95
<b>Table 12:</b> Number (%) of cases by age group and gender in Framework I audit .....	95
<b>Table 13:</b> Median time (years) the current clients have been in contact with ASC.....	96
<b>Table 14:</b> Ethnicity of ASC Clients where coded as having dementia with ethnicity in the three boroughs’ population from GLA projections .....	96
<b>Table 15:</b> Number (%) of ASC clients by dementia type recorded .....	97

# 1 Executive Summary

## 1.1 Purpose of the JSNA

The purpose of this Joint Strategic Needs Assessment (JSNA) on dementia is to provide a comprehensive evidence base and information about the **local population** to inform **commissioning intentions** for Hammersmith and Fulham, Kensington and Chelsea, and Westminster, that takes account of national and local policy on dementia, the North West London strategic approach to dementia, guidance and evidence.

Specifically the report aims to:

- Draw together the strategic drivers from central and local government
- Describe the local picture of need and model future trajectories to enable forward planning
- Set out the current pathways and services for people with dementia and their carers including diagnosis, treatment and post –diagnostic support
- Identify and understand the gaps in service provision for local residents and their carers
- Review guidance and evidence to inform best practice locally
- Make recommendations to inform commissioning across the three boroughs and meet likely future needs.

Information has been collected from a variety of sources including audit, relevant policy and research as well as local data provided by stakeholders, providers, service users and carers. This evidence has been analysed to identify gaps and solutions and forms the basis of the recommendations outlined in the next chapter. Further detail on the analysis which informed the recommendations can be found in Appendix A.

An Executive Summary is also available as a separate report on the JSNA website at <http://www.jsna.info/document/dementia>

Throughout this document people with dementia have been referred to as patients, service users, clients or customers. These terms have been employed in different sections depending on the context and relationships.

It is also worth noting that this JSNA overlaps with other JSNA reports that have already been published or are currently in development, such as the End of Life Care JSNA. For further information on other JSNAs please visit <http://www.jsna.info>

## 1.2 Key themes of the JSNA

In the current health and social care climate there is much emphasis on sustainability through better community care, living as well as possible with dementia, keeping people out of hospital and reducing length of hospital stays. This focus is particularly salient when applied to the needs of people with dementia. In the course of writing the report, several priority themes have been highlighted. These are described in the table below.

Table 1: Themes of Dementia JSNA

1. Numbers of people locally <b>who have dementia</b> will increase over the next few decades (around 55% in next 15 years), primarily due to a greater number of older people (aged 80+)	We need <b>adequate resource</b> to deal with this challenge and we need to provide services more <b>efficiently</b> and <b>sustainably</b>
2. <b>Dementia diagnosis rates</b> have been <b>rising</b> in each of the three boroughs	This has to be followed by an equal input into <b>post-diagnostic care</b> to ensure people are <b>living well</b> with dementia
3. Most of the cost of supporting those with dementia falls on <b>unpaid carers</b> and <b>adult social care</b> . With more care provided at home, pressure on carers may increase	We need to <b>support, advise and empower carers</b> to fulfil this enhanced role without a detriment to their own quality of life
4. Whilst it is important to maintain independence for longer, there needs to be <b>appropriate escalation of care</b> when needed	There may be a need for <b>increased training</b> for paid and unpaid carers residential care staff, and other appropriate professionals
5. Dementia services are provided by a <b>range of agencies</b> - acute and primary care, mental health services, social care and third sector	Better <b>cohesion and collaboration</b> is needed via well-coordinated information, advice, advocacy and outreach services
6. People with dementia do not always receive fair access to services which support their <b>mental and physical</b> health needs	People with dementia need to receive <b>parity of access</b> across mental and physical health services



### 1.3 Recommendations

The report draws together population analysis, policy, research and clinician and user views to inform an analysis of gaps and opportunities, and to evidence our recommendations for commissioning intentions. These recommendations are arranged according to the following priority areas:

- Memory Service Care
- Community Care
- Residential Care
- General Medical Care
- Whole Systems Care
- Patients and Carer's Rights

A summary of how each recommendation has been developed from this analysis can be found in Appendix A: RAG rating of local assets.

**Table 2: Recommendations**

	Gap/Opportunity	Recommendation(s)
Memory Service Care	<p><i>A. Memory service care varies between provider: in some cases the patient may not have access to timely diagnostic or adequate community support.</i></p> <p><i>B. Peer support is now being commissioned as part of Living Well service in Westminster and Kensington and Chelsea, however there appears to be a lack of resource in Hammersmith and Fulham.</i></p>	<p>1. Develop a single point of access to diagnostic assessment and ensure all patients across all three Boroughs have equitable access</p> <p>2. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme</p>
	<p><i>C. Diagnosis rates still do not meet estimated prevalence and can be further improved</i></p> <p><i>D. Training is needed for GPs, staff in care and support roles and families to recognise the signs and symptoms of dementia and know what to do next</i></p>	<p>3. Improve screening and diagnosis in care home and Extra Care residents</p> <p>4. Consider training to increase referral from or support diagnosis in primary care, in line with NWL strategy</p> <p>5. Audit completion of diagnostic assessment for those first identified in hospital and address accordingly</p> <p>6. Establish a good standard of training to achieve a level of expertise across all partner agencies including social care, residential care, extra care, clinicians, GPs</p>

	Gap/Opportunity	Recommendation(s)
Community Care	<p><i>E. It is not clearly understood whether voluntary sector resources and support available to carers is adequate to need, distributed equitably and accessible to all. There is variation between boroughs in the extent of such services available</i></p> <p><i>F. There appears to be insufficient community support for people with dementia and their carers to learn to manage distressing signs of dementia, e.g. through purposeful activity.</i></p> <p><i>G. There are Dementia Advisers and Dementia Guides but there appears to be insufficient resources to meet need. There is a lack of dementia advice/care coordination to support timely access to advice. Resources are needed across 3 boroughs to ensure care staff have support to recognise and signpost people for diagnosis and to provide the right interventions and level of support.</i></p>	<p>7. Ensure adequate provision, through 3<sup>rd</sup> sector and health and social care services, of activities and support around living well with dementia and managing distressing behaviours</p> <p>8. Provide adequate infrastructure and training for care staff.</p> <p>9. Ensure people are supported to access the care appropriate to them through the use of personal budgets</p> <p>10. Ensure that there are sufficient Dementia Advisers to coordinate access to services.</p>
	<p><i>H. There is insufficient support for work of the Dementia Action Alliances across the three boroughs (can eventually join up across 3 boroughs and the Pan-London Alliance)</i></p>	<p>11. Ensure adequate resource to support the work of the Dementia Action Alliance and other opportunities to raise public awareness of dementia across the three boroughs</p>

	Gap/Opportunity	Recommendation(s)
Residential Care	<i>I. The provision of care home beds locally (particularly dementia specific beds) tends to be lower than many other areas, meaning a significant proportion of residents are placed out of borough, in some cases away from family and friends.</i>	12. Address supply of local care home beds in future local authority and CCG commissioning intentions, including those specifically for dementia care.
	<i>J. Little is known about the quality of dementia care in care homes locally</i>	13. Address findings from Care Quality Commission (CQC) national report on dementia care in care homes; audit to provide assurance of quality of care in care homes. 14. Ensure there are opportunities for coordinated training and support for care homes to enable recognition of patients with dementia and to improve confidence in care for complex needs and difficult behaviours. 15. Ensure either all staff in intermediate care have appropriate training for looking after people with dementia or a specialist service is provided.
General Medical Care	<i>K. Little is known about adequate use of antipsychotics – an audit is due to take place in Chelsea and Westminster Hospital.</i>	16. Audit and address accordingly use of antipsychotics in hospitals and community prescriptions
	<i>L. A need has been speculated for increased liaison psychiatry provision in Hammersmith and Fulham, dementia specialist nursing in the community and in hospital, and care navigators.</i> <i>M. Opportunities for reducing escalation of problems and care need have been identified through early targeted hospital care.</i>	17. Ensure adequate monitoring, assessment and provision of care for other physical and mental health needs for people with dementia. 18. Ensure timely identification and targeted care of those with dementia in hospital 19. Provide dementia friendly environment within hospitals 20. Ensure adequate provision of liaison psychiatry and dementia nurses, consider expanding remit

	Gap/Opportunity	Recommendation(s)
Whole Systems Care	<i>N. There are few easy channels of communication between different providers of dementia care</i>	<p>21. All patients, carers and clinicians should have consistent and comprehensive information with clear signposting of care pathways</p> <p>22. The current fragmentation in care provision would be addressed through centralised coordination and improved communication/collaboration between services</p>
	<i>O. Numbers of people with dementia are likely to increase by 55% in the next 15 years, all relevant providers and services must be equipped with adequate resource to meet this need.</i>	<p>23. Ensure adequate training and support across all services for staff and carers looking after people with dementia</p> <p>24. Current practice and resources must be scaled to meet increasing need or consider adapting models of care with innovation across health and social care to reduce the scale of care required. Ensure that any changes to services are evidence based.</p> <p>25. Explore joint working with police and other community safety partners to support appropriate and effective use of assistive technology/telecare for patients with dementia.</p>
	<i>P. The Dementia Strategy in Kensington and Chelsea will end in 2016. The Westminster and Hammersmith and Fulham strategies have both expired. The North West London Mental Health Programme Board has recently produced a dementia strategy for diagnosis and treatment support</i>	<p>26. There should be a joint health and social care dementia programme board for the three boroughs to facilitate implementation of the North West London dementia strategy in alignment with findings and recommendations from this JSNA.</p> <p>27. Local services are active stakeholders with wider initiatives to ensure strategy is sensitive to local needs</p>
	<i>Q. Housing, environment and planning strategies do not specifically mention dementia or carers of people with dementia</i>	28. The increasing numbers and needs of people with dementia and their carers are taken into account in wider local authority and health strategies,

	Gap/Opportunity	Recommendation(s)
		especially housing and environment
Patient and Carer's Rights	<p><i>R. Lack of sufficient resource to support with end of life care across the three boroughs.</i></p> <p><i>S. Lack of defined carer support pathway.</i></p> <p><i>T. Support is needed for advocating peoples' best interests and awareness of the Mental Capacity Act 2005</i></p> <p><i>U. There is little supporting infrastructure available to provide help to self-funders to "micro-commission" care as mandated by the Care Act 2014.</i></p>	<p>29. Ensure that there is a clear end of life care pathway for people with dementia with appropriate advanced care planning and powers of attorney and clinicians are responsive to these wishes.</p> <p>30. Provide a clear and comprehensive pathway for carers with equality of access across three boroughs, taking into account the unique needs of carers of people with dementia and services to support them.</p> <p>31. Patients and carers should be aware of advance directives and power of attorney and how to initiate them.</p> <p>32. Ensure there is adequate infrastructure to support self-funders to access care</p>

## 2 Background

### 2.1 National strategy and policy drivers

The **National Dementia Strategy**, 'Living Well with Dementia' (Department of Health, 2009) provides a 5 year plan for dementia care services. The Strategy identifies 17 key objectives which will be largely implemented at a local level.

Figure 1: National Dementia Strategy objectives

#### Key objectives of the National Dementia Strategy (2009)

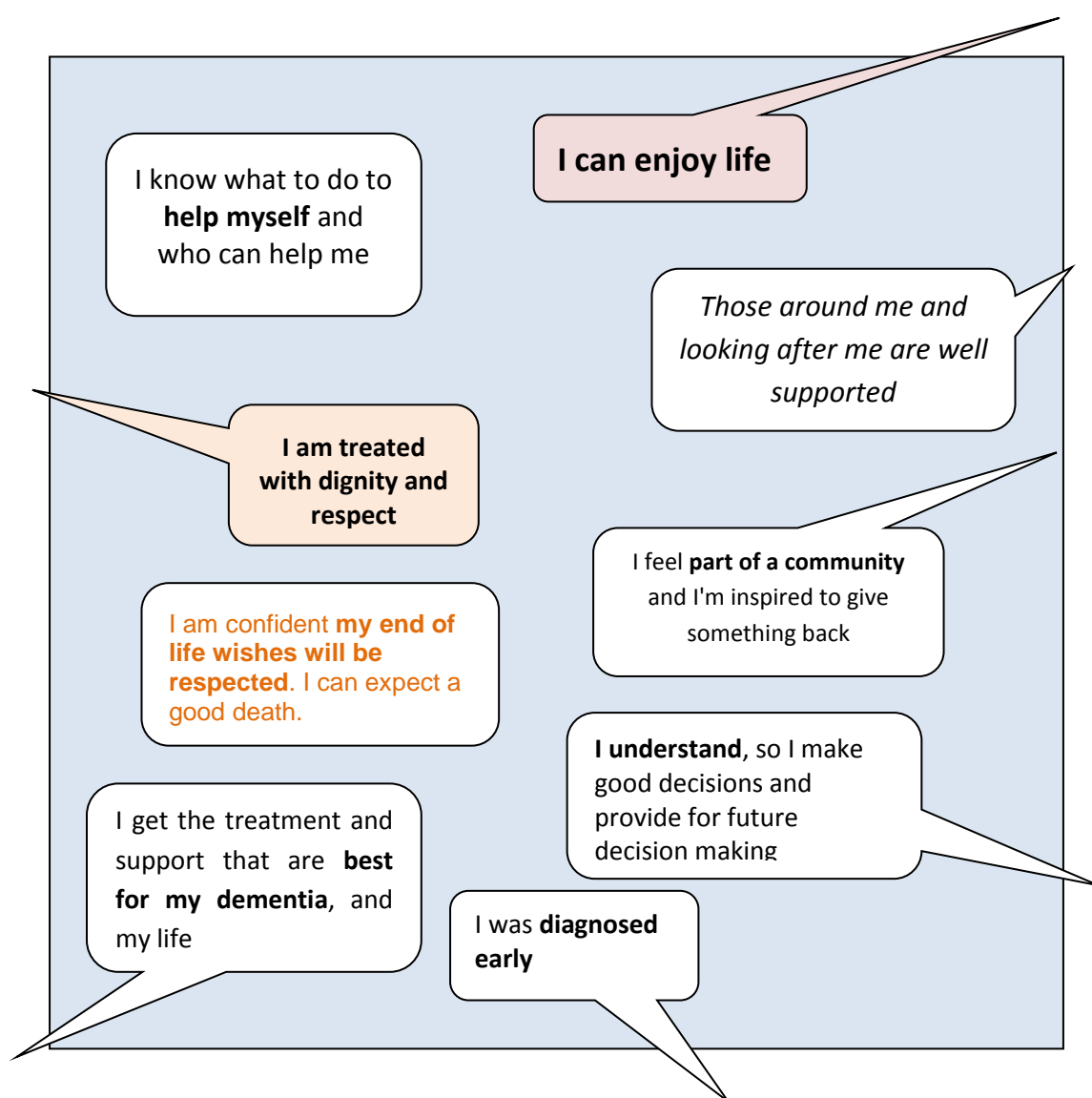
1. Improving public and professional awareness and understanding of dementia: addressing stigma
2. Good-quality early diagnosis and intervention for all: establishing a clear care pathway for people who may have dementia
3. Good-quality information for those with diagnosed dementia and their carers
4. Enabling easy access to care, support and advice following diagnosis: providing a dementia advisor
5. Development of structured peer support and learning networks
6. Improved community personal support services: support for people with dementia living in their own homes
7. Implementing the Carers' Strategy: needs assessments and respite breaks for carers
8. Improved quality of care for people with dementia in general hospitals
9. Improved intermediate care for people with dementia
10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers
11. Living well with dementia in care homes: defined care pathways, specialist in-reach services and inspections
12. Improved end of life care for people with dementia: involvement of people with dementia and their carers in plans for their end of life care
13. An informed and effective workforce for people with dementia: basic training and CPD for all relevant staff
14. A joint commissioning strategy for dementia
15. Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers: inspections of care homes and other services
16. A clear picture of research evidence and needs
17. Effective national and regional support for implementation of the Strategy

In 2010 the Department of Health published an implementation plan for the strategy, called '[Quality Outcomes for People with Dementia](#)'<sup>1</sup>. It focused on the following four priorities

- Priority 1 Good-quality early diagnosis and intervention for all (updated to 'timely' diagnosis)
- Priority 2 Improved quality of care in general hospitals
- Priority 3 Living well with dementia in care homes
- Priority 4 Reduced use of antipsychotic medication.

Using the National Dementia Strategy quality outcomes (Department of Health, 2010) and NICE guidance, people should be able to say:

Figure 2: Quality Standards



<sup>1</sup> Department for Health

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213811/dh\\_119828.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213811/dh_119828.pdf)

Prime Minister's challenge of dementia 2020<sup>2</sup> was published during the course of writing this report. It sets out the following goals and aspirations to follow on from the 2009 strategy:

#### *Care*

- Improved public awareness and understanding of dementia, for example a dementia awareness component added to NHS health checks
- People with dementia having equal access to diagnosis and assessment within 6 weeks of referral.
- GPs playing a leading role in ensuring coordination and continuity of care for people with dementia.
- Every person diagnosed with dementia having meaningful care following their diagnosis in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards: this includes information and advice about support available and respite, education and support for trainers.
- All NHS staff to receive dementia training appropriate to their role; and healthcare assistants and social care support workers undergoing dementia training as part of the Care Certificate.

#### *Dementia Friendly Environments*

- All hospitals and care homes meeting agreed criteria to become a dementia friendly setting
- An additional 3 million dementia friends and over half of people living in recognised 'Dementia Friendly Communities' and encouragement for businesses to become more dementia friendly
- National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.

#### *Research*

- Dementia research as a career opportunity of choice with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society, and open access to all funded research application.
- Cures or disease modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world.
- More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors.

---

<sup>2</sup> Prime Minister's challenge on dementia 2020, published 21 February 2015

<https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

(accessed 1 July 2015)



The **Care Act 2014**<sup>3</sup> outlines new responsibilities for local government as summarised below:

- Councils have a duty to provide **preventative** services to maintain health rather than reacting to a crisis.
- **Information and advice** is to be made available to support service users to make considered and informed choices regarding care early on. Service users and their carers are allocated personal care budgets and given the right to manage their own care should they wish to; these budgets will cover up to the cost of council sourced services.
- Emphasis is placed on ensuring that duty of care extends to unpaid **carers**; ensuring needs are assessed, information and advice provided; they are able to access to services and pathways established for raising concerns. The carer is afforded rights independent of financial capabilities or needs of the dependent.
- There is greater emphasis on **integration** of care between health, social and voluntary sector providers. There is also a new duty to create a service market of diverse and high quality service providers.
- A maximum cap of £72,000 on care costs per service user is introduced. A higher means testing threshold of £123,000 of assets will be introduced for state contributions to care costs.
- National standardised eligibility criteria have also been introduced for local authority funded care to reduce discrepancy between boroughs.
- Increased **oversight for quality and financial security of services**, and protection of care provided when service users move from one borough to the next.
- Safeguarding for adults at risk of abuse or neglect
- Ease of transition from child to adult services

The **Better Care Fund**<sup>4</sup> was introduced in July 2013 and consisted of a £3.8 million pooled budget to fund integration of health and social care services. A 2014 amendment stipulates the £1million NHS contribution will be commissioned through Out of Hospital or reducing emergency admission initiatives. Providers can apply for funding from this budget to support integration plans.

---

<sup>3</sup> HM Government. Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents>

<sup>4</sup> NHS England <http://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/>

## 2.2 National guidelines and standards

The 2006 NICE Guidelines “[Dementia: supporting people with dementia and their carers in health and social care](#)”<sup>5</sup> made recommendations on the diagnosis, management, and care of people with dementia as well as support and interventions for carers. An integrated approach is required from agencies if patients with dementia and their carers are to benefit. The following areas are highlighted as priorities for implementation:

- *Non-discrimination* – there should be equitable access to services for all people with dementia
- *Valid consent* – health and social care professionals should always seek valid consent from people with dementia
- *Carers* – carers of people with dementia should receive an assessment of needs and, where appropriate, receive psychological therapy
- *Coordination and integration of health and social care* – care should be coordinated and integrated across all agencies, with a combined care plan put in place
- *Memory services* – memory services should be the single point of referral for a potential diagnosis of dementia
- *Structural imaging for diagnosis* - structural imaging should be used to assess suspected dementia and to help identify the type of dementia
- *Behaviour that challenges* – people with dementia who develop distressing behaviour be offered an assessment to establish the likely factors that may generate, aggravate or improve such behaviour
- *Training* – staff working with older people in the health, social care and voluntary sectors should have access to dementia-care training<sup>6</sup>
- *Mental health needs in acute hospitals* - hospitals should provide services that address the specific needs and the health of people with dementia who use their facilities

Full details of these priorities can be found in Appendix B. It is recommended that commissioners also refer to the [NICE Commissioning Guide for Dementia Care](#)

In 2014 the Care Quality Commission published their themed review of care for people with dementia as they move between care homes and hospitals, ***Cracks in the Pathway*** (Care Quality Commission, 2014).

Overall, they found more good care than poor care in the 20 hospitals and 129 care homes they visited but found that the quality of care for people with dementia varied considerably, and that transition between services needed to be improved.

---

<sup>5</sup> NICE (2006) Dementia: supporting people with dementia and their carers in health and social care <http://www.nice.org.uk/guidance/cg42/>

<sup>6</sup> National quality standards for content quality and frequency of training in different care setting have not been produced to date, however support for residential and community organisations is available through organisations such as the Alzheimer’s society and Social Care Institute for Excellence (SCIE)

The CQC found aspects of variable or poor care in how a person's needs were assessed; how the care met people's physical and mental health and emotional and social needs; the arrangements for how information was shared when people moved between services; staff's understanding and knowledge of dementia care; people with dementia (or their families and carers) not being involved in decisions about their care and choices about how to spend their time; and the way providers monitored the quality of dementia care.

The report concluded that a person with dementia "is likely to experience poor care at some point along their care pathway" and three actions for CQC were identified:

- Appoint a new national specialist adviser for dementia care.
- Train inspectors across all inspecting teams to understand what good dementia care looks like so that their judgements of the performance of providers are consistent and robust.
- Include a separate section in hospital inspection reports that shows how well the hospital cares for people living with dementia.

## 2.3 Relation to commissioning

The North West London Strategic approach to dementia was finalized in the course of writing this report. The strategy includes a co-produced 'exemplar framework,' outlining the ideal client and carer-centred dementia service. A high level clinical pathway and service specification has also been produced to accompany this with an outcomes framework set against achieving the 'I statements' for both people with dementia and their carers based upon the national quality outcomes framework (see 2.1).

The purpose of this JSNA is to provide a comprehensive evidence base and information about the local population, drawing together national and local evidence held across a variety of organisations and stakeholders, to inform the development of commissioning intentions and support the strategic approach taken across North West London.

It provides an opportunity to understand the whole landscape and customer journey for people with dementia and their families and carers, and to highlight areas for improvement.

## 3 About Dementia

### 3.1 What is dementia?

Dementia is a condition that affects about 800,000 people in the UK<sup>7</sup>. Dementia is an umbrella term that is used to describe a group of progressive symptoms such as memory loss, changes in personality, and difficulties in day-to-day living. Symptoms are characterised by a widespread impairment of mental function.

The World Health Organisation defines dementia as:

“a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.”

The symptoms experienced by people with dementia can be categorised in the following three groups:

- **Cognitive dysfunction.** This is characterised by problems with memory loss, language, attention, thinking, orientation, calculation, and problem-solving.
- **Psychiatric and behavioural problems.** This can be demonstrated as changes in personality, emotional control, social behaviour, depression, agitation, hallucinations, and delusions.
- **Difficulties with activities of daily living.** People with dementia can experience problems with a range of activities such as driving, shopping, eating, and dressing.<sup>8</sup>

There are many different types of dementia, often named after the condition that has caused the dementia, or the doctor who first described it. The most common causes of dementia are<sup>9</sup>:

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy bodies (DLB)
- Frontotemporal dementia

These are the main causes of dementia and account for over 90% of cases. There are no interventions that reverse the disease process for these causes. The rate of deterioration in vascular dementia can be slowed by optimising management of blood pressure,

---

<sup>7</sup> Alzheimer's Society <http://www.alzheimers.org.uk/statistics>

<sup>8</sup> NICE Clinical Knowledge Summaries <http://cks.nice.org.uk/dementia#!background> (accessed 1 July 2015)

<sup>9</sup> NICE Clinical Knowledge Summaries <http://cks.nice.org.uk/dementia#!background> (accessed 1 July 2015)

cholesterol, and other cardiac risk factors. Drugs for Alzheimer's disease can noticeably reduce symptoms for some with mild and moderate disease, but the effect is temporary, and the underlying disease progression is not altered.

The mainstay of management is to provide supportive care and an environment tailored to individuals, and their carers, that allows people with dementia to function at their maximum capacity. Poorly designed support and environments make it much more difficult for those with dementia and their carers. There are several conditions which have a high rate of associated dementia prevalence including obesity, diabetes, neurodegenerative disorders, and Down's syndrome. In alcohol related dementias, stopping alcohol can result in some reversal after a period of years.

Contrary to previous research findings, a recently published cohort study (Qizilbash et al., 2015) found that, compared with a healthy weight, people who were underweight had a 34% higher risk of dementia in mid to late life and those who were overweight had a 19% lower risk. Although the authors highlight the strengths of the study (sample size of over 1.9 million GP records and UK setting) they also acknowledge that these findings are contrary to existing research and that further research is required to better understand the consequences of these findings.

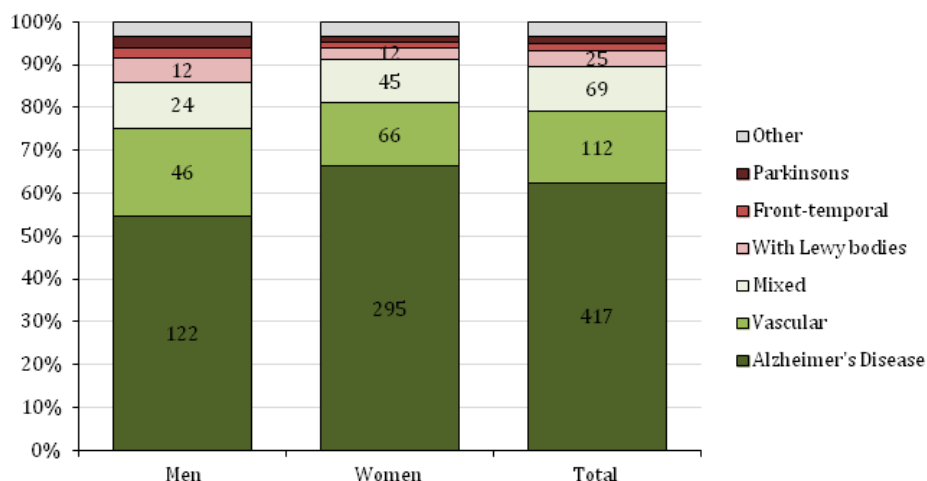
The risk of developing Alzheimer's disease and Vascular Dementia is reduced by a normal healthy lifestyle; good nutrition, no more than recommended alcohol consumption, and adequate physical activity.

It is also possible for a person to have more than one dementia (commonly referred to as mixed dementias) e.g. a combination of Alzheimer's disease with vascular dementia.

### 3.2 Types of Dementia

There are many causes of dementia. 62% of dementia is due to Alzheimer's disease, 17% is vascular dementia, 10% is mixed and the remaining 11% is dementia with Lewy bodies, Fronto-temporal dementia, Parkinson's disease and other forms of dementia.

**Figure 3: Number of people in the UK with dementia subtypes, thousands (Kings College London & London School of Economics, 2007)**



#### Early-onset dementia

According to the Alzheimer's Society there are over 40,000 younger people (i.e. under the age of 65) who have dementia in the UK<sup>10</sup>. Often referred to as 'early-onset dementia' or 'young-onset dementia' or 'working-age dementia' these younger people with dementia experience similar symptoms as older people with dementia but may have specific needs and requirements.

Younger people are more likely, for example, to be in work themselves, to have a partner who works, have children, be more physically active, and have financial commitments such as mortgages. Services need to consider the specific needs and interests of younger people, which may well be different from those designed for the over 65s.

Younger people tend to have a different type of dementia than over 65s. The Alzheimer's Society indicate the following breakdown of the types of dementia among younger people:

- Alzheimer's disease - around 33%
- Vascular- 20%
- Fronto-temporal dementia - 12%
- Alcohol-related - 10%
- Dementia with Lewy bodies- 10%
- Rarer forms of dementia (e.g. caused by Parkinsons) - 20%

<sup>10</sup> Alzheimer's Society <http://www.alzheimers.org.uk/statistics> (accessed 1 July 2015)

Locally, service provision for younger people with dementia has been delivered through the memory assessment service in Hammersmith and Fulham which specializes in early onset dementia and takes referrals from across North West London.

### **3.3 Risk factors for dementia**

The main risk factor for dementia is growing old and ageing. Research into preventing dementia has indicated that most success lies with modifying cardiovascular risk factors and is discussed in more detail in 7.1. Other risk factors are summarised in the table on the following page (Solomon et al., 2014).

Table 3: Risk and preventative factors for dementia

	Risk Factors	Protective factors
Genetic	<ul style="list-style-type: none"> <li>Familial aggregation (where family members share a trait)</li> <li>Certain genes have been proposed</li> </ul>	<ul style="list-style-type: none"> <li>Certain genes have been proposed</li> </ul>
Vascular & metabolic	<ul style="list-style-type: none"> <li>Cerebrovascular lesions</li> <li>Cardiovascular diseases</li> <li>Diabetes mellitus and pre-diabetes</li> <li>Midlife positive association but late-life negative association</li> <li>Hypertension</li> <li>High BMI (overweight and obesity)</li> <li>High serum cholesterol</li> </ul>	<ul style="list-style-type: none"> <li>None known</li> </ul>
Lifestyle	<ul style="list-style-type: none"> <li>Smoking</li> <li>High alcohol intake</li> <li>Diet</li> <li>Saturated fats</li> <li>Low B vitamins/high homocysteine</li> <li>Homocysteine</li> </ul>	<ul style="list-style-type: none"> <li>Healthy lifestyle such as physical activity and moderate alcohol intake</li> <li>Mediterranean diet, PUFAs and fish-related fats</li> <li>Vitamins B6 and B12, folate</li> <li>Antioxidant vitamins (A, C and E)</li> <li>Vitamin D</li> </ul>
Psychosocial	<ul style="list-style-type: none"> <li>None known</li> </ul>	<ul style="list-style-type: none"> <li>High levels of education and SES</li> <li>High level of complexity of work</li> <li>Rich social network and social engagement</li> <li>Mentally stimulating activity</li> </ul>
Drugs	<ul style="list-style-type: none"> <li>None known</li> </ul>	<ul style="list-style-type: none"> <li>Antihypertensive drugs</li> <li>Statins</li> <li>Hormone Replacement Therapy (HRT)</li> <li>NSAIDs (Non-steroidal anti-inflammatory drugs)</li> <li>Ongoing research into drugs that prevent amyloid deposition</li> </ul>
Others	<ul style="list-style-type: none"> <li>Depression</li> <li>Traumatic brain injury</li> <li>Occupational exposure (heavy metals, ELF-EMFs)</li> <li>Infective agents</li> </ul>	<ul style="list-style-type: none"> <li>None known</li> </ul>

Recent research which contradicts previous evidence on the association between obesity and dementia is highlighted above in section 3.1



### 3.4 Impact of dementia

#### Living with dementia

Dementia has a significant impact on an individual's health and quality of life. It can result in a range of health and social problems which can be challenging for the person with dementia, their carers, and health and social care professionals. The prognosis for a person with dementia varies depending on the cause of the dementia and the pattern of symptoms (see 3.7 *Dementia and Mortality* below).

As the dementia progresses, people with dementia experience severe cognitive impairment and memory loss. Psychological and behavioural problems such as depression, disorientation, and aggression will develop and get worse over time and can be difficult to manage.

Research shows that a large proportion of people with dementia feel unsupported and do not feel part of their community. They often experience anxiety and depression and three quarters do not feel society is geared up to deal with dementia (Alzheimer's Society, 2012).

While a survey undertaken by the Alzheimer's Society (Alzheimer's Society, 2013) suggests that progress is being made, with almost two-thirds (61%) of respondents reporting that they were living well with the condition, the report also found that quality of life is still varied for a significant number of people with dementia. Environment, presence of depression, social isolation and loneliness are key drivers for quality of life for people with dementia.

In addition to this, as life expectancy increases for people with complex disabilities, parent carers may develop dementia which will affect their ability to provide care. Many parent carers are single parents, which is an additional risk factor delaying identification. Of the 884 adult carers who responded to the 2014/15 carers' survey, 4% reported having a learning disability in LBHF and RBKC and 6% reported a learning disability in WCC

#### Impact on carers

Nationally, provision of unpaid care for those with dementia contributes more in financial terms than contributions from any other agency (45% of the total, with social care second providing 40% (Kings College London & London School of Economics, 2014). Carers are often old themselves, more likely to be women, and are likely to be providing a substantial number of hours of support.

Research on carers has found that those providing care are more likely to be in poor health than those not providing care<sup>11</sup> (Pinquart & Sorensen, 2003). Emotional and mental health problems tend to be more often associated with care giving than physical health problems: nationally, carers providing substantial levels of care are twice as likely to have mental

---

<sup>11</sup> ONS Carers Week <http://www.ons.gov.uk/ons/guide-method/census/2011/carers-week/index.html>

health problems as those providing a lower level of care (27% against 13%). One review suggests that carers of people with dementia have worse health outcomes than other carers (Pinquart and Sörensen, 2003).

In addition to poorer physical and mental health, carers can often suffer from social deprivation, isolation, fewer opportunities to paid employment or education, or having time to themselves or with friends. For young carers, it can often mean life chances are severely limited.

Caring responsibilities are known to have a significant impact on carers' quality of life and, in the case of RBKC and WCC, quality of life was poorer for those looking after someone with dementia than carers generally. Comments from the Adult Carers Survey identified challenges around the lack of a break for those caring for someone with dementia and having to do "everything for them".

*'Looking after someone with dementia is the most difficult job in the world'* Local Carer, 2014/15 Survey of Adult Carers

NICE recommendations on how carers can be supported are highlighted in Chapter 7

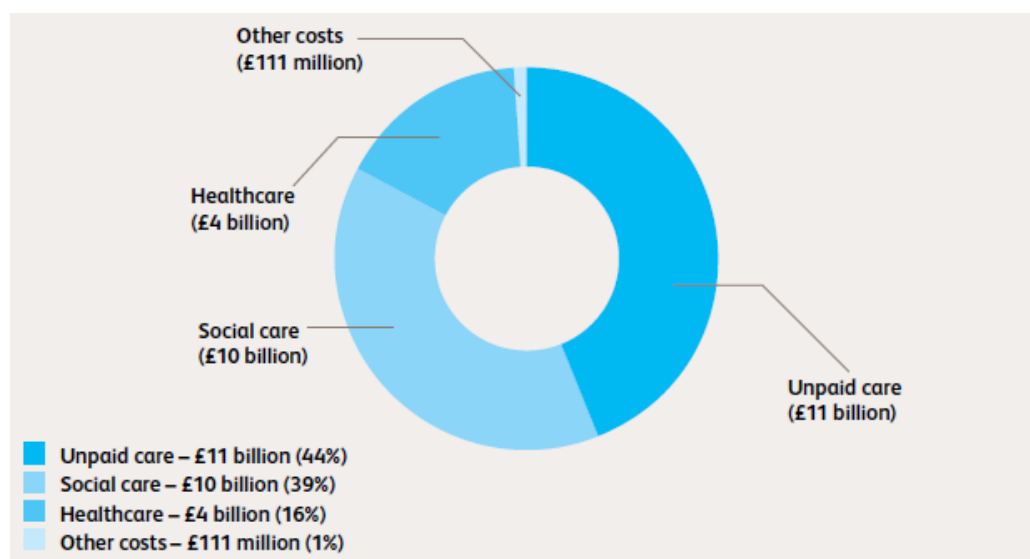
### The cost of dementia

Research undertaken by Kings College London and London School of Economics (2014) has estimated the total cost of dementia to society in the UK to the value of £26.3 billion. This includes:

- Healthcare costs - £4.3 billion
- Social care costs (publicly and privately funded) - £10.3 billion
- Relative contributions from work of unpaid carers - £11.6 billion
- Police costs – between £22.1 and £40.3 million
- Research expenditure - £75 million

A unique feature of dementia is that social costs present a significantly larger burden than health costs. This is in comparison to, for example, diabetes where the total cost to the UK was estimated at £23.7 billion with £9.8 billion attributable to direct healthcare and £13.9 billion attributable to indirect costs including social care, loss of work and death and illness (Hex, Bartlett, Wright, Taylor, & Varley, 2012).

Figure 4: Estimated breakdown of costs of dementia for the UK, 2013 (Kings College London & London School of Economics, 2014)



The average costs of caring for people with dementia in England are approximately £37k per year for people in residential care and £29k per year for people in the community. This cost varies according to severity. Current costs in London will be higher due to higher wages<sup>12</sup>, other service costs and land prices. For the most complex cases, annual costs of c.£70k have been reported<sup>13</sup>.

If the national figures are apportioned locally using the number aged 75+, then the total cost of dementia care in the three boroughs is expected to be £161 million of which £70 million is for unpaid care.

Table 4: Estimated local cost of dementia care in the three Boroughs

Cost Type	Amount (£)
Unpaid Care	70,000,000
Social Care	64,000,000
Healthcare	25,000,000
Other Costs	700,000
<b>Total</b>	<b>161,000,000</b>

### Co morbidities

The most common long term conditions among older people are hypertension, depression, asthma, diabetes and coronary heart disease, and 25% of all over-60-year-olds have two or more long term conditions (Department of Health, 2012). Therefore it is not surprising that many dementia patients have these conditions.

<sup>12</sup> London Living Wage <https://www.london.gov.uk/priorities/business-economy/vision-and-strategy/focus-areas/london-living-wage>

<sup>13</sup> London Dementia Needs Assessment 2011, NHS London

However, some long-term conditions might be specifically associated with dementia, but the evidence is mixed. A large cross-sectional study of older people in Spain showed that dementia patients are more likely to have some conditions, particularly anxiety, chronic skin ulcers and anemia (Poblador-Plou et al., 2014). The study found that 70% of dementia patients had at least one additional condition, and 48% had two or more. On average, people with dementia had 2.7 additional conditions.

The study found that in the population they studied a range of other medical problems were significantly more common, in those with dementia than those without. In decreasing order of likelihood these conditions were:

- Anxiety and neuroses (*three times as likely*)
- Parkinson's Disease
- Chronic Skin ulcers
- Anaemia
- Retinal disorders
- Cerebrovascular disease
- Cardiac arrhythmias
- Thyroid Disease
- Prostatic hypertrophy in men (*twice as likely*)

However, a large cross-sectional study in the US did not find a significantly different number of co morbidities, or different prevalence of common conditions, between patients with dementia and without dementia (Schubert et al., 2006). The average number of additional conditions for patients with dementia was 2.4.

In the UK, depression and anxiety are commonly associated with dementia (NICE, 2006). For example, a narrative literature review suggested that 20% of dementia patients in contact with services have depression (Ballard, Bannister, Solis, Oyebode, & Wilcock, 1996).

### 3.5 National prevalence of dementia

The current estimate of people living in the UK with dementia is 800,000. This is based on consensus estimates largely taken from the Cognitive Functioning and Aging Study (CFAS) in 1998 which identified the prevalence in England by age and gender in 7,500 participants (MRC CFAS, 1998).

**Table 5: Consensus estimates of the population prevalence of late onset dementia (Kings College London & London School of Economics, 2007) (used in current models)**

Age	Female	Male	Total
65-69	1.0%	1.5%	1.3%
70-74	2.4%	3.1%	2.9%
75-79	6.5%	5.1%	5.9%
80-84	13.3%	10.2%	12.2%
85-89	22.2%	16.7%	20.3%
90-94	29.6%	27.5%	28.6%
95+	34.4%	30.0%	32.5%

These prevalence rates applied to the predicted future population indicate that there will be 1.1M with dementia in 2025 and 2.1M in 2050. These are the figures used by the Alzheimer's Society and also in the 2009 National Dementia Strategy.

In older age groups, women have higher rates of dementia than men, and overall there are twice as many women with dementia as men because women tend to live longer than men.

The difference in rates might possibly be explained by:

- only very healthy men who are less likely to get dementia survive to very old age,
- prevalence of certain risk factors, such as hypertension, may be lower among older men,
- men with dementia may have shorter survival (which would explain differential prevalence, but not incidence).

#### Uncertainty about prevalence

However, CFAS I was conducted in 1989-1994 and was repeated as CFAS II in 2008-2011 in exactly the same way. Dementia prevalence in those 65+ in 2008-2011 was predicted to be 8.3% by CFAS I but was actually found to be 6.5% in CFAS II - a 22% reduction (F. E. Matthews et al., 2013).

The reason for the reduction is thought to be healthier lifestyles over the years in those who are currently elderly compared with those at the same age in the previous study, with less smoking, lower alcohol consumption, healthier diet and greater levels of exercise. Studies from elsewhere in the world support this trend. In the Rotterdam Study in the Netherlands, new dementia cases in people aged 60-90 fell by a quarter between 1990 and

2000, although the finding just missed statistical significance (Schrijvers et al., 2012). Two cross-sectional studies in Sweden showed that prevalence is stable while survival is increasing, suggested decreased incidence (Qiu, von Strauss, Backman, Winblad, & Fratiglioni, 2013). The new rates would indicate that 670,000 people in the UK currently live with dementia rather than the current consensus prediction of 800,000 (used in this report).

While there are likely to be fewer people currently living with dementia than previously estimated, it is difficult to predict what future numbers will be nationally because the lifestyle factors that have presumably led to improvement may not be maintained. In particular, obesity rates among the under 65's are higher now than they were for those who are now elderly when they were under 65.

The Alzheimer's Society now takes the view the previous estimates are a **worst case scenario** and the Society's overall current consensus rate has been reduced only slightly. The Department of Health has commissioned a review to reach a new consensus on prevalence rates. Nationally, expected prevalence is currently estimated from the original Alzheimer's society consensus rates.

It is expected that the national dementia prevalence calculation will be altered in 2015/2016 and be based on CFAS 2 in. This will reduce the total number of people in England currently estimated to have dementia from 670,000 to 620,000.

### 3.6 Incidence of dementia

The CFAS1 study results produced an estimate of 180,000 new cases of dementia in England and Wales per year in the mid-1990s (F. Matthews & Brayne, 2005), or approximately 3.5 per 1,000 person-years, with no evidence of variation between the six sites included in the study. The sites were chosen to include north and south England, rural and urban, and deprived and non-deprived areas. In the table, "person years" allows for people dying before they reach the age at the top of the age band. Two people living for 6 months produces one whole year during which there is a risk of someone developing dementia.

**Table 6: Incidence rate per 1,000 person years with 95% confidence intervals (Matthews and Brayne, 2005)**

Age group	Men	Women	Men & Women
65-69	6.9 (3.3-14.5)	6.3 (2.9-15.6)	6.7 (3.8-12.4)
70-74	14.5 (7.4-34.1)	6.1 (2.8-12.6)	10.3 (6.2-19.9)
75-79	14.2 (6.7-25.1)	14.8 (8.5-25.1)	14.5 (9.6-20.7)
80-84	17.0 (6.7-34.1)	31.2 (21.2-34.1)	26.5 (18.3-37.7)
85+	58.4 (27.3-96.7)	71.7 (52.0-96.7)	68.5 (52.5-88.1)

### 3.7 Dementia and mortality

Dementia is associated with significantly early death. This is due to both the dementia itself as well as the difficulty managing co-morbidities, which may also be more common in patients with dementia (Rait et al., 2010).

Rait et al estimated survival after a diagnosis of dementia (22,529 patients) was first recorded in primary care, compared with people without dementia (112,645 patients) between 1997 and 2007 who could be followed up in the 384 participating GP practices for 10 years (or until they died). The average age at diagnosis of dementia was 83.2 years and 2/3rds were female. The table below shows how long people survive from diagnosis with dementia compared with those who do not have dementia. For example, for those aged 80-89 25% had died within 1.3 years following a diagnosis of dementia compared with 2.6 years for those who did not develop dementia.

**Table 7: Median number of years survival in study following a diagnosis of dementia (red line) and for those that do not get dementia (blue line) with inter quartile range (25% dying and 75% dying. The values for "all" are taken from the ONS life tables**

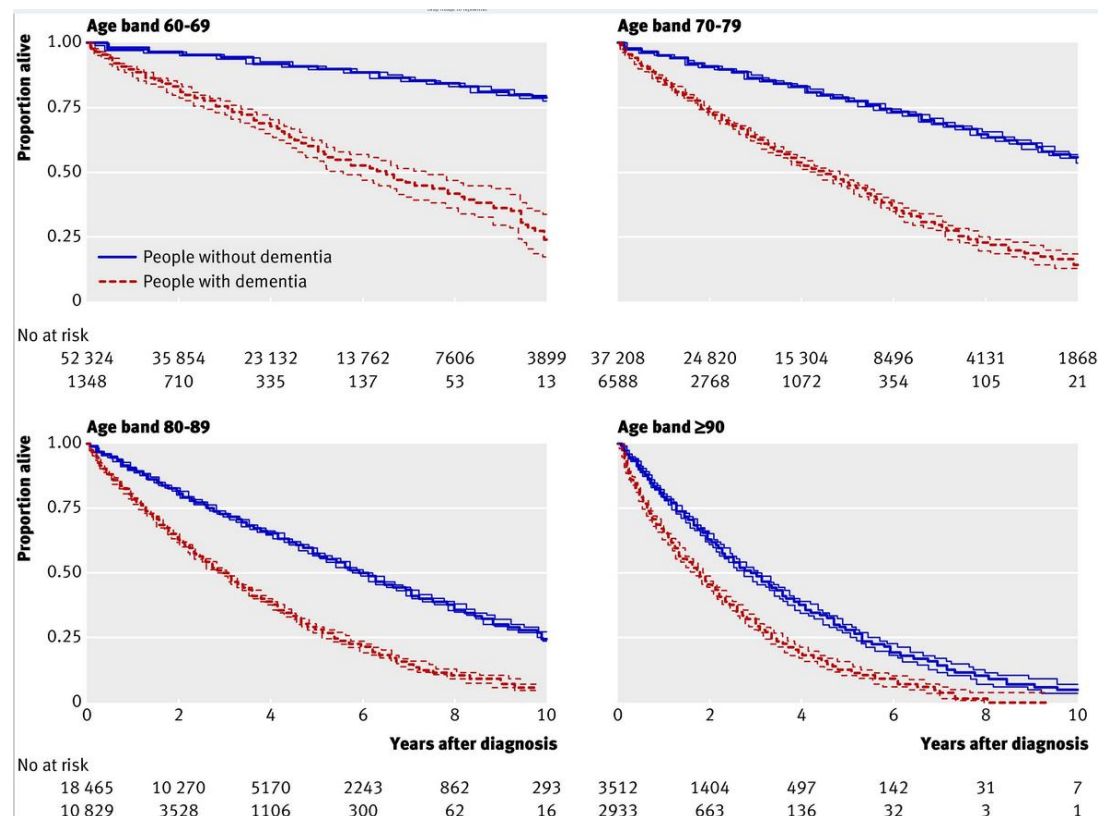
Years to dying		Lower Quartile	Median	Upper Quartile
age when diagnosed	Proportion Dying	25%	50%	75%
age 60-69	No Dementia*	>10 yrs	>>10 yrs	>>>10 yrs
	Dementia	3.1 yrs	6.5 yrs	10.0 yrs
	All (from ONS)	11.2 yrs	18 yrs	23.4 yrs
age 70-79	No Dementia	5.7 yrs	>10 yrs	>>10 yrs
	Dementia	1.8 yrs	4.5 yrs	7.4 yrs
	All (from ONS)	5.1 yrs	10.0 yrs	14.4 yrs
age 80-89	No Dementia	2.6 yrs	5.9 yrs	9.9 yrs
	Dementia	1.3 yrs	3.0 yrs	5.3 yrs
	All (from ONS)	1.4 yrs	4.4 yrs	8.2 yrs
age 90+	No Dementia	1.3 yrs	3.0 yrs	5.3 yrs
	Dementia	0.6 yrs	1.8 yrs	3.3 yrs
	All (from ONS)	0.8 yrs	2.2 yrs	3.4 yrs

\* >10, greater than 10, >>10 much greater than 10, >>> very much greater than 10 year. Study stopped after 10 years and duration of survival is implied both from projection and national survival rates.

The figure below gives information for the whole study. The space between the blue (no dementia) and red (dementia) survival curves indicates how many years of life are lost on average over the 10 years of the study by someone with dementia because of their dementia. While comparatively few people are diagnosed at age 60-69, and they live

longer, they die proportionately earlier and lose far more years of life than someone diagnosed at age 90 or more.

**Figure 5: Survival Curves for people with dementia (red) and without dementia (blue) by age at diagnosis, with 95% confidence limits**



In the year after the initial diagnosis was recorded mortality was nearly 4 times higher than those without dementia, possibly indicating that diagnosis was likely to be made at a time of crisis. In the following years it was a relatively constant 2.5 times higher.

In addition to age and sex, the study looked at other risk factors; deprivation; smoking; alcohol; diabetes; hypertension; cardiovascular disease; cerebrovascular disease; and high cholesterol. These increased the likelihood of dying early by the same amount whether or not the patients had dementia. However, the study did suggest that risk factors for cardiovascular disease, associated with progression of vascular dementia, were managed less comprehensively than in those with no dementia.

Since 2007 there has been an initiative to increase rates of diagnosis of dementia. Most moderate and severe cases will have always been identified and increasing recognition of people with dementia is likely to identify disproportionately more mild cases which who will live longer. If this study on patients between 1997 and 2007 were repeated today, then survival following diagnosis would be likely to be longer. However, the average age at which people actually die would be relatively unchanged as early diagnosis is associated with longer awareness of dementia rather than longer survival from it. Early diagnosis does



allow more appropriate support for patients and carers that can significantly improve their quality of life.

### **3.8 Ethnicity and dementia**

Nationally, there are no evidence that rates of dementia by ethnic group are either the same or different to the general population. Studies of sufficient size and robustness have not been undertaken that would provide reliable results to detect any difference between ethnic groups. In the absence of evidence, dementia prevalence and incidence are taken to be the same in all ethnic groups as the whole of the UK. This approach is the approach of Alzheimer's UK and in the National Strategy.

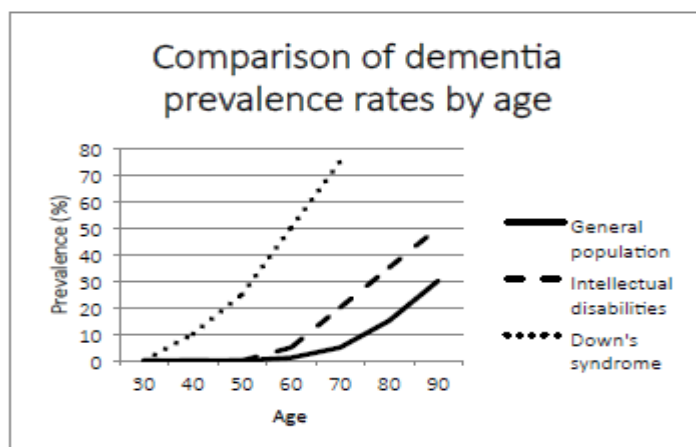
### **3.9 Dementia and people with learning disabilities**

Dementia is more prevalent among people with a learning disability than the general population, and as people are living longer the numbers of people with a learning disability who develop dementia are increasing. It has been predicted that the proportion of people with a learning disability over 65 years of age will have doubled by 2020, with over a third of all people with intellectual disabilities being over 50 years of age by that time (Dodd et al., 2015).

Research suggests that people with a learning disability are five times more likely to develop dementia compared to the general population, and people with Down's Syndrome are at particular risk of developing dementia (Improving Health and Lives, 2013). It has been calculated that nearly 70% of older adults with Down's syndrome are likely to develop dementia symptoms should they all live to age 70. The most common cause of dementia for people with Down's syndrome is Alzheimer's disease (Dodd et al., 2015).

The following figure, reported by the British Psychological Society and Royal College of Psychiatrists, compares the age-related prevalence rates of dementia in people with Down's syndrome with those with intellectual disabilities without Down's syndrome, and the general population. While acknowledging that exact prevalence rates must be treated with caution they also reports that this trend is generally accepted.

Figure 6: Comparison of dementia prevalence rates for people with learning disabilities and general population (Dodd et al., 2015)



This figure indicates that people with Down's syndrome are at increased risk of developing dementia from the age of 30 onwards when compared with other population groups.

While the symptoms of dementia are the same for people with a learning disability as with the general population there are a number of features which are different<sup>14</sup>. People with a learning disability:

- are more likely to develop dementia at a younger age, especially those with Down's Syndrome
- may present with different symptoms in the early stages
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
- may experience a more rapid progression of dementia
- may already be in a supported living environment
- may have already learned different ways to communicate
- will require specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses.

In order for people with learning disabilities to live well with dementia and to access services effectively, public sector organisations are required to put reasonable adjustments into place to ensure this group are not disadvantaged. This may involve making physical adjustments to buildings, altering policies and procedures, staff training, and service redesign. The Improving Health and Lives report (Improving Health and Lives, 2013) on reasonable adjustments for people with learning disabilities and dementia provides a number of case studies from across the UK. Examples cover:

- clear pathways for people with a learning disability and improved access to appropriate memory clinics
- learning disability training for staff working with older people, and dementia awareness training for learning disability staff

<sup>14</sup> Alzheimer's Society

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=103](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103)

- establishing networks for staff to share good practice, provide support and learn from each other
- adaptations to community/hospital buildings and refurbishments to create dementia friendly environments.
- screening services for people with Down's Syndrome
- information and training for carers and people providing support to people with dementia
- easy read booklets for people with learning disabilities about dementia

Overall, dementia in people with a learning disability has been less well studied, however there is an emerging body of evidence. The recent review by the Royal College of Psychiatrists highlights the importance of an integrated care pathway for the assessment, diagnosis, and support for people with learning disabilities. The elements of an excellent service are listed as:

- Demographics are known, including having a database of all adults with intellectual disabilities which includes identification of people with Down's syndrome and those in out of area placements.
- A multi-agency dementia strategy.
- A multi-agency care pathway for assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.
- A multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services including baseline assessment for people with Down's syndrome by the age of 30.
- Person-centred dementia care.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions.
- All living and day service environments are dementia friendly.
- The person is supported to remain in their familiar home with additional supports provided in a timely manner.
- Support is available to family carers and service providers.
- There is a capable workforce able to deliver excellence in dementia care.
- End of Life care follows the requirements of the National End of Life Strategy.

The importance of person centred care in the management of dementia is also highlighted by NICE and the Alzheimer's Society, with due consideration given to the needs and preferences of the person with a learning disability. It is important to ensure that people with a learning disability, and those caring or supporting them, understand the consequences of a diagnosis of dementia.

In their priorities for implementation NICE highlight that *"People with dementia should not be excluded from any services because of their diagnosis, age or coexisting learning disabilities."*

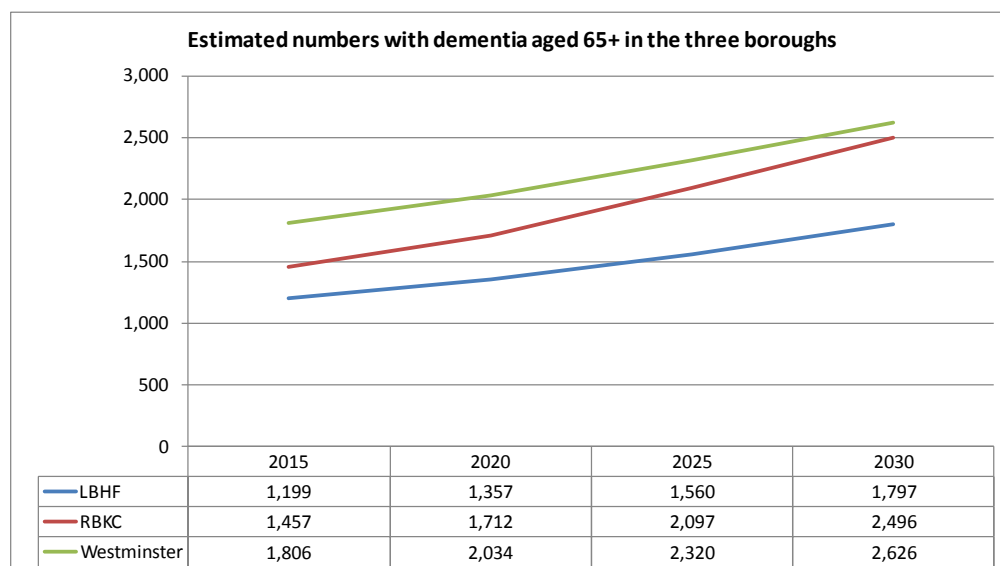
## 4 Dementia in our local population

### 4.1 Estimated prevalence of dementia

The number of people with dementia is increasing, mirroring the increase in the size of the elderly population who are at particular risk of dementia. This is especially so for the relatively large increase elderly aged 85+ over the next 15 years: 65% for Hammersmith & Fulham; 95% for Kensington and Chelsea; and 60% for Westminster<sup>15</sup>. The growth is due to the large number of people born in the baby boomer generation are now becoming elderly who also have a longer life expectancy.

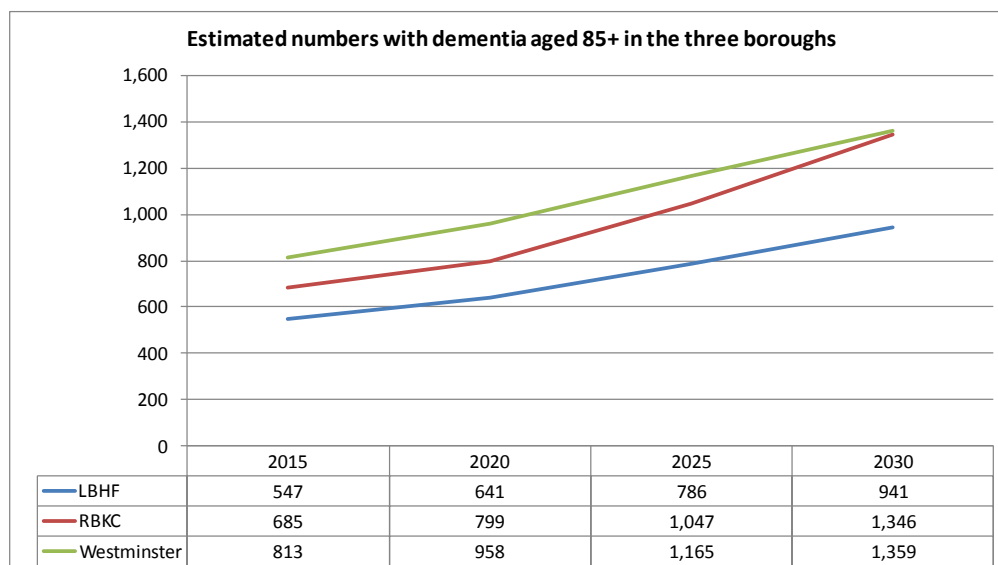
The figures for local estimates using the national rates (see 3.5 above) are given in the charts below. The total across the three boroughs rises from 4,500 in 2015 to 7,000 in 2030 for those aged 65+. About half of these are in those aged 85+.

Figure 7: Estimated numbers with dementia aged 65 years and older by borough



<sup>15</sup> GLA Population Projections <http://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables> (accessed 1 July 2015)

Figure 8: Estimated numbers with dementia aged 85 years and older by borough



In the charts, the national prevalences are applied to local population figures, and any growth in the number of cases is explained by the increase in the elderly population, not by dementia becoming more common in any age group. Differences between the three boroughs, for example the growth of cases in RBKC, represent expected relative changes in the numbers of the at risk population in the three boroughs.

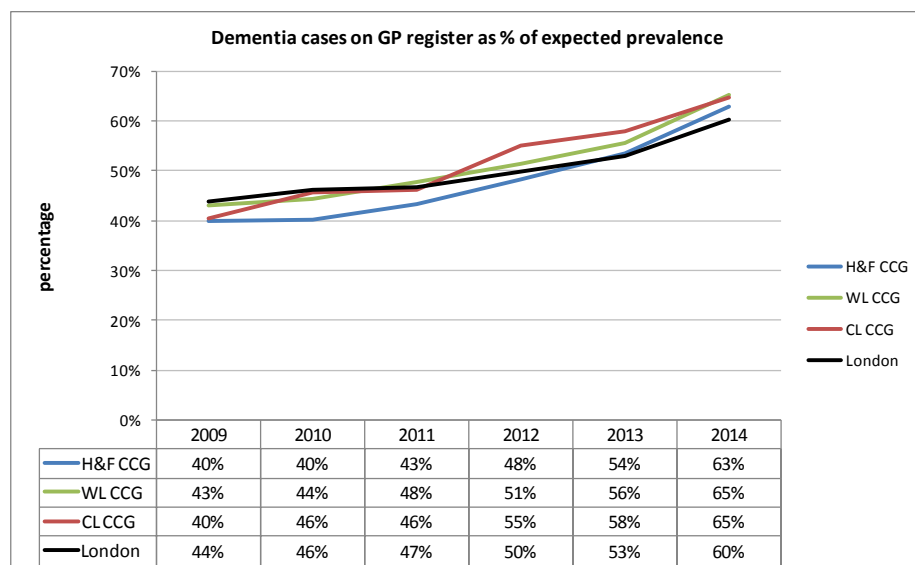
As indicated above (see 3.5), there is evidence that prevalence has changed from the figures currently used nationally. Whatever the estimated prevalence rates are taken to be, if the actual current age and gender specific rates remain constant, then the aging population will produce a 55% increase in the number of people across the three boroughs most at risk of dementia over the next 15 years: 50% for Hammersmith & Fulham; 70% for Kensington & Chelsea; and 45% for Westminster. Diagnostic, treatment and care service provision will need to expand proportionately.

## 4.2 Diagnosed prevalence of dementia

The figures above are estimates of the actual number of people with dementia, but not all of these will be diagnosed and accessing support. GPs have a register of patients known to have dementia; a record is made of which of these has been seen during the previous year, and which are actively monitored. The percentage of the population in England on the registers is 0.63% (0.37% in London which has a young population who have a very low risk of having dementia).

*'A significant proportion of people [with] dementia don't want to know, they won't bring it up of their own accord'* Local Clinician, 2014

Figure 9: Cases of dementia known to GPs (QoF prevalence), by CCG



There are currently nearly 2,900 patients in the three boroughs recorded as having dementia, having risen from 1,600 in 2010. The increase over time is produced by a combination of better formal recording of cases and an increase in the number in the population generally. The three boroughs proportion is 64% and was 41% in 2010. This compares with London as a whole which is 60% and was 44% in 2010. In 2013/14 the proportion of the estimated number of cases identified in England averaged 48% but varied from 33% to 75% across CCGs. However, as indicated above, the expected number used may be too high currently, and the actual proportion on the register may be higher than indicated here.

In March 2015 H&F CCG had a diagnosis rate compared with expected prevalence of 68%, WL CCG 73%, and CL CCG 72%. This compares with 66% in London and 65% nationally. Over the coming year the national dementia prevalence calculator will be changed to use the lower CFAS 2 prevalence figures, and these diagnosis rates will therefore increase without any change in the number of people being diagnosed.

When using these figures which are not directly available to the public we are required to give the following caveat in full:

*“Dementia diagnosis rates contained in the Dementia Prevalence Calculator (DPC) are estimated. They are calculated based on a model which attempts to standardise for age, gender and the increased prevalence of dementia in patients living in residential care settings.*

*The numerator in the calculation is the Dementia register, as recorded in GP practice systems.*

*The denominator is an estimated prevalence currently based on a Delphi consensus from 2007. This national estimate means that local estimated diagnosis rates need to be treated with intelligent understanding that they are not appropriate for*

*performance management, but can assist in estimating the local challenge and progress within wide confidence intervals.*

*Not every GP practice has monthly dementia registers data published by Health and Social Care Information Centre (HSCIC), this can be for a number of reasons (refer to [www.hscic.gov.uk](http://www.hscic.gov.uk)). In these cases, NHS England have agreed internally that for those practices which HSCIC have not been able to extract data 'in month', or for practices which have opted out of having their data collected, the latest available data point is used as a proxy (i.e. published QOF 2013/14 figure).*

*Dementia Register data is owned and published by Health and Social Care Information Centre and remains the sole and exclusive property of the Health and Social Care Information Centre."*

The expected prevalence figures also take into account the very early stages of dementia which may be very mild (but identifiable in the CFAS research). These patients are unlikely to be diagnosed by GPs or hospitals until their symptoms worsen. Almost all cases of severe dementia are likely to have been identified. Less than 5% of dementias are in the under 65's, and patients in this age group may also be diagnosed late as the dementia is so uncommon under the age of 65.

### 4.3 Estimated incidence of dementia

The nationally accepted incidence figures (3.6 Incidence above) applied locally suggest a large expected increase in the number of people first diagnosed with dementia over the next 20 years, particularly in RBKC. The numbers for LBHF and WCC increase by over half, while in RBKC they almost double.

**Table 8: National incidence rate applied to GLA borough population projections. Note this is population incidence (rather than the number presenting to services)**

	New cases of dementia 2013	New cases of dementia 2023	New cases of dementia 2033	Growth 2013 - 2023	Growth 2013 - 2033
LBHF	322	391	506	22%	57%
RBKC	388	524	718	35%	85%
WCC	486	597	760	23%	56%
<b>Total</b>	<b>1,196</b>	<b>1,513</b>	<b>1,985</b>	<b>26%</b>	<b>66%</b>

**Figure 10: Expected number of new case of dementia in the population each year by borough**

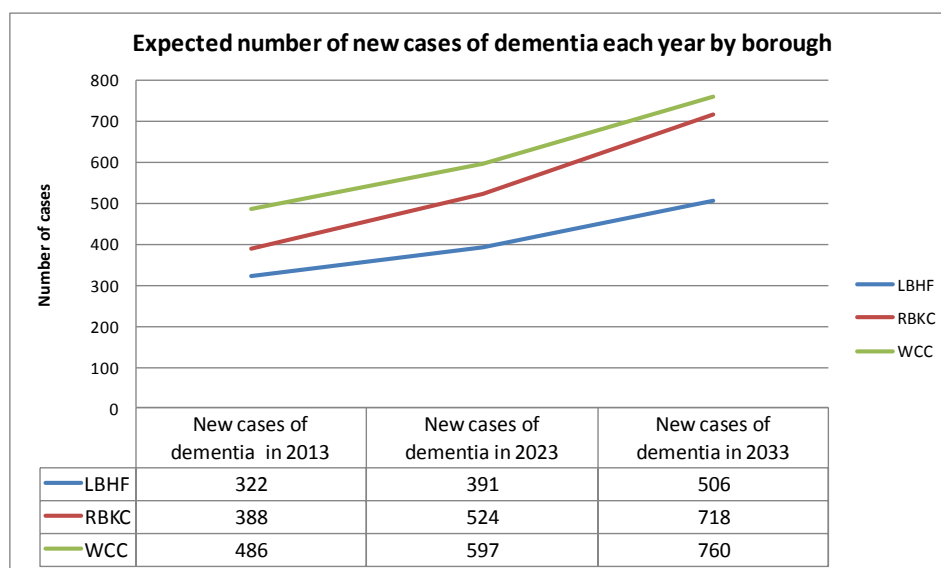
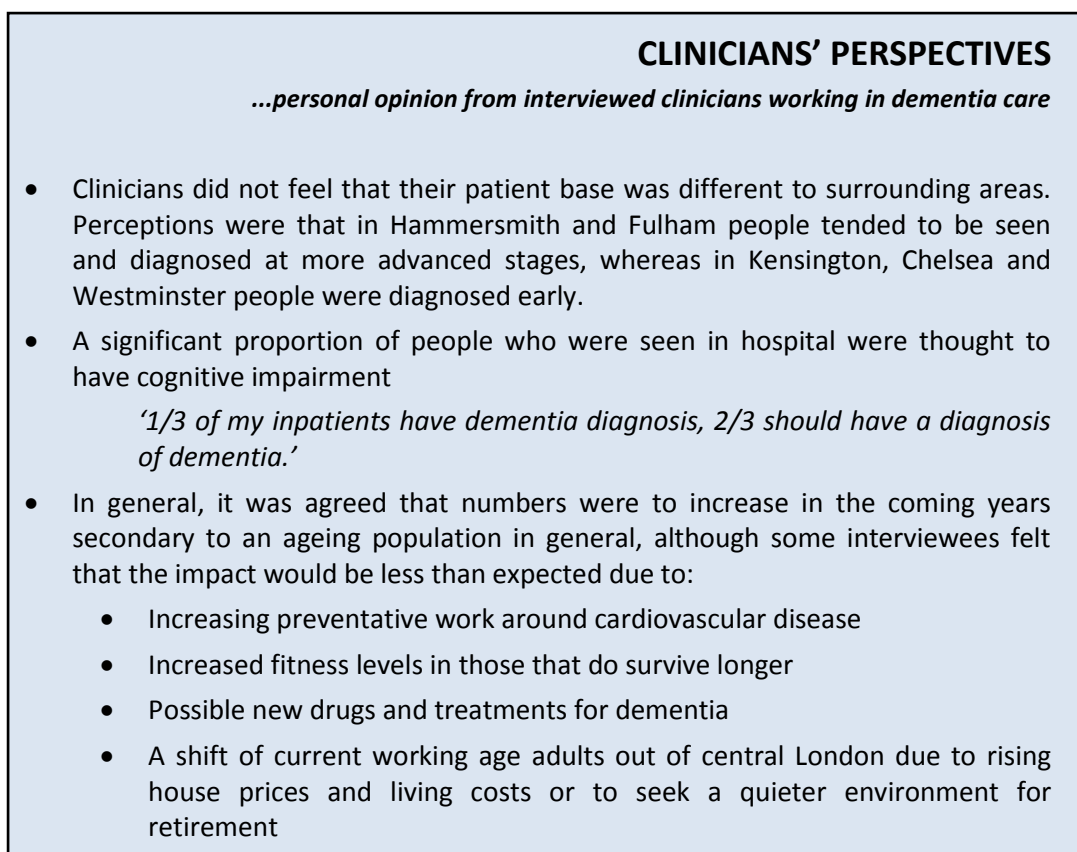




Figure 11: Clinicians perspectives 2



#### 4.4 Unpaid Care

Across the three Boroughs there are approximately 39,000 carers<sup>16</sup>. According to the Survey of Adult Carers<sup>17</sup> in the three boroughs, around a quarter of carers known to Adult Social Care services in WCC and RBKC care for someone with dementia, rising to a third in LBHF. Of the survey responders, over 50% were providing more than 50 hours a week of unpaid care, with many living with the person they care for. Around 50% had been caring for the person for 5 years or more. Providing informal care has a significant detrimental impact on carers when the level of informal care given exceeds 20 hours per week.

*'My mother is unaware she has dementia and is very depressed and anxious and depends entirely on me. She refuses to pay for a carer insisting that I am there and care for her. She is scared of being left alone and I am afraid of leaving her for any length of time'*

Local Carer, 2014/15 Survey of Adult Carers

<sup>16</sup> JSNA Carers Evidence Pack <http://www.jsna.info/document/carers-evidence-pack>

<sup>17</sup> Personal Social Services Survey of Adult Carers in England, 2014/15  
<http://www.hscic.gov.uk/catalogue/PUB12630/per-soc-ser-sur-ad-car-eng-2012-13-fin-rep.pdf>

## 4.5 Local Audit

The Adult Social Care computer record has 284 clients coded as having dementia on Framework I, the case management system, but this flag is inconsistently used, and relates only to where dementia is the primary need. Therefore an audit of cases known to services was undertaken and several individuals in teams were asked to select a representative sample from their clients to include those not on Framework I. This service audit was completed for 79 clients. This could not be a random sample and almost all cases audited were open and active.

Adult Social Care largely organizes care by the level of support required, and not the condition causing the need. Records may have some formal coding of the cause of the need, but this is not systematic. For example, LBHF has 32 people it is responsible for coded as having a primary need for dementia compared with an estimated prevalence of 1,189 of whom 641 have been identified by GPs. This coding will not be representative of the far larger number of people that LBHF actually organises support for. In contrast RBKC codes 111 people, and Westminster 141. See Appendix C for detailed tables.

### Number, gender and age group of audited cases

The two audits mirrored the national picture age and gender distribution for dementia cases. The gender split females (70%) and males (30%). The service audit had only 2 (2.5%) out of 79 aged under 70, while the Framework I audit had 12 (4%) of 284 aged under 65 and cases were concentrated in the 80+ group.

### Time in contact with service

Contact time was only assessable in the Service audit. The median contact time (half the clients have had more and half less) for those currently in contact with local services was 2.8 years with little variation between genders and across age groups. Sixteen clients (20%) have been in contact with services for more than 5 years, with 5 (6%) more than 10 years and one nearly 30 years. These long contact periods may be associated with other needs rather than dementia (e.g. Parkinson's), and the average is higher than the median. These figures do not take into account those who have died or moved away.

### Ethnicity

The ethnicity of the clients in the audits is known, but the ethnicity in the population for comparison is estimated from projections based on the 2011 census. In these projections, 87% of the population aged over 80 is "White" and 13% "Non White". This compares with 79% "White" in the Framework I audit, and 70% in the Service audit for those with dementia, whose median age is around 85.

In combination this suggests that those that are "White" are underrepresented in ASC clients known to have dementia. These are not exhaustive or random samples so differences are difficult to interpret. However, the other anomaly was that those with

dementia who were “Black” were twice as likely to be male as female, which is the opposite of the overall distribution.

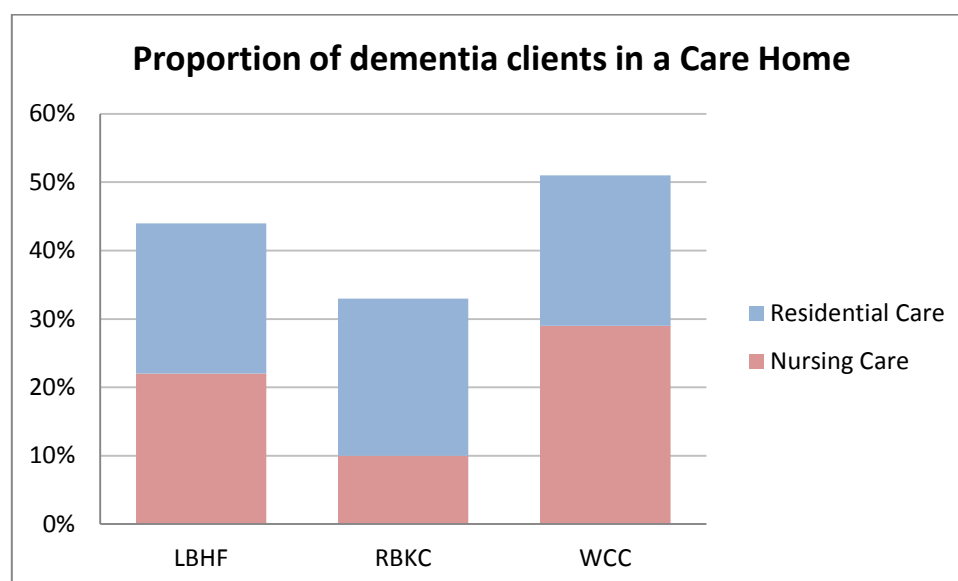
### Accommodation

The Framework I audit showed 44% of those recorded as having dementia were supported in a care home. In the Service audit the figure was 25%. This contrasts with the national average of 34%. There was no significant difference between genders in either audit. In addition, 9 % were living in Extra Care or Sheltered accommodation with 6% not specified.

There were differences between the boroughs on the type of accommodation and services accessed. Overall, 44% of clients were supported in a nursing home or residential home, but the figure for RBKC was 33% and for WCC 51%.

There was also a difference in the relative use of Nursing to Residential Homes. The percentage of those in a Care Home who were in a Nursing Home was 50% in LBHF (small numbers), 30% in RBKC, and 57% in WCC. The low proportion in a Nursing Home in RBKC reflects the general pattern among all clients in Care Homes in RBKC.

**Figure 12: Proportion of dementia clients living in a Care Home in Framework I audit**



### Level of support

Those completing the audit were asked to indicate whether clients needed a “low level” or a “high level” of care compared with the average for all clients (not just those with dementia) in the accommodation setting the client was in.

Overall 61% needed a “high level” of support, but 95% (all but one) in a residential or nursing care required a “high level” of care relative to others in the same setting.

### Carer availability

75% of clients with dementia had a carer identified, of whom half lived at the same address. 20% had no carer (for 5% there was no record). There was no significant difference by gender whether there was a carer, and whether they lived at the same address. Those who were “White” were less likely to have a carer (75%) compared with those who were “not White” (88%) but this difference was not significant.

90% of those living in their own home had a carer identified, and this was much less (as expected) for clients in a care home where 50% had a carer.

### Dementia type

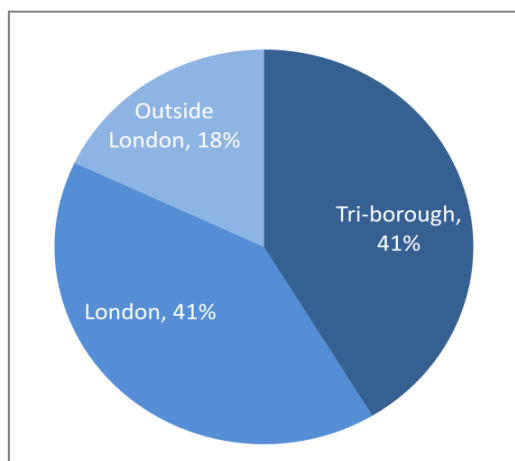
Adult Social Care provide services on the basis of need and not diagnosis, and may see different people to the GP. Accurate diagnoses are therefore not necessarily coded in records, particularly as there is no access to medical records. It was possible to extract the dementia type in 52 (66%) of the 79 cases. A third of the “Not Known” cases have a comment that the diagnosis is informal.

The distribution of cause, where it is known, is very different to the national picture for all patients (whether in contact with Adult Social Care or not). Nationally, 63% have Alzheimer’s (37% in the audit), 16% have vascular dementia (46% in the audit), and 10% have mixed (6% in the audit). This difference is very highly significant and suggests that locally those with vascular dementia either have greater needs than those with Alzheimer’s, or are more readily able to access support.

### Dementia identified care home usage

Of the total of 284 people in the Framework 1 audit, 128 (45%) are supported in a care home (residential or nursing) and the balance are supported either in their own home or with services they access outside their home. Reflecting the very low provision of care home beds, 41% of the 128 in a care home in this audit were in a home within the three boroughs, 41% were in a care home elsewhere in London, and 18% were in a care home outside London. A large proportion of the care homes elsewhere in London are relatively close to the borders of the local authority, particularly in RBKC.

Figure 13: Care home location of ASC clients in care homes known to have dementia



It is not possible to identify previous residents who were placed in a care home outside the three boroughs independently of Adult Social Care, either by themselves or their family. The actual outplacement of people with dementia will therefore be higher, probably much higher, than these figures suggest.

### Care Homes

The England average care home provision as measured in the End of Life Care Profiles produced by Public Health England is 114 per 1,000 residents aged 75 and over (range 36 to 169). Locally the in borough provision of care homes is the lowest (WCC 36), second lowest (RBKC 47) and sixth lowest (LBHF 59) in the country<sup>18</sup>. Collectively they are also the lowest at 1/3<sup>rd</sup> the national rate. However, the majority of beds actually funded for residents are outside the boroughs; 40% in borough; 40% in the rest of London; and 20% outside London. The England average provision would suggest that the three boroughs residents collectively would use 3,300 beds while there are 1,886 beds funded by the LAs and NHS for residents (57% of expected). In addition there will be self-funders who are not known to the LAs and given the nature of the boroughs there may be higher numbers of these than elsewhere. These self-funders would increase the percentage further.

Reconstructing the national indicator in this way shows that it is not as low as the in borough provision alone would suggest. This is a difficult indicator to assess because care home beds are used by all ages (1/3<sup>rd</sup> are under 65), for a variety of causes, and there is no comparator for London. However, about half of the occupants would be expected to have dementia.

The table below shows that considering total numbers only that the in borough capacity at the time the indicator was constructed was able to cover 2/3<sup>rds</sup> of current usage for all reasons across the three boroughs, just over half in RBKC and WCC and 80% in LBHF. The actual beds available may not be appropriate for LA clients.

<sup>18</sup> End of Life Care Profiles [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/la\\_2012\\_pdfs](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_2012_pdfs)

**Table 9: Total care home placements for all reason by the three boroughs in 2013 (ASC), with rates per 1,000 aged 75+ (GLA estimates) compared with in-borough capacity**

Borough	Known Placements				In Borough Capacity**		Relative
	LA*	NHS	Total	Rate per 1,000 75+	Total	Rate per 1,000 75+	
LBHF	525	98	623	79.9	506	64.9	81%
RBKC	333	73	406	44.5	228***	25.0	56%
WCC	630	227	857	71.4	459	38.3	54%
<b>Total</b>	<b>1,488</b>	<b>398</b>	<b>1,886</b>	<b>65.2</b>	<b>1,193</b>	<b>41.2</b>	<b>63%</b>

\*2013/14 LA figure includes small number with zero contribution from LA, less than 5% of total

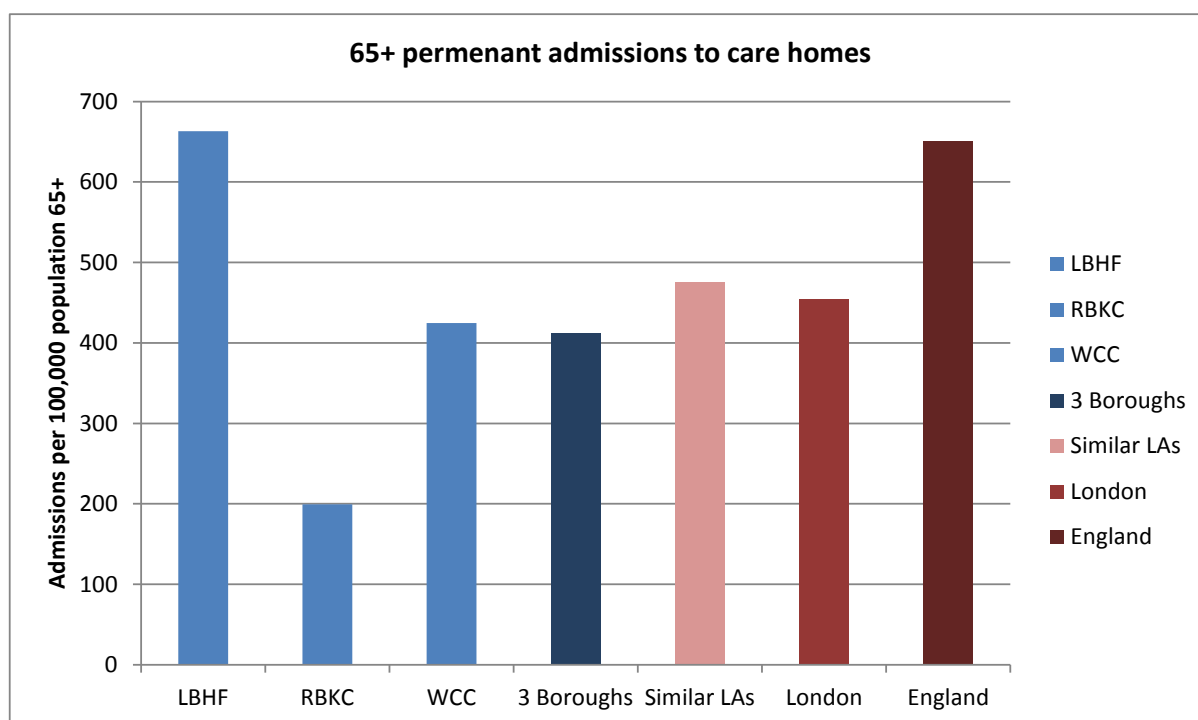
\*\*From Public Health England End of Life Care Profiles 2011/12

\*\*\* 300 removed from capacity for Royal Hospital Chelsea Pensioners

The Adult Social Care Outcomes Framework 2013/14 presents an indicator on permanent admissions to care homes in those aged 65+ as the number over one year per 100,000 in the age group.<sup>19</sup> This shows that the three boroughs collectively admit at 63% of the England rate (similar to the 57% for the number of beds above). However, there are major differences between the boroughs with LBHF admitting at near the England rate and RBKC at less than 1/3<sup>rd</sup>. See Figure 14 below. The ASC data allows comparison at a London level and with similar LAs (which includes the three boroughs). The boroughs are collectively slightly less than the average for London and similar LA's.

<sup>19</sup> Adult Social Care Outcome Framework <http://ascof.hscic.gov.uk/Outcome/713/>

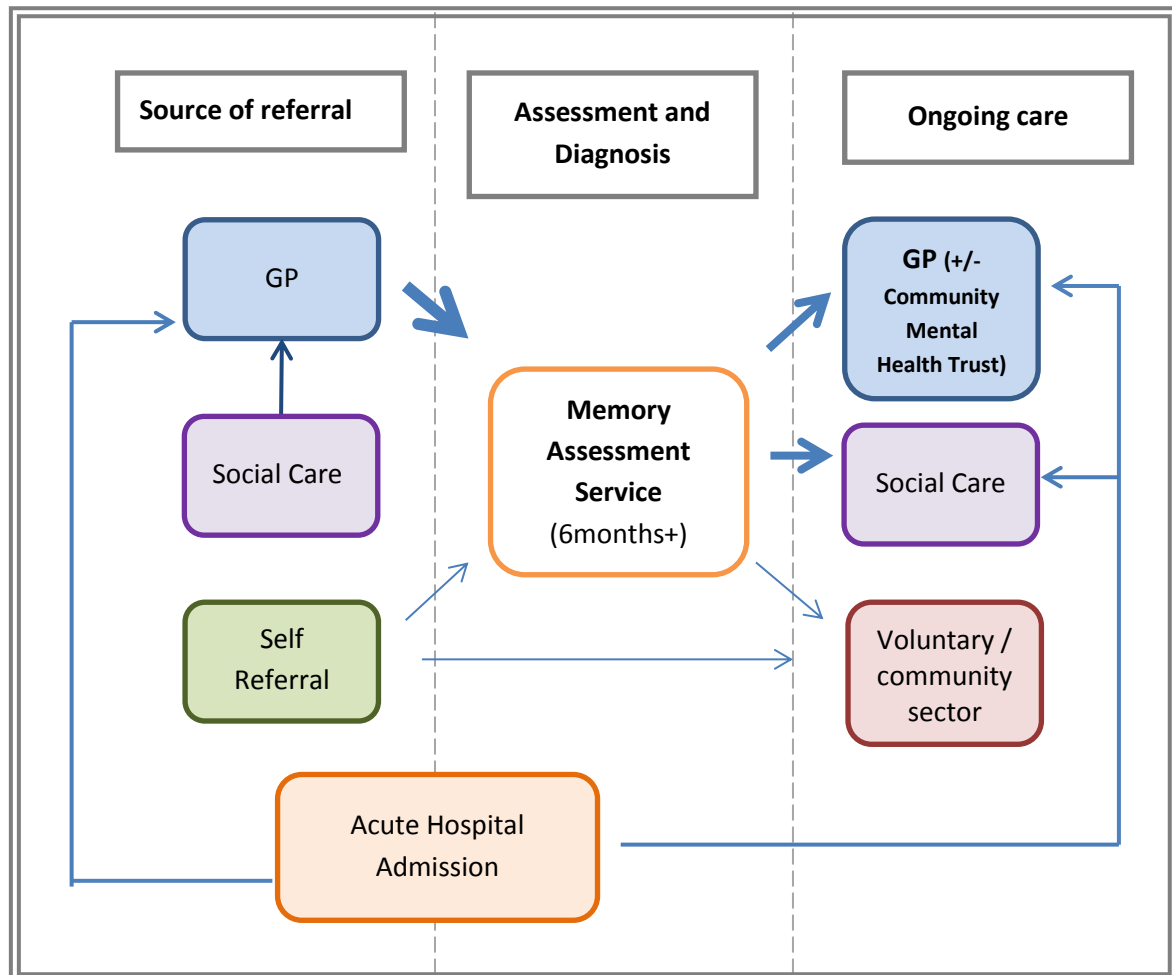
Figure 14: Number of permanent admissions to care homes in 65+ age group per 100,000 aged 65+ from ASC Outcomes Framework



A third of patients registered with the three CCGs covering the boroughs who die in a care home do so in a home that is outside the boroughs. Care homes outside London account for 2% of deaths in care homes. While the percentage is small it is significant because a care home will rapidly reregister patients with a local GP (within a few days), especially ones who are ill and need urgent care. This small percentage implies a very significant, but not quantifiable, movement of residents to care homes outside London.

## 5 Dementia services and asset mapping

Figure 15: Dementia Service Pathways



This diagram describes the pathways used in dementia care, with weighted arrows proportionate to use. It is intended as a backdrop to understanding the complex web of service provision and usage as mapped out below



Figure 16: Range of support provided locally (key below)

	LBHF	RBKC plus QPP	Westminster minus QPP
	(Hammersmith and Fulham CCG – dementia services co-commissioned with Ealing and Hounslow CCG)	(West London CCG)	(Central London CCG)
Memory assessment service	<b>'One stop shop' memory assessment service</b> (led by neurology at Charing Cross/Hammersmith hospitals) specialises in Early Onset Dementia takes ref. from all NWL <b>H&amp;F memory service</b> (led by community mental health team (West London Mental Health Trust))	<b>K&amp;C memory assessment service</b> (led by Central North West London Mental Health Trust) <b>Diagnostic Dementia Clinic</b> at Chelsea and Westminster hospital	<b>Westminster memory assessment service</b> (led by Central North West London Mental Health Trust)
	Multidisciplinary team decision (MDT) for every referral Cognitive stimulation therapy 6 months post diagnosis – called 'Mind Gym' in KCW <b>Dementia advisor service</b> (to signpost to community services) <b>Admiral nursing service</b> (has been running for 20 years in KCW, new to H&F)		
	In house psychology – works with OT to assess functional/psychological needs of patient; <b>oversubscribed service</b>	Younger onset dementia nurse x 1 (KCW) NEW	KCW 'Living well' service: outreach for preventing admission and supporting discharge post diagnosis
		None only in this borough	Dementia voice nurse (end of life care)
Primary Care	GP referral to <b>memory service</b> for diagnosis and assessment After 6 months GP resumes ongoing management <b>Coordinate My Care</b> - service sharing information between healthcare providers including decisions and expressed wishes about care while patient has capacity		
		Potential future plans to adopt CL CCG model	GP and primary care staff: training model delivered by lead GP/lead psychiatrist from memory service; 'Dementia friends' briefings for practice staff

Key Geography

LBHF

RBKC plus Queens Park and Paddington

Westminster minus Queens Park and Paddington

All three boroughs

RBKC plus Westminster

Secondary / Acute services	LBHF	RBKC plus QPP	Westminster minus QPP
	<p><b>Dementia nurses</b> at each hospital established approximately 2 years ago providing support for staff and dementia CQUIN</p> <p>Across St Mary's and Charing Cross nurses form part of the <b>Dementia Care team</b> – advising on strategy, providing staff training, and providing direct clinical care and advice.</p>		
	<p><b>All age CMHT home treatment service</b></p> <p><b>Psych liaison service</b> H&amp;F: currently has no designated old age psychiatrist as underfunded for post; has less strong links with community sector)</p> <p><b>OPAL</b>(older people's assessment and liaison) service for joint medical psychiatric needs at Charing Cross only</p> <p>Meridian ward Charing Cross Claybrook centre MH (2 beds for older people) – Likely some use of Ealing beds</p>	<p>Older adults <b>Home Treatment Team</b> (KCW)</p> <p><b>Psych liaison service</b> across St Mary's and Chelwest NEW - looking to expand to have an A+E based practitioner, increasing collaborative working</p> <p>Oakwood and Redwood ward St Charles' Hospital? beds (KCW)</p> <p>Some referrals received from UCH / Queens square</p>	
		None only in this borough	Intermediate mental health and physical healthcare service for older adults
Adult Social Care	<p>Adult social care <b>assessment</b> under a national eligibility threshold; financial assessment; signposting to other services</p> <p>Social worker attends <b>MDT meetings</b>.</p> <p>Offer one-to-one <b>home care (majority of provision)</b>/day care/outreach services/respite</p> <p>Placement in <b>residential care</b> Assess eligibility for <b>continuing healthcare</b> (CHC) with CHC nurses – decide funding from health or social care</p> <p>3 borough placements team – <b>review placements</b> for individuals and improve care home standards by getting to know all customers in one place</p> <p>Can opt for <b>personal health budget</b> if meet CHC criteria and are able to manage direct payment</p> <p><b>Carer's assessments</b> – financial support</p> <p><b>Financial Nursing Care</b> at Care home.</p> <p><b>Reablement</b> services 6 weeks post hospital admission</p>		
	Care Uk St Vincent's and Farm lane care homes – known to have high dementia caseload but do not offer specific dementia services	<p>Beatrice Place (24 bed); Alan Morkill house; 'The Quest' dementia specific care homes</p> <p>Dementia floor at Princess Louise care home (20 beds)</p>	<p>Specific dementia care home Butterworth Centre (45 beds)</p> <p>Dementia floor within Care UK care home (15 beds)</p> <p>Leonora House (5 dementia specialist beds and 21 ECH)</p>
	<p>Independent dementia specific care homes: Nazareth house, Red and Yellow Care</p> <p>Extra Care Housing (ECH): retirement housing with 24 hour domiciliary care and support available</p>		

Voluntary and community services (See sources for full guides)	LBHF	RBKC plus QPP	Westminster minus QPP
	Independent Mental Health Advocacy for older people (across three boroughs)		
	Dementia Action Alliance (DAA) Group recently closed <b>Age UK</b> : information and advice <b>Open Age</b> : various activities and link-up project to support vulnerable/isolated older people access activities <b>Alzheimer's society</b> : Memory café, day services, outreach, carer's training via CRISP programme <b>Arts/activities</b> : Nubian life day service for African-Caribbean Elders; Music 4 Life; Housing 21; Resonate Arts; Singing for the Brain <b>Home support</b> : Bishop-Creighton Centre outreach and support services; Housing 21 provide community outreach services	Primary care navigation service (collaborative with primary care) Admiral nursing <sup>20</sup>	
		<b>Age UK</b> : memory café's and support groups; outreach services and activities; Dementia Volunteer Coordinator <b>Open Age</b> : link-up project to support vulnerable/isolated older people access activities  <b>Arts/activities</b> : Arts4dementia; Culture Dementia UK; Pepper Pot centre; Open Age Second Half centre; New Horizons Chelsea (led by Open Age); The Forum' Music4life, Resonate Arts; Singing for the Brain <b>Home care</b> : Home stead; Health Vision <b>Culture specific</b> : Persian care Centre <b>Memory cafes</b> x 2(Age UK)	<b>Advocacy+</b> as part of advocacy project (will be Tri-B) <b>Arts/activities</b> : Church street drop in centre; Pullen Day Care; St Margaret's Drop-in Centre; All Soul's clubhouse Singing for the Brain; Arts4dementia; Open Age; Penfold community hub; the Abbey Centre; Housing 21; Music4life; Resonate Arts <b>Home support</b> : Age concern Westminster; Housing 21 <b>Diet</b> : Westminster health trainers <b>Culture specific</b> : Jewish Care, Chinese Community Centre; Marylebone Bangladesh Society, British Arab resource Centre <b>Octavia foundation</b> : outreach and befriending services <b>Memory cafe</b> x2 (Housing 21)

<sup>20</sup> According to sources, admiral nurses and adviser/navigator posts have fluctuated and been inconsistently filled across boroughs in recent years. We have thus not included comparison on numbers and reach of this service at this point, however this should be addressed in future strategy.

Carers' services	LBHF	RBKC plus QPP	Westminster minus QPP
	Carer's network (carer's support service and respite)	Carers Kensington and Chelsea (carer's support service and respite), smaller organisations are funded by RBKC ASC and Carers' grants to run specific carer support groups and advice	Carer's network (carer's support service and respite)
	Alzheimer's society: singing for the brain, Carer's training via Crisp programme	Open Age 'Time for me' Carers service	
		Age UK at home respite service; information and advice service; carer's support group RBKC social services line Crossroads care Carer's emergency Card scheme; contact4me scheme	Carer's training; therapeutic massage by dementia pathfinder/London school of beauty therapy; CNWL recovery college courses and workshops for carers; Housing 21 :Evening service/outings for carers activity based group in community PILOT; Supported by Dementia Voice nurse; Moveable Feast carer's group

**Services in Development:** The 'Living Well' service is currently being developed to provide post diagnostic support for people with dementia in RBKC/Westminster. It aims to support people with developing coping skills, social inclusion, increasing quality of life and independence until a more permanent plan and links are established. The service provides intensive post diagnostic support for 4 weeks with a maximum of 12 weeks and regular review after this. Users will be provided with personalised care plans directing to appropriate services both in health, social care and third sector with plans for what to do when things upset the user. Close links will be made with rapid response teams to work around avoiding unnecessary admissions. This pilot will be evaluated and reviewed.

*'Voluntary services are huge and play a massive role'*

**Local Clinician, 2014**

**Personal Budgets:** A personal budget is money that a local authority allocates to a person who needs care and support. The individual's needs must be assessed by the local authority to see whether the person is eligible for support. Some people with dementia may be eligible. The money can be spent in many ways to meet the person's needs. There is currently a low uptake of personal budgets for older people, but their popularity is expected to increase as people become more aware of them, particularly due to the importance of personalisation in The Care Act 2014. Personalisation aims to give individuals independence, choice and control over the support they use, putting them at the centre of their own care.

## 5.1 Local service cohesion

Interviews conducted with several clinicians significantly involved in dementia care in the three boroughs illustrated their views regarding the cohesion and functionality of existing services and pathway. It is important to interpret these with the knowledge that each clinician interviewed experiences a specific part of the service only, and is not necessarily privy to the whole picture. There are definite areas of strength in care with dedicated staff in the three boroughs; but this local snapshot has indicated areas of difficulty, such as structure, culture and operational attitudes, in achieving good service cohesion, that may merit addressing in future service development. Please refer to Appendix D and the separately published Dementia Care qualitative analysis for full report.

*‘Having the same referral strategy across whole trust is important’*

**Local Clinician, 2014**

### Memory services

Some GPs expressed difficulty in understanding memory services’ referral and discharge criteria. Across the board the memory service was reported as not always sticking to the six months post diagnosis limit of care; however reasons for extending care were not always clear to referring clinicians or patients/carers.

In RBKC/Westminster, GPs interviewed were happy with the referral process and felt the memory service was well linked with the community and social care. In Hammersmith and Fulham clinicians interviewed were less confident that patients were well supported following diagnosis. It was also perceived that the one stop shop and the memory service worked separately and did not cross refer. There was some interest in a joint referral strategy across the three boroughs.

The time lapse between referring a patient and subsequently hearing back with an action plan or clinic letter from memory clinic was an area of concern raised. Written letters were thorough but may be delayed in reaching the GP by two to three months or may not reach the GP at all. GPs did not feel they had sufficient capacity to chase each referral.

The diagnostic process in Imperial where patients are seen in one day with neuropsychology input was contrasted with that in West London Mental Health Trust memory service which can be quite protracted. It was felt that whilst a quick assessment had advantages, it was taxing for the patient and perhaps the richness of an assessment over time was lost. It was also raised that neuropsychology input, whilst very beneficial in some cases, was not necessarily needed for each patient and perhaps resources could be distributed differently. A single referral point to triage to the most appropriate diagnostic assessment was advocated.

### Complexity of services

Three clinicians professed difficulty in understanding the 'myriad' of different services available in the community and the complexity of their different referral criteria

### Collaborative work

The RBKC and Westminster mental health led memory service was identified as achieving good outreach and community collaboration. However, frustration was expressed by clinicians in the RBKC/Westminster area working in general medical care where there was a large separation between hospital and community/ mental health trusts, and some felt that patients with complex needs would benefit from joint input by a single team across community and secondary services.

Interviewees working in liaison psychiatry and hospital dementia nursing felt that more inter-hospital collaboration and streamlining of services would be beneficial. Three of those working in hospital spread across the three boroughs also felt that their links with the community were not as good as they could be. In historical transactions some 'guarding' of patches and organisational attitudes were cited as obstructing care collaboration.

An example of a lack of 'joined up thinking' was given where the dementia advisor service was co-funded by CCG and local authority; local authority reduced its funding without collaborating with the CCG leading to significant implications for the service. Increased strategic coordination of dementia care with a long term view and perhaps pan-London GP networking were also desired.

### Communications

For those working in hospital, referral to memory service must be done through the GP however there is little way of following up whether this actually happens. Dementia CQUINs mean there is increased emphasis on recognising potential dementia and communicating this in discharge summaries. However, clinicians have expressed concern that it is not known whether onward referral actually happens, nor are there easy mechanisms for finding out.

The differing electronic systems used by memory service, GP and acute services have been highlighted as impeding collaborative working.

### Liaison psychiatry

Increasing collaboration is happening between liaison psychiatry and hospital dementia nursing teams in Chelsea and Westminster capitalising on the opportunity to intervene earlier in hospital stay to avoid escalation of distressing behaviors and prolonged stays.

Whilst there is interest in expanding the liaison psychiatry role in dementia in Hammersmith and Fulham, capacity is limited. One clinician also highlighted a potentially poor relationship between liaison psychiatry and community mental health teams, citing

that 'there have been some historic frustrations with long stays in psychiatric inpatient wards so the liaison team tend to prefer admitting those with dementia to general hospital.'

Figure 17: Clinicians perspectives 3

### CLINICIANS' PERSPECTIVES

*...personal opinion from interviewed clinicians working in dementia care*

Quality of hospital care has improved with introduction of dementia CQUINS. There are no concerns raised regarding antipsychotic usage, and skin and nutritional care was reported to be good in Chelsea and Westminster. Continuing need for improving environments and increasing range of activities available in hospital were identified.

The relatively new memory service in KCW has been recognised as providing excellent care. Some areas for improvement have been raised for all memory services largely regarding links with social, general medical and community services, communication and delays in assessment.

Clinicians rarely had direct experience of care homes, the interviewees felt that quality of care varied, some were very good, but others could improve in terms of training to pick up dementia, deal with distressing behaviours and needs, and keeping residents hydrated. A short supply of care homes was noted with many patients moving out of borough for care, although few were perceived to move far. Clinicians felt that patients usually preferred to stay in borough and rarely requested to move near family.

One clinician reported that social care staff's understanding of dementia was good in general, but finding and retaining staff was a challenge in London. They felt that care staff could be supported with extra training and encouraged to promote dignity and independence for patients as per the 'living well' agenda. This knowledge, alongside how to create a dementia friendly environment, should be passed on to carers but they were not confident that this was consistently happening.

## 5.2 Use of services – the national picture

### Hospitals

At any one time, a quarter of acute hospital beds are in use by people with dementia (Royal College of Psychiatrists, 2013). Hospital episode data for England shows that in 2012/13<sup>21</sup> there were:

- 13,523 ‘admitted care’ admissions for patients with a primary diagnosis of dementia. This equates to one hospital episode per 43 people with dementia<sup>22</sup>.
- 474,289 ‘admitted care’ admissions for patients with a diagnosis of dementia, but have been admitted for another primary reason. This equates to one hospital episode per 1.2 people with dementia.
- 73,789 ‘outpatient’ attendances for patients with a primary diagnosis of dementia. This equates to one attendance for every 8 people with dementia.

This data shows that people with dementia do not commonly go to hospital because they have dementia, but do commonly go to hospital for other reasons. Other long term conditions associated with age (e.g. diabetes) are likely to be stronger drivers of demand for hospital services, but as the number of people with dementia increases, more patients in hospital who present for any reason will have comorbid dementia.

People with dementia present more commonly to general health services than to specialised dementia services. This is reflected in the hospital episode statistics above, which show approximately one hospital admission per year for any reason per person with dementia, but only 0.02 episodes primarily for dementia. Therefore, the quality of services for people with dementia is primarily dependent on the degree to which general services are designed to be suitable for people with dementia.

Recent reviews have found large deficiencies and variation in the readiness of health services to care for people with dementia. There have been improvements in recent years.

The Royal College of Psychiatrists’ audits of dementia care in hospitals in 2011 and 2012-13 found that the majority of hospitals have not yet considered and implemented measures that would address the impact of hospital admission on people with dementia (Royal College of Psychiatrists, 2011, 2013). At the time of the first audit, only 6% of hospitals had a pathway in place for people with dementia.

In terms of assessments in hospitals, there was a gap between policy and practice. The proportion of hospitals that had procedures specifying assessments such as functioning, nutrition and mental state was much higher than the proportion of patients that received these assessments. As figure 16 shows, the proportion of patients receiving assessments improved between the audits.

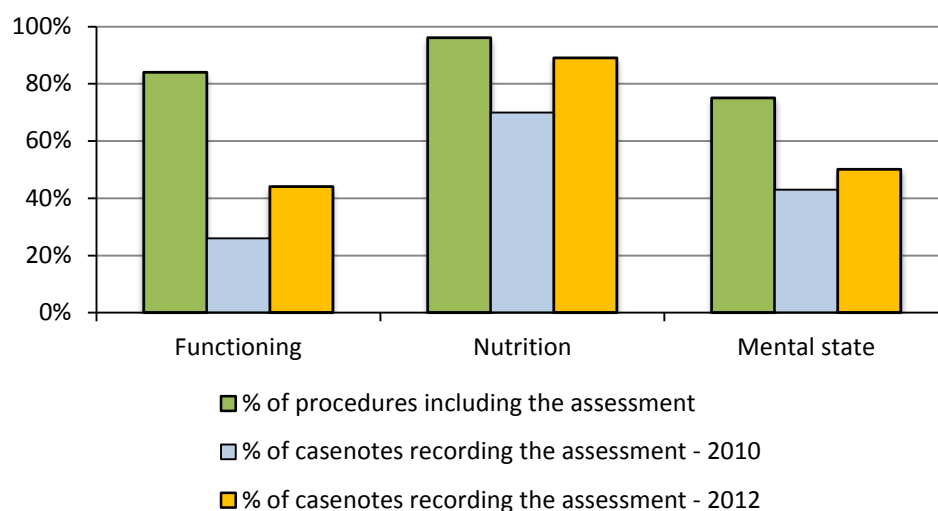
---

<sup>21</sup> Hospital Episode Statistics from HSCIC

<sup>22</sup> Assuming that there are 583,000 people in England with dementia, based on a prevalence of 1.1%.



Figure 18: Assessments of people with dementia in hospital



The audits also found that:

- Almost all hospitals have a psychiatric liaison service, but there is low provision of out-of-hours services. Many patients referred were not seen in a timely way, with long delays in both audit rounds.
- There were large numbers of hospitals without 'dementia friendly' adjustments (e.g. clocks, calendars, clear signs, etc.).
- Levels of training were low in the first round, with only 32% of staff saying they had sufficient training in dementia awareness/care. There was a 'notable improvement' in the second round.
- Very few hospitals collected personal data to inform care plans on discharge. In the first round, only 28% of case notes showed summaries of symptoms at discharge. This appeared to improve in the second round.
- Many hospitals appointed 'dementia champions' between the rounds.

The Care Quality Commission analysed health episodes for people with dementia between 2011 and 2012, and compared the data to similar people without dementia (Care Quality Commission, 2013). The findings were that:

- In most areas, people with dementia in care homes are more likely to be admitted to hospital for avoidable conditions (e.g. dehydration, pressure ulcers, urinary infections).
- Dementia did not affect the likelihood of multiple emergency admissions (supporting the data shown above that people rarely go into hospital primarily due to dementia).
- In 29% of hospital admissions for people with dementia, the person's dementia was not recorded despite it having been recorded in the past. The trend was more pronounced for elective (58% not coded) than emergency (24% not coded).
- Patients with dementia stay in hospital longer when admitted for an emergency or an elective procedure.
- Patients with dementia were significantly more likely to die in hospital than people without dementia.

### Other health services

The Department of Health's *A state of the nation report on dementia care and support in England*<sup>23</sup> found that between 2012 and 2013, 143 out of 160 acute trusts and 24 out of 94 non-acute trusts committed to becoming 'dementia friendly', working in partnership with their local Dementia Action Alliance (Department of Health, 2013).

### Adult Social Care

Dementia has few specific medical treatments and the direct costs fall mainly on adult social care services, as shown in figure 4 (Estimated breakdown of costs of dementia for the UK, 2013). These costs are either for providing one-to-one home care or residential care, with residential care forming the majority of costs (Health Foundation, 2011).

Local authority Adult Social Care Departments are responsible for supporting people with dementia to live safely and independently within their own homes and local community for as long as possible. Staff will assess an individual's social care needs and work with that person to devise and coordinate a tailored, person centred support plan detailing what the person wishes to achieve, what is needed to make this possible and who will provide it.

People who need adult social care services will be allocated a personal budget and can decide either to have the Council arrange help on their behalf or to receive a Direct Payment which allows them to arrange their care themselves.

Support that can be available includes:

- Information and advice
- Practical support within the home
- Equipment or adaptations within the home that can maintain or improve independence
- Assistive technology to help people to do things, maintain safety or reduce risks
- Supporting people to participate in community activities
- Rehabilitation by community therapists or reablement officer to maintain or improve general levels of functional ability
- Devising Emergency Care Plans that can be activated at times of unforeseen crises
- Managing finances should there be no one else to do this
- Discussing and planning for the future
- Planning and arranging moved to either Extra Care Sheltered Housing or Residential care should this be relevant or necessary.
- Enabling and supporting people to be safe and free from harm

---

<sup>23</sup> Department of Health (2013) *Dementia: a state of the nation report on dementia care and support in England* <https://www.gov.uk/government/publications/dementia-care-and-support>

Adult Social Care also provide community services such as day centres and memory cafés for people with dementia. The Care Act places a duty on the Local Authority to assess the needs of carers in their own right and to enable them to lead a healthy, active fulfilling life and so Adult Social Care also commission services to support carers.

It is recognised that carers play a significant role in preventing the need for care and support for the people they care for and it is important to prevent carers from developing their own needs for care and support. There may be specific interventions for carers that prevent, reduce or delay the need for carer's support. This may include but is not limited to:

- Providing comprehensive advice and information about what is available including support groups and networks.
- Enabling carers to care safely and effectively e.g. via timely interventions; advice on moving and handling safely; avoiding falls in the home; training to perform basic care tasks
- Supporting carers to enable them to continue in their caring role should they wish to do so by enabling them to look after their own physical and mental health and wellbeing, including developing coping mechanisms
- Supporting carers to make choices about their own lives, such as managing work, family and leisure commitments
- Make alternative arrangements should a carer no longer feel able to continue in that role
- Carers can also be eligible for personal budgets to enable them to purchase items that make their caring role easier

## 6 Views of people with dementia and their carers

### 6.1 National Context

The views and perceptions of people with dementia and their carers underpin the principles of person centred dementia care. However, recent research on the Dementia Engagement and Empowerment Project (DEEP) undertaken by the Joseph Rowntree Foundation (Williamson, 2012) found that the development of a dementia 'service user movement' was still in the early stages, with only a "small number of groups led by or actively involving people with dementia that are influencing services and policies".

The same report recommends that national and local organisations such as Clinical Commissioning Groups and local authorities need to **"develop and implement involvement plans, allocating resources to develop new groups, link groups together and help them share resources"**. There are several guides on how to consult people with dementia, such as the Department of Health's *Listen to us: Involving people with dementia in planning and developing services*<sup>24</sup>

Research does show that a large proportion of people with dementia feel unsupported, do not feel part of their community, often experience anxiety or depression, and do not feel society is geared to deal with dementia (Alzheimer's Society, 2012). While a survey undertaken by the Alzheimer's Society (Alzheimer's Society, 2013) suggests that progress is being made, with almost two-thirds (61%) of respondents reporting that they were living well with the condition, the report also found that quality of life is still varied for a significant number of people with dementia. Environment, presence of depression, social isolation and loneliness are key drivers for quality of life for people with dementia.

Overall, there is a small and relatively limited evidence base on the views and perceptions of people with dementia and their carers. Further findings from the best available international evidence are summarised below. Consideration should be given to where findings may be relevant to the local population.

---

<sup>24</sup> Department of Health (2005) Listen to us: involving people with dementia in planning and developing services  
<http://webarchive.nationalarchives.gov.uk/20130402145931/http://dementia.dh.gov.uk/listen-to-us-involving-people-with-dementia-in-planning-and-developing-services/>

Theme	Description	Evidence
Services	Care Homes	<p>Research undertaken by the Alzheimer's society (Quince, 2013) found:</p> <ul style="list-style-type: none"> <li>• There are low expectations about the quality of life of people with dementia in care homes.</li> <li>• Positive views on the quality of care for people living with dementia in care homes</li> <li>• Finding information on care homes can be challenging.</li> <li>• A large number of people with dementia had moved care home after they initially moved in. The most common reason was an increase in needs.</li> <li>• Family members and staff were positive about how homes worked with doctors and family members</li> <li>• Views on opportunities for trips out and how the home worked with volunteers were less positive.</li> </ul> <p>Although family members' views on opportunities for activities in care homes were good, there is further evidence which suggests that older people with dementia living in care homes often have differing views from their carers' and staff on what constitutes a meaningful activity (Harmer &amp; Orrell, 2008).</p>
Services	Palliative care	<p>A recent review (Raymond et al., 2014) of carers' and professionals' views on end of life care made the following observations:</p> <ul style="list-style-type: none"> <li>• A lack of communication between professional and carer may lead to a poor experience. Professionals should establish the carers' perspectives and wishes on the care of the patient.</li> <li>• Cultural backgrounds, beliefs and experiences of professionals may influence choices over what kind of support and care is desired</li> <li>• Advance care planning may be helpful to all parties, but may not always be desired</li> <li>• Professionals need to be aware of the possibility of elder abuse or poor quality care when supporting people with dementia and should know their responsibilities</li> <li>• Professionals may benefit from skills development and access to resources in seeking to implement a holistic approach to end-of-life care for people with dementia</li> </ul>

Theme	Description	Evidence
Services	Cognitive Stimulation Therapy	Cognitive stimulation therapy (CST) is highly valued by people with dementia, although staff and family carers expressed some concern about effectiveness (Aguirre, Spector, Streater, Burnell, & Orrell, 2011).
Services	Telecare	There is some limited evidence (Chou et al., 2012) that carers of people with dementia view telecare medical support systems (TMSS) positively. Perceived benefits include the ability to self-diagnose patient's conditions; provide reminders, care, and emotional support; and help stabilize the patient's condition and emotions. The study was conducted in Taiwan and may not be relevant to local populations.
Services	Assistive Technology	<p>Research from the UK and Israel (Landau, Werner, Auslander, Shoval, &amp; Heinik, 2010; McCabe &amp; Innes, 2013) indicates that, despite some ethical concerns, the use of Global Positioning Systems (GPS) to promote safe walking and tracking of people with dementia were acceptable to older people, people with dementia, and their carers.</p> <p>Users of the tracking devices, their carers, and professionals should be involved in the design of the devices in discussions regarding their use.</p>
Interventions	Crisis interventions	<p>One study (Toot et al., 2013) reported the following to address crises for people with dementia:</p> <ul style="list-style-type: none"> <li>• People with dementia preferred support from family and friends, access to mobile phones and home adaptations to reduce risks</li> <li>• Carers were keen on assistive technology and home adaptations</li> <li>• Both carers and staff valued carer training and education, care plans and well-coordinated care.</li> <li>• Staff emphasized more intensive interventions such as emergency home respite and extended hours services.</li> </ul> <p>Practical interventions such as home adaptations, assistive technology, education and training for family carers, and flexible home care services were highly valued by service users and their families during times of crisis and may help prevent hospital admissions. Specialist home care was highly valued by all groups.</p>

Theme	Description	Evidence
Vulnerable groups	People with a visual impairment and dementia	<p>One study (Lawrence, Murray, Banerjee, &amp; Ffytche, 2008) considered the implications for people with dementia and visual impairment. Six themes were identified from a number of case studies:</p> <ul style="list-style-type: none"> <li>• Disorientation, including the inability to orientate oneself due to a lack of memory and visual cues.</li> <li>• Loss of independence</li> <li>• Accepting multiple losses, with acceptance identified as a key coping strategy</li> <li>• Risk of isolation. Day centres and one-to-one interaction were both highly valued</li> <li>• Hallucinations, with over a third of the older adults interviewed experiencing visual hallucinations</li> <li>• Challenges to services. Professionals reported difficulties in coping with patients who developed dementia, and a lack of training.</li> </ul>

## 6.2 The Local Context

To inform the development of a local strategic approach, Healthwatch have undertaken research to identify and capture local views on dementia care. Evidence was collected through 'enter & view' visits to hospitals and care homes; patient stories; outreach; the Dementia Project Group; Dementia Action Alliance; and from day centres. Some of the views expressed are captured below.

### Day centre

*'...the people here are lovely, we sing and dance together' (Service User)*

*'...transportation does become a problem for people as the illness develops' (Worker)*

### Diagnosis

*'Diagnosis took a long time'*

*'...hospitals should test all new patients because some of the people here may need extra assistance'*

### Memory Cafés

*'...(x) is great; she organises a book club... read book out loud, ...royal academy workshop discuss paintings - once a month'*

*'...(would like to) leave her husband for half or a full day as opposed to a 2 hour slot'*

### Care homes and hospitals

*'...nursing staff were not differentiating between someone who has dementia and someone who did not, unclear if hospital staff have extra training to learn about the illness?'*

*'The residents are not taken out in to the wider community' (Carer)*

*'...families are not involved in care until something goes wrong' (Family carer)*

### Care and support

*'... care not reviewed'*

*'...her husband felt very isolated because early on he refused to pay for anything (self funders)'*

*'Father was already discharged and was on his way to his flat by ambulance.... when (she) got to father's flat...found him lying on the sofa in his vomit in a dazed medicated state.'*

### Areas for improvement

Based on this research the following were perceived as areas for improvement:

- Confidence in GP ability to effectively screen for dementia
- Regularity of care reviews – GP and social services every year/15 months?
- Integration of health and care services
- Staff training (inc. GPs, support staff, hospital staff)
- Information on how to access services especially for self funders
- Inpatient care including discharge planning
- Respite and support for carers
- Quality and confidence in care homes and home care, particularly staff
- Personal control when choosing services

### Carer satisfaction from the ASC Carers Survey

Every two years, ASC seeks views from carers who have been assessed in the previous 12 months on their quality of life and satisfaction with local services for themselves and the person they care for.

The 2014/15 Survey of Adult Carers identified that 3-4 of every 10 carers assessed in LBHF provided care for someone with dementia, with slightly lower rates in the other two boroughs.

On average, carers in WCC and LBHF provide more hours of unpaid care per week than is typical of many other areas and they are more likely to live with the person they care for.



The survey has told us that carer quality of life and overall satisfaction with services have increased in WCC and LBHF in the last two years. However, the majority of carers in all three boroughs would still like to have more social contact with people. Quality of life of those caring for someone with dementia in RBKC is slightly lower than for the overall caring population but satisfaction is slightly above

Those caring for people with dementia in Westminster have the lowest quality of life score of the three boroughs and satisfaction is also lower than for the overall carer population in the borough.

Figure 19: Proportion of carers assessed who are caring for someone with dementia

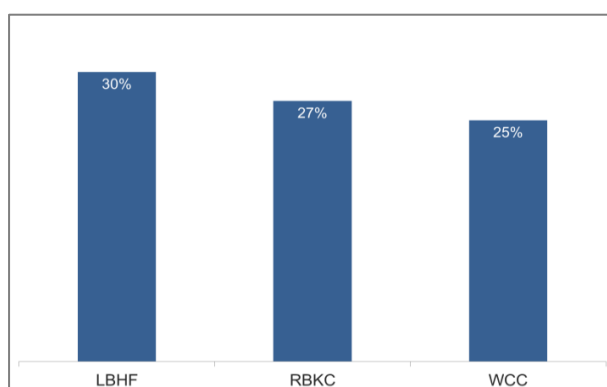


Figure 20: Carers quality of life score (out of 12) – for all carers and those caring for someone with dementia

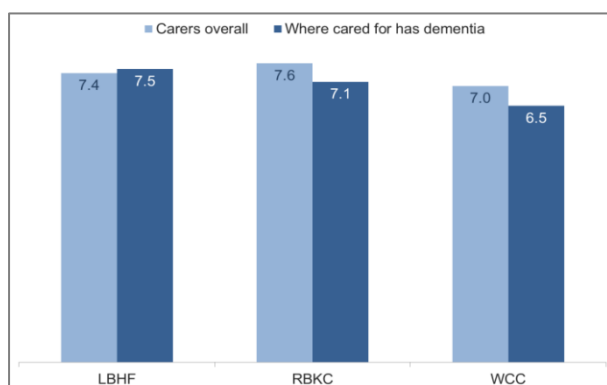
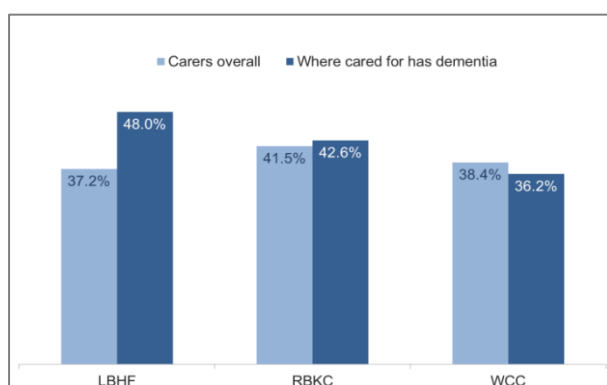


Figure 21: Carers satisfaction score (extremely and very satisfied) – for all carers and those caring for someone with dementia



**Carer's issues from survey**

*"I am really suffering being my husband's main carer. As he rejects other people's help I have to do everything for him. I have no rest and haven't been on holiday for 12 yrs. Looking after someone with dementia is the most difficult job in the world"*

*"My mother is unaware she has dementia and is very depressed and anxious and depends entirely on me. She refuses to pay for a carer insisting that I am there and care for her. She is scared of being left alone and I am afraid of leaving her for any length of time"*

*"Because my mother has dementia, carers usually ignore her e.g. Carers on their phones, no encouragement to take a drink, carers always asking what to do"*

*"When people phone my mum to ask her is everything is ok or she needs everything, [they should] not to believe her when she says no. She has dementia and always says everything is ok. It would be more helpful for social worker to visit and make a decision based on what they see rather than what she says on the phone"*

**What helped most or what could change:**

*"The Dementia Assessment Process [helped most], after which I asked for respite care"*

*"Direct debits that enable purchase of a professional carer specialising in dementia care [helped most], and 2 afternoons a week for respite care"*

*"To receive a service that allows me to go out for shopping/chores, from someone with experience in dementia - the same person each time"*

*"More resources for people with dementia living at home. More day centres for vulnerable people so all caregivers get a break. Improve communication between service providers and service users and their caregivers"*

*"After 3 years I found that, because my husband is a sufferer of dementia, I should have had a reduction of 25% in my council tax - this was not made clear to me. More info on things like this would help"*

## 7 Review of evidence and models of care

### 7.1 Evidence of what works

This section provides a brief review of published evidence on the efficacy and effectiveness of interventions for dementia care, management, support and prevention. The review focuses on the following areas:

- prevention of dementia
- management and care of people with dementia
- living well with dementia
- dementia friendly communities
- telehealth/telecare for people with dementia
- support for carers

#### Prevention of dementia

The main risk factor for dementia is growing older and ageing. Other risk factors are summarised in the table above at section 3.3 (Solomon et al., 2014). Key routes to prevent dementia are modifying cardiovascular risk, maintaining mental stimulation, social engagement, and physical activity and treating depression.

Evaluating the effectiveness of these factors in preventing both cognitive decline and dementia proves slightly problematic. Most factors have a relatively weak association with the disease so an effective intervention should ideally address the spectrum of factors.

Following a meeting of experts in 2014, Public Health England and the UK Health Forum issued the Blackfriars Consensus<sup>25</sup>. This recognised the overlap between risk factors for vascular disease and dementia, and the potential for effective approaches to prevent non-communicable diseases (e.g. cardiovascular disease) to also improve brain health in populations.

#### Future developments in prevention of dementia

The evaluation of prevention interventions is complicated by timescales, mode of diagnosis, and a lack of reliable biomarkers (Imtiaz, Tolppanen, Kivipelto, & Soininen, 2014). Three large multicentre trials are currently taking place in Europe and the results will inform the case for preventive intervention. These interventions look at nutritional guidance, physical activity, cognitive training and social activity, and management of metabolic and vascular risk factors (Kivipelto et al., 2013); omega 3 (Carrie et al., 2012); and cardiovascular risk factors, comprising of treatment of hypertension, hypercholesterolemia, diabetes and reducing overweight, smoking cessation, and stimulating physical exercise (Richard et al., 2009).

---

<sup>25</sup> Public Health England/UK Health Forum. *Blackfriars Consensus*  
[http://nhfshare.heartforum.org.uk/RMAssets/Dementia/Blackfriars%20consensus%20%20\\_V19b.pdf](http://nhfshare.heartforum.org.uk/RMAssets/Dementia/Blackfriars%20consensus%20%20_V19b.pdf)

NICE are currently developing guidelines referring to midlife prevention of dementia.<sup>26</sup> Advances in drug treatments are also in the early stages (Schneider & Sari, 2014).

At present, as many of the risk factors are addressed by a wider public health agenda and there is little robust evidence for preventive intervention, it seems prudent to wait before considering initiation of a targeted preventive intervention. However, some thought should be given to promotion of social cohesion, mental stimulation and treatment of comorbid depression in terms of secondary prevention.

### Management and care of people with dementia

Almost all forms of dementia are progressive and cannot be cured. Medication may be prescribed for some dementias to prevent symptoms from getting worse and psychological treatments may help patients to cope with some of the symptoms. The NICE guidelines on dementia (NICE, 2006) make recommendations for the identification, treatment and care of people with dementia and the support of carers.

Recommended pharmacological therapies include:

- Acetylcholinesterase (ACE) inhibitors to improve mild to moderate Alzheimer's disease
- Memantine hydrochloride to improve severe Alzheimer's disease
- Antipsychotic medication may be used to treat distressing behavior, although should be used with caution due to the uncertainty of the adverse effects of overuse of antipsychotics in dementia
- Antidepressants may be prescribed for people with dementia who also have depression or anxiety

Cognitive stimulation therapy (CST) is the only psychological intervention specifically recommended by NICE for mild to moderate dementia, although cognitive behavioural therapy (CBT) may also be appropriate for people with dementia who are also experiencing depression or anxiety.

The NICE guidelines also recognize the importance of promoting and maintaining the independence of people with dementia. Care plans should be drawn up which maximize independent activity, enhance function, and minimize the need for support. Care plans should include:

- consistent and stable staffing
- retaining a familiar environment
- minimise relocations
- flexibility to accommodate fluctuating abilities
- assessment and care-planning advice regarding activities of daily living (ADL), and ADL skill training from an occupational therapist (OT)
- assessment and care-planning advice about independent continence care

---

<sup>26</sup> NICE <http://www.nice.org.uk/guidance/indevelopment/GID-PHG64> (accessed 01 July 2015)

- environmental modifications to aid independent functioning, including assistive technology, with advice from an OT and/or clinical psychologist
- physical exercise, with assessment and advice from a physiotherapist
- when needed support for people to go at their own pace and participate in activities they enjoy.

Appendix B NICE 'Priorities for Implementation' summarises the key priorities for implementation highlighted in the NICE guidelines.

### Living well with dementia

Underpinning the idea of person centred care is the idea of supporting people to accept their diagnosis, cope with inevitable strains and maintain as good a quality of life as possible despite it.

Red and Yellow Care and the Alzheimer's Society have jointly published a document that outlines 6 facets of 'a good life with dementia' (Rowe, Brown, Holland, & ESRO, 2014) and addresses some of the more subtle nuances regarding factors that affect quality of life, based upon ethnographic research and experience with people with dementia:

- Respecting identity
- Embracing now
- Sustaining relationships
- Valuing contrast (good days and bad days)
- Supporting agency (risk versus restriction)
- Maintaining health

These facets are described more fully in Appendix E 'Six Paths to a Good Life with Dementia'.

The work is supported by feedback from local clinicians<sup>27</sup> which indicated that those who were able to maintain hobbies and/or keep working had an especially good quality of life. Those with younger onset dementia were highlighted as having specific challenges related to relinquishing role and purpose in life. One clinician felt that the patients in their area had a much better quality of life than the average as the majority were affluent, well-educated and a high proportion of self-funders with live-in carers. Another touched upon the importance of good relationships, citing those with family as carers had better outcomes, largely because of the discontinuity of paid care.

Resources such as this can be used to supplement best practice care both by front-line staff and to empower people with dementia and their carers to 'live well.'

---

<sup>27</sup> Appendix D: Dementia Care Qualitative Analysis

### Dementia friendly communities

Dementia friendly communities are recognised as important in improving the everyday lives of people with dementia and raising awareness of the condition, and the term has become widely used in UK policy. The term represents an amalgamation of:

- evidence regarding environments that facilitate functioning and reduce mental distress in the cognitively impaired
- enhancing the role of people with dementia within their communities via methods of increasing access to various facilities and reducing stigma in society.

There is no clear prescription of what a dementia friendly community should look like. The Alzheimer's society has outlined areas of focus that include accessing community services, support such as befriending services to enable community engagement; adjusted housing, transport and travel arrangements and respectful and responsive businesses and services. Much of this will require working with the voluntary and community sector and small businesses to implement. There is opportunity for housing and urban planning as well as design of residential and inpatient units to incorporate facets of a dementia friendly environment.

Consideration should be given by designers and planners to the following (Mitchell, 2012):

- natural light and outdoor views
- clear hierarchy of public and private spaces
- clear colour changes between walls and floor or furnishings
- distinctive furniture to aid way finding.
- Improved access to street
- wide non-slip pavements
- good street lighting
- public seating
- distinct landmarks
- quiet calm environments
- transport links
- new technologies

As part of the Enhancing the Healing Environment programme, the King's Fund developed resources and assessment tools for hospitals, care homes, primary care premises and specialist housing providers to become more dementia friendly<sup>28</sup>. The assessment tools are based around five design principles which are known to enable the following outcomes:

- Easing decision-making
- Reducing agitation and distress
- Encouraging independence and social interaction
- Promoting safety

---

<sup>28</sup> Kings Fund <http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia>

- Enabling activities of daily living

The design principles are Meaningful Activity; Legibility; Familiarity; Wayfinding; and Orientation. The specific assessment tools available are:

- [Is your care home dementia friendly?](#) – for use in care homes
- [Is your health centre dementia friendly?](#) – for use in health centres and GP premises
- [Is your housing dementia friendly?](#) – for use in any ‘housing with care’ setting including extra care housing, retirement communities, sheltered housing and very sheltered housing of any tenure
- [Is your ward dementia friendly? Is your hospital dementia friendly?](#) – one tool for use in wards and clinical areas and the other for areas such as Outpatients

### Peer support and befriending services

Both the goals of living well with dementia and dementia friendly environments/communities can be supported by peer support, befriending and community based activities, largely provided by the voluntary and community sector. They have the added benefit of supporting not just the person with dementia but also the caregiver.

*‘Caring communities are difficult in an urban inner city’*

**Local Clinician, 2014**

A national evaluation of peer support networks<sup>29</sup> highlighted their ability to enhance community engagement and dementia awareness, and that people with dementia and their carers ‘spoke about the positive aspects of identifying with other people in a similar position, and the unique quality in peer-to-peer relationships: decreased isolation, increased confidence emerging from discussing struggles and triumphs.’ It was also emphasized that peer support was useful immediately post diagnosis, often filling a needs gap, and the flexibility of support was seen as a strength. However, care was advised regarding the variability between people at different stages of dementia and their relationships with carers. Peer support networks worked better when they were supported by a strong infrastructure and worked well in collaboration with other services such as dementia advisers.

Dementia or memory café’s consist of regular forums where people with dementia and carers can get together and share experiences, providing peer support. There is little formal quantitative evaluation bar a confirmation of their ongoing benefit in Australia (Dow, Haralambous, Hempton, Hunt, & Calleja, 2011) but their widespread popularity is an

<sup>29</sup> Healthbridge: a national evaluation of peer support networks and dementia advisers in implementation of the national dementia strategy for England  
<https://www.gov.uk/government/publications/peer-support-networks-and-dementia-advisers-evaluation>

indicator that they are well received and meeting a need (Capus, 2005; Halley, Boulton, McFadzean, & Moriarty, 2005). Locally a couple of clinicians cited this as one of the best parts of the current dementia service.

Befriending services, where trained volunteers help people with dementia access activities or help provide respite for carers, are also popular and have been shown to increase quality of life. A cost-effectiveness analysis indicated that befriending services led to an ICER of £2,800 per QALY gained when carers and people of dementia were included, but that a non-significant increase in costs across all sectors (health and social care, voluntary sector, family care costs) indicated that the intervention may not be cost effective to society as a whole (Wilson, 2009).

A systematic review of interventions for supporting caregivers concluded that well designed psychoeducational or interventions with multiple components were effective at improving caregiver quality of life and preventing depression (Parker, 2008). Factors that appear to positively contribute to effective interventions are those which:

- Provide opportunities within the intervention for the person with dementia as well as the caregiver to be involved
- Encourage active participation in educational interventions for caregivers
- Offer individualised programs rather than group sessions
- Provide information on an ongoing basis, with specific information about services and coaching regarding their new role
- Target the care recipient particularly by reduction in behaviours

Factors which do not appear to have benefit in interventions are those which:

- Simply refer caregivers to support groups
- Only provide self help materials
- Only offer peer support

For residential services, improving social interaction, mental stimulation and physical activity are areas that can be useful for improving quality of life and thus reducing comorbid depression and forming a role in secondary prevention. This may also impact upon inappropriate use of antipsychotic medication. Some more novel innovations include 'living room theatre' (van Haeften-van Dijk, van Weert, & Drees, 2014) and dance therapy (East London NHS Foundation Trust, 2011). Whilst a strong evidence base would be required to justify spending for a community based preventive intervention, implementation in a care home would require more thought into the feasibility and acceptability of any intervention in the environment. The National Strategy has already highlighted problems with quality of care. In the local context staff knowledge, skill and time would have to be taken into consideration.



Figure 22: Clinicians' perspectives 4

**CLINICIANS' PERSPECTIVES**

*...personal opinion from interviewed clinicians working in dementia care*

Most clinicians were very keen for the community and the environment to become 'dementia friendly.' There are already actions improve hospital environments through creating social areas, colour coding and social activities.

The following quote illustrates the tension between the ideal and local situation:

*...'I think dementia friendly communities are great. The idea is fantastic for me: it means people being aware- having an awareness of what dementia is and the impact that that could have on a person. Things like not standing behind someone and 'tutting' when they're struggling to count out their change; being more mindful of others, learning how to pick up somebody who is confused and may feel agitated and helping them in they feel comfortable; shops in particular being geared towards patients who may have memory problems.*

*...There was a great example of a community out in the country where there was a gentleman that drunk in the local pub for years. He developed dementia and stopped going down because he kept getting lost; his daughter became really concerned but locals who knew him suggested she give a certain amount of money a month to a landlord who can then run off a tab so he doesn't have to handle money and be vulnerable. His friends then used to take turns to walk back with him or collect him so his daughter knew he would be safe, getting a regular meal, could socialize – that is the epitome of 'dementia friendly' – people adjusting to allow an individual to lead an independent life for as long as possible.*

*...It's difficult in London, people don't make eye contact don't talk to anybody, we're all in our bubbles. Its achievable but it's about the willingness- people like Tesco have signed up to dementia action alliances, I have now become a dementia friend champion so I will be offering the training sessions to the local newsagent, Starbucks and Subway to get a few organisations with more awareness- it would be a marvelous thing if this could happen all over London.'*

**Assistive technology (AT)**

The term assistive technology (AT) covers a range of technological devices and solutions designed to support people to live independently in their home, in safety, and with dignity (Bonner & Idris, 2012). AT can be used to support independent living by:

- Reducing hospital stays by supporting earlier discharge
- Monitoring the safety of persons with dementia who live alone
- Use of reminder systems e.g. medication
- Use of home security and social alarm systems

As well as promoting independence and autonomy, AT can enable people to manage potential risks around the home, reduce the need for early entry into care homes and hospital, facilitate memory and recall, and reduce stress on carers.

AT covers a range of electronic devices to support people with dementia<sup>30</sup>. This can include a range of memory aids, e.g:

- Voice recorded reminder messages which are activate, for example, when a person enters or leaves their home e.g. reminder to pick up their keys or lock the front door
- Clocks and calendars. Clocks that show whether it is evening or morning can help prevent disorientation
- Medication aids e.g. automatic pill dispensers beep and dispense pills when medication is due to be taken
- Locator devices which can be attached to items that are often mislaid and will beep when activated by a radio transmitter

One form of AT is telecare such as alarm systems usually activated by a neck or wrist-worn pendant. Any alerts are usually monitored by a call centre who will then contact the resident, their family, carer or emergency service depending on the seriousness of the situation. Examples of telecare include:

- Flood sensors – can be fitted on skirting boards or floors. The system can shut off the water and raise the alarm
- Gas sensors – can detect if the gas is left on, shuts off the gas, and raises the alarm
- Bed or chair sensors – can detect if a person doesn't get up in the morning or stands up and doesn't return in a set time. Sensors in or around the bed activate when someone gets up in the night and call assistance
- Falls – sensors worn on the hip can detect the impact of a person falling
- Door sensors can be set up to trigger an alarm if the front door is opened, e.g. during specified times such as nighttime

Further examples of AT include tracking devices using satellite technology (GPS) to locate people who have gone missing, sensors to monitor people's activity in their own home, mobility aids and continence devices.

Some concerns have been raised about the application of AT (Bonner & Idris, 2012)

The Alzheimer's Society identified the following potential issues<sup>31</sup>:

- Risk of social exclusion as AT may replace human contact
- Potential threat to independence
- People's lives or living environments may become more complicated

---

<sup>30</sup> Alzheimer's Society Assistive Technology – devices to help everyday living  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=109&gclid=CLzQieqUv8YCFWv3wgodfEcKqA](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109&gclid=CLzQieqUv8YCFWv3wgodfEcKqA)

<sup>31</sup> Alzheimer's Society  
[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=587](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=587)

- Focus on a person's problems and does not promote their strengths
- AT may be employed without the full consent of the person with dementia
- Data protection issues
- Many people may feel stigmatised by AT

A person-centred approach is required to AT, with solutions tailored to the individual and in consultation with the end-user, their family and/or carers. Telecare should be introduced in the early stages of dementia so that the patient is able to understand how the equipment works and becomes familiar with it, before their dementia progresses (York Health Economics Consortium, 2013).

It should be noted that the evidence base on the efficacy of AT is still limited and mixed, with relatively few robust studies published (Fleming & Sum, 2014; Leroi et al., 2013). Fleming and Sum (2014) highlight a number of issues such as small samples, high drop-out rates, very basic statistical analyses, lack of adjustment for multiple comparisons, and poor performance of the technology. Another review reports a lack of scientific evidence either for, or against, the use of Skype for clinical telehealth (Armfield, Gray, & Smith, 2012).

However, there are studies and examples of best practice from across the UK and international settings which do demonstrate the potential impact of AT to enable people with dementia to maintain their abilities for longer, support activities of daily living, and improve their quality of life, and provide support for carers (Bewernitz, Mann, Dasler, & Belchior, 2009; Bonner & Idris, 2012; Dunk & Schuette, 2009; Mokhtari et al., 2012).

An evaluation of an AT pilot programme in Finland (Riikonen, Makela, & Perala, 2010) found that the technology increased the amount of time spent by elderly people in their home by an average of eight months, demonstrating the potential to postpone the need for institutional care. In practical terms, the surrounding infrastructure, for example response pathways for alarms, will greatly influence the effectiveness and cost-effectiveness of the technology.

### Support for carers of people with dementia

NICE recommend that the needs of carers should be assessed regularly to identify any psychological distress or psychosocial impact. Care plans should include a range of tailored interventions, which may consist of a mixture of psychoeducation, peer-support groups, support and information, training courses, and involvement of other family members in family meetings

Carers may require access to a range of support services, including

- Psychological therapies (e.g. cognitive behavioural therapies)
- Respite/short break services (e.g. day care, day and night sitting, short break/overnight residential care) with meaningful and tailored activities
- Transport to access these services

Health and social care managers should ensure that carers of people with dementia have access to these services.

### Respite Care

A key service for carers is respite care. Respite care can take various different forms: in house day care, day centre, overnight or longer holiday breaks in a host-family or institution.

Interestingly, both national and international reviews of the literature (Arksey et al., 2004; Neville, Beattie, Fielding, & MacAndrew, 2015) have indicated that whilst respite care is highly valued, uptake is poor. Experiences of respite care indicate that there is a balance to be struck between the needs of the carer and the needs of the patient.

Some studies found carers to be initially conflicted about using respite. Feelings of guilt and perceived failure in the fulfillment of their duty, and apprehension that the person with dementia would become angry, resentful or distressed were commonly cited themes.

Respite care was less likely to be required where other family, social care or health service support was available and able to meet needs. Those looking after people with higher personal care needs were more likely to seek respite.

Neville et al (2015) also found staff to be a key feature of respite success. Attributes that tend to be well regarded by carers included showing respect, providing emotional support, being willing to listen and talk to the carer, relieving the family's feelings of guilt and providing education and information

No one respite model was seen to be superior to another, and Arksey et al (2004) recommended that a range of services should be available to support carers to have a choice over timing, flexibility and length of respite break. Home care respite was less disruptive to the carer's routine; however carers were sometimes hesitant to let unknown staff into their home. Some evidenced indicated they might also use the time to perform activities that require two people rather than take a proper break. Day care was often enjoyable and sociable – a component valued by people with dementia, but for the carer incurred a considerable amount of extra work and preparation. The authors also suggested that the available literature indicated a possible over-reliance on the day-care model of delivery.

Although Arksey et al (2004) reported that there was no conclusive evidence to show that respite care improved the health and wellbeing of carers or care recipients, both studies noted a lack of high quality trial evidence and, crucially, did not discount the actual benefits of respite care despite this apparent lack of evidence.

## 7.2 Models of care

### Integrated Care Models

The NHS 5 year strategy has a clear agenda for the introduction of Out Of Hospital care and Primary and Acute Care Systems. North West London CCGs are a pioneer group for the Whole Systems Integrated Care working, which seeks to wrap different services around the individual for an integrated and effective treatment. This provides an opportunity to consider new integrated models for dementia care in a setting where there are complex care pathways that struggle to maintain service cohesion. A couple of examples are considered below:

### 8 Pillars Model

Scotland's National Dementia Strategy<sup>32</sup> prioritises community integration via the 8 pillars model of care, centred around a dementia practice coordinator who is a skilled allied health practitioner (e.g. community psychiatric nurse) to coordinate care:

**Pillar 1:** The Dementia Practice Coordinator

**Pillar 2:** Therapeutic interventions to tackle the symptoms of the illness

**Pillar 3:** General health care and treatment

**Pillar 4:** Mental health care and treatment

**Pillar 5:** Personalised support

**Pillar 6:** Support for carers

**Pillar 7:** Environment

**Pillar 8:** Community connections

This model will be evaluated for effectiveness nationally.

### Gnosall primary-care based memory clinic

The use of allied health professionals is also championed in the Gnosall primary care based memory service<sup>33</sup>. In this model a primary care based 'Eldercare Facilitator' (ECF) typically a health visitor by training, collates background history and relevant information through contact with the patient and practice notes to present to the assessing clinician at the assessment appointment. Supporting tests take place and a diagnosis is obtained on the day when possible with appropriate referral to secondary services.

The clinic has reported increasing its diagnostic rates to circa 100% estimated prevalence since adoption of the new model.

---

<sup>32</sup> Scottish Government <http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>

<sup>33</sup> [http://www.gnosallsurgery.co.uk/website/M83070/files/Gnosall\\_Memory\\_Clinic\\_-\\_The\\_Basics\\_April\\_2013.pdf](http://www.gnosallsurgery.co.uk/website/M83070/files/Gnosall_Memory_Clinic_-_The_Basics_April_2013.pdf)

### Dual frailty ward and delirium recovery programme

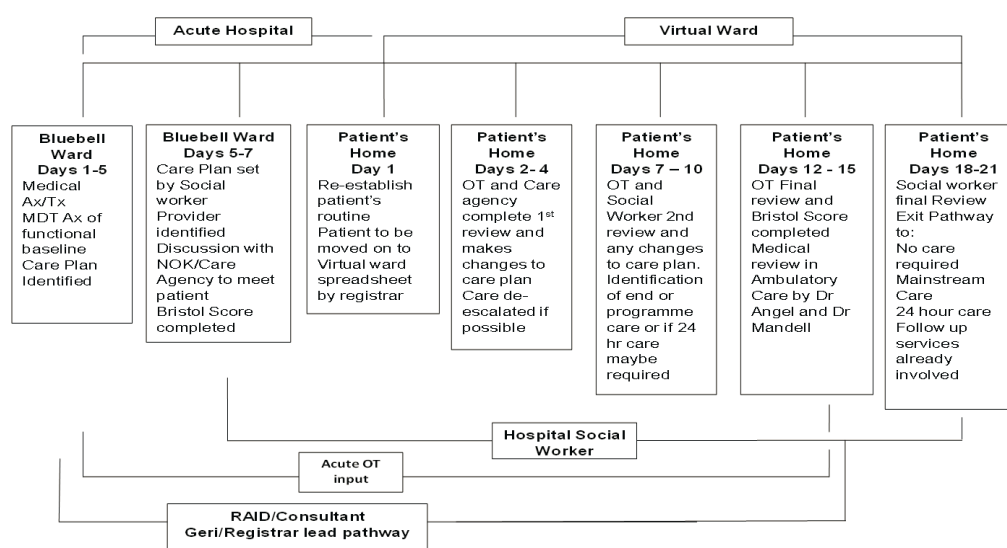
Findings from the qualitative analysis and discussion with lead commissioner highlighted a gap in:

*“A specialist multidisciplinary team input to assess and coordinate appropriate in-patient care when an elderly person is admitted to hospital, so that all health needs can be addressed, efficiently minimising the length of stay.”*

(Recommendations from a “Spotlight on dementia care: A Health Foundation improvement report”, The Health Foundation, 2011)

The provision of only one specialist dementia nurse and current psychiatry liaison scope of working does not allow this agenda to be fully met. A local example where this has been achieved is that of Watford where a joint medical and psychiatric ward was created with an early discharge care pathway as outlined below:

**Figure 23: Delirium Recovery Programme (DRP): Pilot study of Cognitive Enablement at Home following hospital admission**



In the pilot study 16/20 patients returned home and 4 progressed to residential care. The team estimated that 12 long term residential care placements and 3 short term placements were avoided and all 20 had benefitted from a shorter hospital stay than would otherwise have been the case. The cost of in hospital care was marginally more than standard care but large savings were estimated through avoidance of care placement. The scheme cost £217,004 (DRP and ongoing care costs). Comparative care costs were estimated at £506,532, producing a **full-year net cost benefit of £225,648**.<sup>34</sup> Models such as these may be worth considering in the context of joint commissioning and integrating health and social care, as highlighted in the North West London exemplary framework.

<sup>34</sup> <http://www.rcpsych.ac.uk/pdf/RAID%20Delirium%20Recovery%20programme2.pdf>

Figure 24: Clinicians perspectives 5

**CLINICIANS' PERSPECTIVES***..personal opinion from interviewed clinicians working in dementia care*

- General opinion was that dementia care would be improved with greater integration and collaboration between services; some ideas for achieving this were offered:
- A single point of referral for dementia care and diagnostics; with patients able to cross over between services and reliable information governance
- A lay key worker to navigate appointments and patient engagement with services, including voluntary sector
- A dual frailty ward with joint elderly care and psychogeriatric ward rounds. A Watford pilot had promising results in regards to reducing need for residential placement, with an opportunity to save significant amounts of care budget.
- Extension of the 'virtual ward' model as operated by Aglaja Dar in the Charing Cross OPAL service to other areas and dementia focused. A virtual ward is where patients are given the same care by same staff with same routines as in hospital but remain at home. Aims are usually to prevent admission or provide cost/resource effective care.
- A mechanism by which dementia investigations can be initiated via elderly care services
- Screening based in residential care
- A rapid advice line with advice from secondary care clinicians to support care homes to work with people with behavioral issues

## 8 References

- Aguirre, E., Spector, A., Streater, A., Burnell, K., & Orrell, M. (2011). Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia*, 10(4), 459-473. doi: 10.1177/1471301211417170
- Alzheimer's Society. (2012). *Dementia 2012: a national challenge*: Alzheimer's Society.
- Alzheimer's Society. (2013). *Dementia 2013: the hidden voice of loneliness*: Alzheimer's Society.
- Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Hare, P., Baldwin, S. (2004). *Review of respite services and short-term breaks for carers of people with dementia*. London: National Health Service, Service Delivery Organisation.
- Armfield, R., Gray, C., & Smith, C. (2012). Clinical use of Skype: A review of the evidence base. *Journal of Telemedicine and Telecare*, 18(3), 125-127.
- Ballard, C., Bannister, C., Solis, M., Oyebode, F., & Wilcock, G. (1996). The prevalence, associations and symptoms of depression amongst dementia sufferers. *J Affect Disord*, 36(3-4), 135-144.
- Bewernitz, M. W., Mann, C., Dasler, P., & Belchior, P. (2009). Feasibility of machine-based prompting to assist persons with dementia. *Assistive Technology*, 21(4), 196-207.
- Bonner, S., & Idris, T. (2012). Assistive technology as a means of supporting people with dementia : a review.
- Capus, J. (2005). The Kingston Dementia Cafe: The benefits of establishing an Alzheimer cafe for carers and people with dementia. *Dementia: The International Journal of Social Research and Practice*, 4(4), 588-591.
- Care Quality Commission. (2013). *Care Update*, Issue 2: March 2013.
- Care Quality Commission. (2014). *Cracks in the pathway: People's experiences of dementia care as they move between care homes and hospitals*. Gallowgate: Care Quality Commission.
- Carrie, I., van Kan, G. A., Gillette-Guyonnet, S., Andrieu, S., Dartigues, J. F., Touchon, J., Vellas, B. (2012). Recruitment strategies for preventive trials. The MAPT study (MultiDomain Alzheimer Preventive Trial). *J Nutr Health Aging*, 16(4), 355-359.
- Chou, H. K., Yan, S. H., Lin, I. C., Tsai, M. T., Chen, C. C., & Woung, L. C. (2012). A pilot study of the telecare medical support system as an intervention in dementia care: the views and experiences of primary caregivers. *Journal of Nursing Research*, 20(3), 169-180.
- Department of Health. (2009). *Living well with dementia: a National Dementia Strategy*. London: Department of Health Retrieved from



<https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>.

Department of Health. (2010). *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*. London: Department of Health Retrieved from <https://www.gov.uk/government/publications/quality-outcomes-for-people-with-dementia-building-on-the-work-of-the-national-dementia-strategy>.

Department of Health. (2012). *Long Term Conditions Compendium of Information: Third Edition*. Leeds: Department of Health Retrieved from <https://www.gov.uk/government/news/third-edition-of-long-term-conditions-compendium-published>.

Department of Health. (2013). *Dementia : a state of the nation report on dementia care and support in England*.

Dodd, K., Coles, C., Finnamore, T., Holland, T., Gangadharan, S. K., Scheepers, M., . . . British Psychological Society. (2015). *Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia*. Leicester: British Psychological Society.

Dow, B., Haralambous, B., Hempton, C., Hunt, S., & Calleja, D. (2011). Evaluation of Alzheimer's Australia Vic Memory Lane Cafes. *Int Psychogeriatr*, 23(2), 246-255. doi: 10.1017/s1041610210001560

Dunk, B., & Schuette, M. (2009). The use of assistive technologies to support people with dementia at home. *Journal of Care Services Management*, 4(1), 90-99.

East London NHS Foundation Trust. (2011). *Dancing down Memory Lane: Circle Dancing as a Psychotherapeutic Intervention in Dementia*. Best practice. East London NHS Foundation Trust, . London. Retrieved from <https://www.nice.org.uk/savingsAndProductivityAndLocalPracticeResource?ci=http%3a%2f%2fsearch.nice.org.uk%2fusingguidance%2fsharedlearningimplementingniceguidance%2fexamplesofimplementation%2feximpresults.jsp%3fo%3d144>

Fleming, R., & Sum, S. (2014). Empirical studies on the effectiveness of assistive technology in the care of people with dementia : a systematic review. *Journal of Assistive Technologies*, 8(1), 14-34.

Halley, E., Boulton, R., McFadzean, D., & Moriarty, J. (2005). The Poppy Cafe: A multi-agency approach to developing an Alzheimer cafe. *Dementia: The International Journal of Social Research and Practice*, 4(4), 592-594.

Harmer, J., & Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging & Mental Health*, 12(5), 548-558.

Health Foundation. (2011). *Spotlight on Dementia Care: A Health Foundation Improvement Report*. London: Health Foundation.

- Hex, N., Bartlett, C., Wright, D., Taylor, M., & Varley, D. (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabet Med*, 29(7), 855-862. doi: 10.1111/j.1464-5491.2012.03698.x
- Improving Health and Lives. (2013). Making Reasonable Adjustments to Dementia Services for People with Learning Disabilities: Public Health England.
- Imtiaz, B., Tolppanen, A. M., Kivipelto, M., & Soininen, H. (2014). Future directions in Alzheimer's disease from risk factors to prevention. *Biochem Pharmacol*, 88(4), 661-670. doi: 10.1016/j.bcp.2014.01.003
- Kings College London, & London School of Economics. (2007). Dementia UK: A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry  
at King's College London, for the Alzheimer's Society. London: Alzheimer's Society.
- Kings College London, & London School of Economics. (2014). Dementia UK: update. London: Alzheimers Society.
- Kivipelto, M., Solomon, A., Ahtiluoto, S., Ngandu, T., Lehtisalo, J., Antikainen, R., . . . Soininen, H. (2013). The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER): study design and progress. *Alzheimers Dement*, 9(6), 657-665. doi: 10.1016/j.jalz.2012.09.012
- Landau, R., Werner, S., Auslander, K., Shoval, N., & Heinik, J. (2010). What do cognitively intact older people think about the use of electronic tracking devices for people with dementia? A preliminary analysis. *International Psychogeriatrics*, 22(8), 1301-1309.
- Lawrence, V., Murray, J., Banerjee, S., & Ffytche, D. (2008). The experiences and needs of people with dementia and serious visual impairment: a qualitative study *Occasional Paper 16*. London: Thomas Pocklington Trust.
- Leroi, I., Woolham, J., Gathercole, R., Howard, R., Dunk, B., Fox, C., Ritchie, C. (2013). Does telecare prolong community living in dementia? A study protocol for a pragmatic, randomised controlled trial. *Trials [Electronic Resource]*, 14.
- Matthews, F., & Brayne, C. (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. doi: 10.1371/journal.pmed.0020193
- Matthews, F. E., Arthur, A., Barnes, L. E., Bond, J., Jagger, C., Robinson, L., & Brayne, C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet*, 382(9902), 1405-1412. doi: 10.1016/s0140-6736(13)61570-6
- McCabe, L., & Innes, A. (2013). Supporting safe walking for people with dementia: User participation in the development of new technology. *Gerontechnology*, 12(1), 4-15.

- Mitchell, L. (2012). Breaking New Ground: The Quest for Dementia Friendly Communities *Viewpoint* 25. London.
- Mokhtari, M., Aloulou, H., Tiberghien, T., Biswas, J., Racoceanu, D., & Yap, P. (2012). New trends to support independence in persons with mild dementia-A mini-review. *Gerontology*, 58(6), 554-563.
- MRC CFAS. (1998). Cognitive function and dementia in six areas of England and Wales: the distribution of MMSE and prevalence of GMS organicity level in the MRC CFA Study. The Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). *Psychol Med*, 28(2), 319-335.
- Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health Soc Care Community*, 23(1), 51-53. doi: 10.1111/hsc.12095
- NICE. (2006). Dementia: supporting people with dementia and their carers in health and social care. London: NICE.
- Parker, D., Mills, S. and Abbey, J. (2008). Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence-based Healthcare*, Vol 6; Issue 2 pgs 137-172.
- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging*, 18(2), 250-267.
- Poblador-Plou, B., Calderon-Larranaga, A., Marta-Moreno, J., Hanco-Saavedra, J., Sicras-Mainar, A., Soljak, M., & Prados-Torres, A. (2014). Comorbidity of dementia: a cross-sectional study of primary care older patients. *BMC Psychiatry*, 14(1), 84.
- Qiu, C., von Strauss, E., Backman, L., Winblad, B., & Fratiglioni, L. (2013). Twenty-year changes in dementia occurrence suggest decreasing incidence in central Stockholm, Sweden. *Neurology*, 80(20), 1888-1894. doi: 10.1212/WNL.0b013e318292a2f9
- Qizilbash, N., Gregson, J., Johnson, M. E., Pearce, N., Douglas, I., Wing, K., Pocock, S. J. (2015). BMI and risk of dementia in two million people over two decades: a retrospective cohort study. *Lancet Diabetes Endocrinol*, 3(6), 431-436. doi: 10.1016/s2213-8587(15)00033-9
- Quince, C. (2013). Low expectations: Attitudes on choice, care and community for people with dementia in care homes. London: Alzheimer's Society.
- Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S., & Nazareth, I. (2010). Survival of people with clinical diagnosis of dementia in primary care: cohort study. *Bmj*, 341, c3584. doi: 10.1136/bmj.c3584
- Raymond, M., Warner, A., Davies, N., Iliffe, S., Manthorpe, J., & Ahmedzai, S. (2014). Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia*, 13(1), 96-110. doi: 10.1177/1471301212450538

- Richard, E., Van den Heuvel, E., Moll van Charante, E. P., Achthoven, L., Vermeulen, M., Bindels, P. J., & Van Gool, W. A. (2009). Prevention of dementia by intensive vascular care (PreDIVA): a cluster-randomized trial in progress. *Alzheimer Dis Assoc Disord*, 23(3), 198-204. doi: 10.1097/WAD.0b013e31819783a4
- Riikonen, M., Makela, K., & Perala, S. (2010). Safety and monitoring technologies for the homes of people with dementia. *Gerontechnology*, 9(1), 32-45.
- Rowe, B., Brown, T., Holland, J., & ESRO. (2014). A good life with dementia? London: Red and Yellow Care and Alzheimer's Society.
- Royal College of Psychiatrists. (2011). Report of the National Audit of Dementia Care in General Hospitals 2011. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists. (2013). National Audit of Dementia Care in General Hospitals 2012-13: Second Round Audit Report and Update. London: Royal College of Psychiatrists.
- Schneider, A. R., & Sari, Y. (2014). Therapeutic perspectives of drugs targeting Toll-like receptors based on immune physiopathology theory of Alzheimer's disease. *CNS Neurol Disord Drug Targets*, 13(5), 909-920.
- Schrijvers, E. M., Verhaaren, B. F., Koudstaal, P. J., Hofman, A., Ikram, M. A., & Breteler, M. M. (2012). Is dementia incidence declining?: Trends in dementia incidence since 1990 in the Rotterdam Study. *Neurology*, 78(19), 1456-1463. doi: 10.1212/WNL.0b013e3182553be6
- Schubert, C. C., Boustani, M., Callahan, C. M., Perkins, A. J., Carney, C. P., Fox, C., Hendrie, H. C. (2006). Comorbidity profile of dementia patients in primary care: are they sicker? *J Am Geriatr Soc*, 54(1), 104-109. doi: 10.1111/j.1532-5415.2005.00543.x
- Solomon, A., Mangialasche, F., Richard, E., Andrieu, S., Bennett, D. A., Breteler, M., Kivipelto, M. (2014). Advances in the prevention of Alzheimer's disease and dementia. *J Intern Med*, 275(3), 229-250. doi: 10.1111/joim.12178
- Toot, S., Hoe, J., Ledgerd, R., Burnell, K., Devine, M., & Orrell, M. (2013). Causes of crises and appropriate interventions: the views of people with dementia, carers and healthcare professionals. *Aging & Mental Health*, 17(3), 328-335.
- van Haften-van Dijk, A. M., van Weert, J. C., & Droes, R. M. (2014). Implementing living room theatre activities for people with dementia on nursing home wards: a process evaluation study. *Aging Ment Health*, 1-12. doi: 10.1080/13607863.2014.955459
- Williamson, T. (2012). A stronger collective voice for people with dementia. York: Joseph Rowntree Foundation.
- Wilson, E., Thalanany, M., Shepstone, L., Charlesworth, G., Poland, F., Harvey, I., Price, D., Reynolds, S. and Mugford, M. (2009). Befriending carers of people with dementia: a cost utility analysis. *Int. J. Geriatr. Psychiatry*, 610-623.
- York Health Economics Consortium. (2013). Telecare for people with dementia: evaluation of Renfrewshire project: final evaluation report. York: York Health Economics Consortium.

## **9 Appendices**

### **9.1 Appendix A: RAG Rating of local assets (read across two pages)**

This page has been left blank intentionally.

To view the following Appendix A 'RAG Rating of local assets' please view across two pages. Please note the colour coding of the text corresponds to source of information.

	National Guidance	Local observations
	<b>National Dementia Strategy Key Objectives</b> <b>NICE Priorities</b> <b>Care Act 2014 Responsibilities</b>	<b>Healthwatch HF areas for improvement</b> <b>Healthwatch CNWL areas for improvement</b> <b>Clinicians' Qualitative analysis</b>
1	<p>Improving public and professional awareness and understanding of dementia: addressing stigma</p> <p>Non-discrimination in access to all care and services for people with dementia</p>	<p>Clinicians were very keen to support dementia friendly communities and some were involved in initiatives with local providers. There were challenges identified locally with a less community orientated population and difficulties in urban planning and design in a London borough.</p>
2	<p><u>Good-quality early diagnosis and intervention for all</u>: establishing a clear care pathway for people who may have dementia</p> <p>Structural imaging for diagnosis</p>	<p>Confidence in GP ability to effectively screen for dementia</p> <p>Confidence in GP ability to effectively screen for dementia</p> <p>Memory service in HF to have a stronger community and social care presence, possibly modelling upon the KCW service; Clarify diagnostic pathways with 'one front door' and possibility to refer straight from hospital with GP acknowledgement rather than only via GP</p>
3	<p>Good-quality information for those with diagnosed dementia and their carers</p> <p>Valid consent; Carers</p> <p>Information and advice is to be made available to support considered and informed choices regarding care early on</p>	<p>Information on how to access services especially for self-funders</p> <p>Information on how to access services especially for self-funders</p> <p>The remit and referral criteria for different services are not clear to all clinicians using them. Clinicians expressed interest in working more closely with voluntary and charity sectors to inform better care with holistic decision-making, fill gaps in dementia care provided by traditional services; and ensure equitable access to support. The services already provided by Alzheimer's Society, Age UK and Housing &amp; Care 21, as well as various day centres and activity groups are highly valued, but the perception is that there is little strategic oversight of provision.</p>

RAG Rating			Identified Gaps	Recommendation
LBHF	RBKC	WCC		
			<p>There is insufficient support for work of the Dementia Action Alliances across the 3 boroughs (can eventually join up across 3 boroughs and the Pan-London Alliance)</p> <p><i>Please see section 3.5 for evidence of the effect of comorbidities on mortality. Please see section 7.2 for information on dementia action alliances.</i></p>	<p>1. Ensure adequate resource to support the work of the Dementia Action Alliance and other opportunities to raise public awareness of dementia across the three boroughs.</p> <p>2. Ensure adequate monitoring, assessment and provision of care for other physical and mental health needs for people with dementia.</p>
			<p>1. Diagnosis rates still do not meet estimated prevalence and can be further improved;</p> <p>2. There are few easy channels of communication between different providers of dementia care; at different levels of intensity.</p> <p>3 Training is needed for GPs, staff in care and support roles and families to recognise the signs and symptoms of a dementia and know what to do next.</p> <p><i>Please see section 4.2 for information on diagnosis rates. Please see section 5.3 for information regarding service cohesion.</i></p>	<p>1. Develop a single point of access to diagnostic assessment and ensure all patients across all three Boroughs have equitable access.</p> <p>2. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme.</p> <p>3. Improve screening and diagnosis in care home and Extra Care residents.</p> <p>4. Consider training to increase referral from or support diagnosis in primary care, in line with NWL strategy.</p> <p>5. Audit completion of diagnostic assessment for those first identified in hospital.</p>
			<p>There are dementia advisers and dementia guides but insufficient resources to meet need. Lack of dementia advice/care coordination to support timely access to advice. Support is needed for advocating peoples' best interests and awareness of the mental capacity act 2005.</p> <p><i>Please see section 2.1 for information on Care Act 2014; section 5.2 for a map of services and resources; Section 6 for national intelligence on user and carer views.</i></p>	<p>1. All patients, carers and clinicians should have consistent and comprehensive information with clear signposting of care pathways.</p> <p>2. Patients and carers should be aware of advance directives and power of attorney and how to initiate them.</p>



	National Guidance	Local observatio
	<b>National Dementia Strategy Key Objectives</b> <b>NICE Priorities</b> <b>Care Act 2014 Responsibilities</b>	<b>Healthwatch HF areas for improvement</b> <b>Healthwatch CNWL areas for improvement</b> <b>Clinician's Qualitative analysis</b>
4	<p>Enabling easy access to care, support and advice following diagnosis: providing a dementia advisor</p> <p>Memory services</p>	<p>Regularity of care reviews – GP and social services every year/15 months?</p> <p>Regularity of care reviews – GP and social services every year/15 months?; Personal control when choosing services</p> <p>Improve links with voluntary sector, consider strategic commissioning and provision of more admiral nurses/dementia advisers. The current elderly demographic is stoical and less likely to seek help than younger patients; thus may be better reached by outreach and informal services.</p>
5	<p>Development of structured peer support and learning networks</p>	
6	<p>Improved community personal support services: support for people with dementia living in their own homes</p> <p>Coordination and integration of health and social care; Behaviour that challenges</p> <p>Service users and their carers are allocated personal care budgets and given the right to manage their own care should they wish to; these budgets will cover up to the cost of council sourced services. A maximum cap of £72 000 on care costs per service user is introduced. A higher means testing threshold of £123000 of assets will be introduced for state contributions to care costs.</p>	<p>Integration of health and care services</p> <p>Review ways of increasing cohesion and communication between services. The majority of clinicians endorsed individualised care due to the large variation in presentation and need seen.</p>
7	<p>Implementing the Carers' Strategy: needs assessments and respite breaks for carers</p> <p>Carers</p> <p>Emphasis is placed on ensuring that duty of care extends to unpaid carers; ensuring needs are assessed, information and advice provided; they are able to access to services and pathways established for raising concerns. The carer is afforded rights independent of financial capabilities or needs of the dependant</p>	<p>Support for carers; Respite</p> <p>Support for carers; Respite</p> <p>Consider ways of providing extra support for carers</p>



RAG Rating			Identified Gaps	Recommendation
LBHF	RBKC	WCC		
			<p>(1) Memory service care varies greatly between provider: in some cases the patient may not have access to timely diagnostic or adequate community support;</p> <p>(2) A need has been speculated for increased liaison psychiatry provision in Hammersmith and Fulham, dementia specialist nursing in the community and in hospital, and care navigators.</p> <p><i>Please see section 5 for information on service provision and cohesion.</i></p>	<p>1. The current fragmentation in care provision should be addressed through centralised coordination and improved communication/collaboration between services.</p>
			<p>Peer support is now being commissioned as part of Living Well service in Westminster and K&amp;C, however there is lack of resource in H&amp;F.</p> <p><i>Please see section 5 for information on service provision.</i></p>	<p>1. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme.</p>
			<p>1. There is little supporting infrastructure available to provide help to self-funders to "micro-commission" care as mandated by the Care Act 2014.</p> <p>2 There is insufficient community support for people with dementia and their carers to learn to manage challenging signs of dementia, e.g. through purposeful activity.</p> <p><i>Please see section 2.1 for information on the Care act 2014.</i></p>	<p>1. Ensure there is adequate infrastructure to support self-funders to access care.</p> <p>2. Ensure people are supported to access the care appropriate to them through the use of personal budgets.</p> <p>3. Provide adequate infrastructure and training for care staff and carers.</p> <p>4. Ensure adequate provision, through 3rd sector and health and social care services, of activities and support around living well with dementia and managing distressing behaviours.</p>
			<p>It is not clearly understood whether voluntary sector resources and support available to carers is adequate to need, distributed equitably and accessible to all. There is variation between boroughs in the extent of such services available.</p> <p><i>Please see section 5.2 and 5.3 for information on service provision and cohesion.</i></p>	<p>1. Provide a clear and comprehensive pathway, including respite care, for carers with equality of access across three boroughs, taking into account the unique needs of carers of people with dementia.</p>

	National Guidance	Local observation
	National Dementia Strategy Key Objectives NICE Priorities Care Act 2014 Responsibilities	Healthwatch HF areas for improvement Healthwatch CNWL areas for improvement Clinician's Qualitative analysis
8	<u>Improved quality of care for people with dementia in general hospitals</u> Mental health needs in acute hospitals	Inpatient care including discharge planning <u>Inpatient care including discharge planning</u> Consider improving in-hospital care from point of admission for those known to have dementia; (it is noted that KCW are piloting implementing a nurse in A+E for this purpose.)
9	Improved intermediate care for people with dementia	
10	Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers Coordination and integration of health and social care	Integration of health and care services <u>Integration of health and care services</u> Clinicians were very keen to support dementia friendly communities and some involved in initiatives with local providers. There were challenges identified locally with a less community orientated population and difficulties in urban planning and design in a London borough.
11	<u>Living well with dementia in care homes: defined care pathways, specialist in-reach services and inspections</u> Coordination and integration of health and social care	Quality and confidence in care homes and home care, particularly staff. <u>Integration of health and care services</u> Review quality and supply of residential care; Patients were likely to want to stay in borough once diagnosed.

RAG Rating			Identified Gaps	Recommendation
LBHF	RBKC	WCC		
			<p>(1) Little is known about adequate use of antipsychotics – an audit is due to take place in Chelsea and Westminster Hospital.</p> <p>(2) Support is needed for the person to prevent avoidable admission, but to ensure the right intervention at the right time.</p> <p><i>Previous audits in the 3 boroughs have shown a fall in the use of antipsychotics.</i></p>	<p>1. Audit and address accordingly use of antipsychotics in hospitals and community prescriptions</p> <p>2. Ensure timely identification and targeted care of those with dementia in hospital</p> <p>3. Provide dementia friendly environment within hospitals</p> <p>4. Ensure adequate provision of liaison psychiatry and dementia nurses, consider expanding remit to improve admission related support.</p>
			<p>It is not known how people with dementia are specifically supported in generic intermediate care services, but clinical staff in NW London are expected to complete dementia awareness training by April 2015.</p> <p><i>Please see section 5 for information on service provision.</i></p>	<p>1. Ensure either all staff in intermediate care have appropriate training for looking after people with dementia or a specialist service is provided.</p>
			<p>Housing and environment strategies do not specifically mention dementia or carers of people with dementia</p>	<p>1. The increasing numbers and needs of people with dementia and their carers are taken into account in wider local authority and health strategies, especially housing and environment</p> <p>2. Explore joint working with police and other community safety partners to support appropriate and effective use of assistive technology/telecare for patients with dementia</p>
			<p>1. The supply of care homes currently does not match need therefore a significant proportion of residents are moved out of borough;</p> <p>2. Little is known about quality of care in care homes – a CQC report is awaited. There is a gap between those who are eligible and able to be funded by social care and those who meet the criteria for continuing health care. The Care Act 2014 will have a finance section added in October 2015.</p> <p><i>Please see section 4.6 for discussion on supply of care homes and figure 14 on quality of care in care homes.</i></p>	<p>1. Address supply of local care home beds in future local authority and CCG commissioning intentions, including those specifically for dementia care.</p> <p>2. Address findings from Care Quality Commission (CQC) national report; audit to provide assurance of quality of care in care homes.</p> <p>3. Ensure there are opportunities for coordinated training and support for care homes to enable recognition of patients with dementia and to improve confidence in care for complex needs and difficult behaviours.</p>

	National Guidance	Local observation
	National Dementia Strategy Key Objectives NICE Priorities Care Act 2014 Responsibilities	Healthwatch HF areas for improvement Healthwatch CNWL areas for improvement Clinician's Qualitative analysis
12	Improved end of life care for people with dementia: involvement of people with dementia and their carers in plans for their end of life care Valid consent; Carers; Coordination and integration of health and social care	Integration of health and care services Integration of health and care services Review ways of increasing cohesion and communication between services
13	An informed and effective workforce for people with dementia: basic training and CPD for all relevant staff Training	Staff training (inc. GPs, support staff, hospital staff) Staff training (inc. GPs, support staff, hospital staff) Consider increased provision of training in managing difficult behaviour and spotting warning signs for paid and unpaid carers
14	A joint commissioning strategy for dementia Coordination and integration of health and social care There is greater emphasis on integration of care between health, social and voluntary sector providers. There is also a new duty to create a service market of diverse and high quality service providers.	Integration of health and care services Integration of health and care services Review ways of increasing cohesion and communication between services
15	Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers: inspections of care homes and other services Coordination and integration of health and social care Increased oversight for quality and financial security of services; protection of care provided when service users move borough	Integration of health and care services Integration of health and care services; Review ways of increasing cohesion and communication between services
16	A clear picture of research evidence and needs	
17	Effective national and regional support for implementation of the Strategy	

RAG Rating			Identified Gaps	Recommendation
LBHF	RBKC	WCC		
			Lack of sufficient resource to support with end of life care across 3 boroughs. Westminster commissions an EoLC nurse (Dementia Voice Nurse). Care home staff are trained in end of life care support, but due to undiagnosed dementia as above people are sometimes moved out prior to needing EoLC or are not known. There is a lack of hospice care for people with dementia in the boroughs and carers express difficulty if the person is moved away for end of life care. <i>This is addressed in the End of Life JSNA</i>	1. Ensure that there is a clear end of life care pathway for people with dementia with appropriate advanced care planning and powers of attorney and clinicians are responsive to these wishes.
			There has been more training support for care home and domiciliary staff in Westminster in recent years. Resources are needed across 3 boroughs to ensure care staff have support to recognise and signpost people for diagnosis and to provide the right interventions and level of support.	1. Ensure adequate training and support across all services for staff and carers looking after people with dementia 2. Establish a good standard of training to achieve a level of expertise across all partner agencies including social care, residential care, extra care, clinicians, GPs
			The Dementia Strategy in RBKC will end in 2016. Westminster and H&F strategies have expired. NWL MH programme board has commissioned a dementia strategy for diagnosis and treatment support, however, it is not known how much this will impact on non-clinical services. Resource is needed for strategic planning.	1. There should be a joint health and social care dementia programme board for the 3 boroughs to facilitate strategic planning and implementation of action plans.
			CQC is undertaking a programme of inspections in care homes and secondary care  <i>Please see figure 14 and section 5.1 for information of quality of care in care homes.</i>	1. Address findings from CQC report on care homes (awaiting publication); 2. Audit to provide assurance of quality of care in care homes
			The proportion of people with dementia requiring support is likely to increase by 25% in the next 20 years, all relevant providers and services must be equipped with adequate resource to meet this need.  <i>Please see section 4.1 on prevalence.</i>	1. Current practice and resources must be scaled to meet increasing need or consider adapting models of care with innovation across health and social care to reduce the scale of care required. Ensure that any changes to services are evidence based
			Adequate resource is required for service development and strategic planning	1. Local services are active stakeholders with wider initiatives to ensure strategy is sensitive to local needs.

## 9.2 Appendix B: NICE Priorities for Implementation

Priority	Statement
<b>Non-discrimination</b>	People with dementia should not be excluded from any services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.
<b>Valid consent</b>	Health and social care professionals should always seek valid consent from people with dementia. This should entail informing the person of options, and checking that he or she understands, that there is no coercion and that he or she continues to consent over time. If the person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed.
<b>Carers</b>	<ol style="list-style-type: none"> <li>1. 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.</li> <li>2. Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner.</li> </ol>
<b>Coordination and integration of health and social care</b>	<ol style="list-style-type: none"> <li>1. 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, including jointly agreeing written policies and procedures. Joint planning should include local service users and carers in order to highlight and address problems specific to each locality.</li> <li>2. Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve: <ul style="list-style-type: none"> <li>• a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers</li> <li>• assignment of named health and/or social care staff to operate the care plan</li> <li>• endorsement of the care plan by the person with dementia and/or carers</li> <li>• formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes</li> </ul> </li> </ol>
<b>Memory services</b>	Memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia.

Priority	Statement
<b>Structural imaging for diagnosis</b>	Structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used. Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear. Specialist advice should be taken when interpreting scans in people with learning disabilities.
<b>Behaviour that challenges</b>	<p>People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish the likely factors that may generate, aggravate or improve such behaviour. The assessment should be comprehensive and include:</p> <ul style="list-style-type: none"> <li>• the person's physical health</li> <li>• depression</li> <li>• possible undetected pain or discomfort</li> <li>• side effects of medication</li> <li>• individual biography, including religious beliefs and spiritual and cultural identity</li> <li>• psychosocial factors</li> <li>• physical environmental factors</li> <li>• behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.</li> </ul> <p>Individually tailored care plans that help carers and staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly. The frequency of the review should be agreed by the carers and staff involved and written in the notes.</p>
<b>Training</b>	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 (skill development) that is consistent with their roles and responsibilities.
<b>Mental health needs in acute hospitals</b>	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.

### 9.3 Appendix C: Local audits of dementia

#### Number, gender and age group of audited cases

##### *Service audit*

Details on 79 cases were provided by the three borough teams, 30 from LBHF, 28 from RBKC and 21 from Westminster. The gender and age split mirrors that suggested by national information. The average age of all clients was 84.8 years, 86 for women and 82 for men. Only two clients were under 70 and the largest group were women aged 80 to 89.

**Table 10: Number (%) of cases by age group and gender in Service audit**

Age	Female	Male	Male & Female
All	<b>55 (70%)</b>	<b>24 (30%)</b>	<b>79</b>
60-69	1 (50%)	1 (50%)	2
70-79	11 (55%)	9 (45%)	20
80-89	28 (72%)	11 (18%)	39
90+	15 (83%)	3 (17%)	18

##### *Framework I audit*

Framework I information was prepared by different age groups. The gender split mirrors national information. Over half of the clients were aged 85+ which indicates that the median age is higher in the Framework I audit than the Service audit. The gender split by age was similar in the two audits

**Table 11: Number (%) of cases by age group and gender in Framework I audit**

Age	Female	Male	Male & Female
All	<b>205 (72%)</b>	<b>79 (28%)</b>	<b>284</b>
<65	6 (50%)	6 (50%)	12
65-74	15 (56%)	12 (44%)	27
75-84	63 (65%)	34 (35%)	97
85+	121 (82%)	27 (18%)	148



## Time in contact with service

### Service Audit

Table 12: Median time (years) the current clients have been in contact with ASC

Age	Female	Male	Male & Female
All	2.7	2.8	2.8
60-69	2.5	2.8	2.7
70-79	2.4	3.0	2.8
80-89	2.8	2.8	2.8
90+	3.6	1.4	3.1

## Ethnicity and dementia

Ethnicity is recorded for those clients supported by Adult Social Care, including those who are coded as having memory problems as the main reason for support. There is some variation in percentage between the three boroughs for the smaller ethnic groups but the low numbers recorded mean that the differences are not significant. The table below compares the percentage of different ethnic groups in clients with the percentage in the borough population in relevant age groups (65+, 75+ and 85+). About half of ASC dementia and expected dementia cases nationally occur in the 85+ age group, with the majority are in the 75+ age group. Almost all are in the 65+ group.

Table 13: Ethnicity of ASC Clients where coded as having dementia with ethnicity in the three boroughs' population from GLA projections

	ASC Dementia Clients	65+ Population	75+ Population	85+ Population
Percentage Ethnicity	Proportion of clients in age group →	0.95	0.85	0.52
White	79%	79%	81%	87%
Non-White	21%	21%	19%	13%
Black	8%	9%	10%	7%
Asian	4%	9%	7%	5%
Other	9%	5%	4%	2%

The table shows that the split between "White" and "non-White" mirrors the 65+ population, but as half the cases occur in the 85+ age group, and the majority in the 75+ age group in which ethnic diversity is lower, there is a suggestion that the "White" group are slightly under represented and "non-White" over represented. More accurate assessment would require a more detailed ethnicity and age breakdown of ASC clients but the small numbers might present Information Governance issues. Additionally, the GLA do not breakdown "White" into "White British" and "White Other".

The split between non-White ethnic groups in the Adult Social Care data is more difficult to assess because of both very low numbers in sub groups and the sub groups not aligning precisely. In particular, the “Other” category may contain clients that could fall into other categories in the GLA information. The proportion of those who are categorised as “Black” among ASC clients matches the proportion in the relevant population. Collectively so do those categorised as “Asian” and “Other”, but it is possible that “Asians” are under-represented.

## Dementia type

### Service Audit

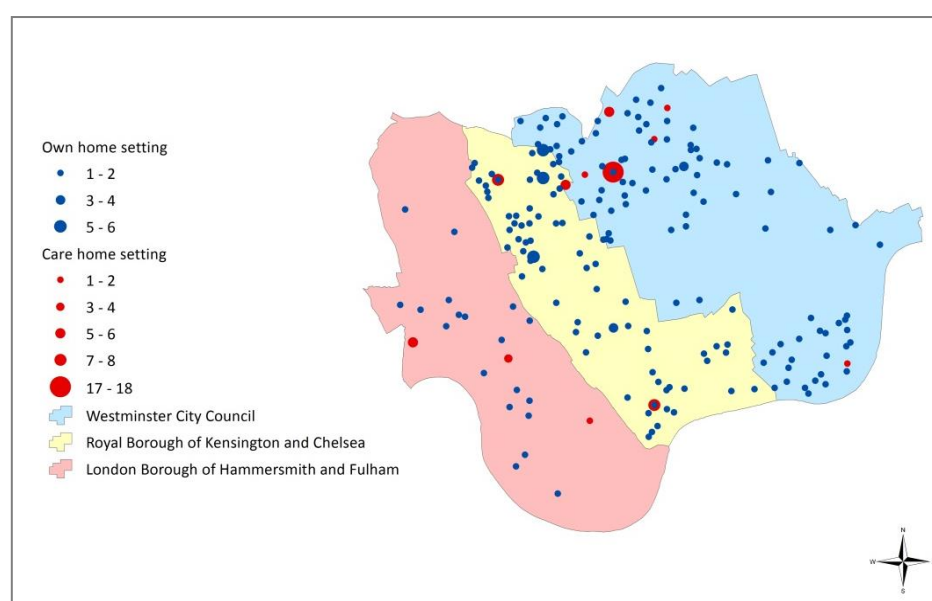
Table 14: Number (%) of ASC clients by dementia type recorded

Dementia type	Number	% of All	% of Known
Alzheimer's	19	24%	37%
Vascular	24	30%	46%
Mixed	3	4%	6%
Parkinson's	3	4%	6%
Alcohol	2	3%	4%
Lewy Body	1	1%	2%
Not Known	27	34%	n/a

## Accommodation

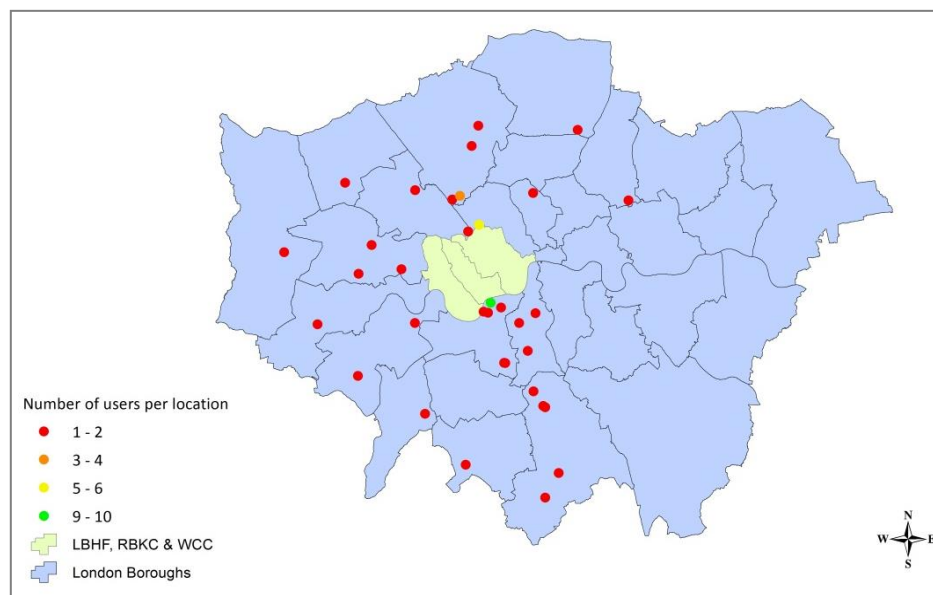
### Framework 1 audit

Figure 25: Location of Adult Social Care clients recorded as having dementia (From Adult Social Care)



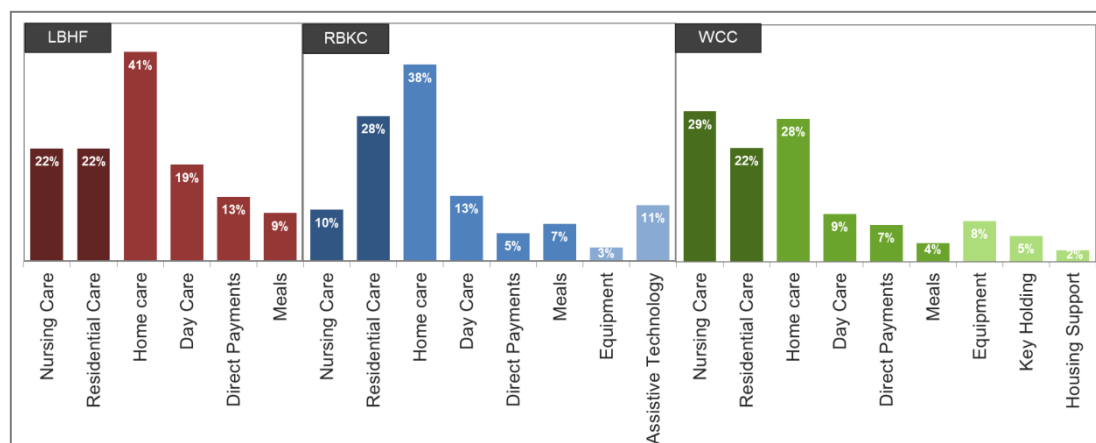
The map highlights the different level or recording of dementia, the split between care homes and own home, as well as the location of care homes in the three boroughs.

**Figure 26: Location and numbers of Adult Social Care clients in Care homes in the rest of London (from Adult Social Care)**



The map shows where residents Adult Social Care is responsible for who are identified as having dementia and need to be placed in a care home in the rest of London are situated.

### Accommodation and service use comparison



The LBHF % figures are based on a number of 32 cases so are included for completeness.

### *Residential/nursing to community ratio*

For those with a primary need of dementia, around 4 in 10 were in nursing or residential care at August 2014, with a slightly higher proportion in Westminster than the other two boroughs. Kensington and Chelsea had a greater proportion in residential than nursing care, which follows the general pattern among all clients in the borough. A recent audit identified dementia as common among 6-7 out of 10 new admissions, which is similar to nationally.

*Note: the split of residential/nursing to community services will be influenced by accuracy of coding of dementia*

### *Community services*

Four in 10 of those with a primary need of dementia receive home care, although this appears slightly lower in Westminster due to higher residential/ nursing. A higher proportion in Hammersmith and Fulham receive day care and direct payments compared to the other two boroughs. Some services are not consistently captured in the data, but 1 in 10 in Kensington and Chelsea receive assistive technology, a similar proportion receive equipment in Westminster, and 1 in 20 also receive the key holding service in Westminster.

*Caution: there may be accuracy issues to the data*

## 9.4 Appendix D: Dementia Care Qualitative Analysis Summary

A summary of the qualitative analysis is presented below.

**Title:** Dementia Care Qualitative Analysis

**Author:** Neha Shah, Public Health

**Acknowledgements:** Paula Arnell; Steven Falvey

**Date:** February 2015

### Objective of report

The objective of this report is to analyse and interpret the opinions of various clinicians on the key factors that influence dementia care in the three boroughs; in order to inform future service development. This report presents the results of a thematic analysis conducted with 10 different clinicians involved in dementia care in Westminster (W), Royal Borough of Kensington and Chelsea (KC) and Hammersmith and Fulham (HF) areas in November to December 2014. Conclusions made are from the findings of this report only and are intended to form one source of evidence in the context of service review and decision-making in dementia care.

### How diagnoses are made

Psychiatry and specialist neurology/geriatric services both add value to the diagnostic process for different groups. Post diagnosis support tends to be stronger via mental health led services. GPs are variable in their engagement with assessment and dementia care, and are short on time and resources.

Clinicians were sceptical about screening and diagnostic incentives for dementia in primary care without emphasis and linkage to better post diagnostic support. They would need extra training and/or support from secondary services to do increase diagnosis. Ideally, there is one point of referral and an experienced member of staff would triage to appropriate service. Acute hospital admissions represent an opportunity for detection and could be better linked into the diagnostic process.

### Factors affecting diagnosis rates

Physical comorbidities can distract from a patient obtaining a dementia diagnosis. Those picked up in hospital do not get referred directly to the memory service and there is the possibility of losing referrals in this step. Cultural beliefs and stigma can affect patients' willingness to present.

### Service cohesion

The remit and referral criteria for different services are not clear to all clinicians using them, and memory services may exclude patients with non-Alzheimer's or vascular dementia. The two memory services in Hammersmith and Fulham do not currently cross-refer appropriate patients. There is little oversight of the range of different services available to dementia

patients and how to access them – admiral nurses when available are very useful in this context.

Specific strengths in service cohesion are highlighted as: the good links between memory service and community mental health/ social care in Westminster and Royal Borough of Kensington and Chelsea; the links between Charing Cross services and specialist dementia nurses; increasing role of psychiatry liaison and dementia nurses in Chelsea and Westminster/St Mary's hospitals.

Specific areas for improvement in service cohesion are highlighted as: lack of joint decision-making across health and social care in resource allocation in Kensington, Chelsea and Westminster; links between geriatric and memory/community services in Kensington Chelsea and Westminster; links between the two memory services in Hammersmith and Fulham, links between memory services and community/social care in Hammersmith and Fulham; links between memory services, dementia care team and psychiatry liaison in Hammersmith and Fulham..

Top down support is required to drive collaborative working and historically this may have been lacking in HF. This may go some way to explain the difference between HF and KCW. 'Borough boundaried' and 'specialty boundaried' funding and commissioning have been highlighted as leading to difficulties in resource distribution and access to services for patients.

### **Communication**

Communication between memory services and GPs is not standardised or always timely. Communication to patients and carers regarding access to support and changes they could make does not seem to always happen from memory service or GP. Communication between specialties is hindered by different IT and governance systems.

#### **Service capacity**

Key areas where service capacity is currently strained were identified as: the supply of residential and nursing homes in borough, availability of admiral nurses, liaison psychiatry in HF; time and resource for GP-led dementia assessments.

### **Escalation of care**

Difficulties have been noted in escalating people from home to residential care in a timely fashion, avoiding a crisis admission. Focused care from the start of admission may help shorten admissions and reduce need for escalation to interim or residential care.

### **Interface between medical and psychiatric care.**

It is recognised that many patients will present with dementia and physical comorbidities which complicate treatment. The role of liaison psychiatry in dementia care varies, a specialist old age liaison service has been set up in St Mary's and Chelsea and Westminster

but still tends to be used only for complex cases. In Hammersmith hospital liaison psychiatry has minimal involvement with patients who have dementia due to lack of capacity. A dementia care team in Imperial and a dementia nurse in Chelsea and Westminster are present but collaboration between these and psychiatric / medical services has only recently started to happen.

There is some confusion regarding responsibilities of care in patients with dementia related to other physical diagnoses.

Greater collaborative working between services is generally supported, but concerns are raised that entire new models of integrated care would not create as much output as strengthening existing services, especially the community support element, and collaboration between them would. Ideas proposed by clinicians include dual frailty and virtual wards to optimise in hospital care and early discharge, care coordination by a lay worker; extra telecare support for care homes; better designed memory services in HF with a single point of referral and triage.

Clinicians expressed interest in working more closely with voluntary and charity sectors to inform better care with holistic decision-making, fill gaps in dementia care provided by traditional services; and ensure equitable access to support. The services already provided by Alzheimer's society and Age UK, as well as various day centres and activity groups are highly valued, but the perception is that there is little strategic oversight of provision.

### Quality of care

Quality of hospital care has improved with introduction of dementia CQUINS. There are no concerns raised regarding antipsychotic usage, and skin and nutritional care was reported to be good in Chelsea and Westminster. Continuing need for improving environments and increasing range of activities available in hospital were identified.

The relatively new memory service in KCW has been recognised as providing excellent care. Difficulties have been noted with HF services, largely relating to poor links with social and community services, communication and delays in assessment.

Clinicians rarely had direct experience of care homes, the interviewees felt that quality of care varied, some were very good, but others could improve in terms of training to pick up dementia, deal with distressing behaviours and needs, and keeping residents hydrated.

Generally it was felt social care staff had a good understanding of dementia, but finding and retaining good staff was a challenge in London. They could be supported with extra training and encouraged to think of ways to preserve dignity and independence for patients. This knowledge, alongside how to create a dementia friendly environment, should be passed on to carers but it is not clear that this is consistently happening. Few clinicians were aware of availability of independent advocates between clinicians.

### Attitudes and environment

As an inner city area, patients are less likely to have social support from families leading to increased dependence on services and later presentation. Some ethnic minority groups offer much support but may access services later. A lack of public awareness of the significance and ability to treat dementia prevails which limits peoples' willingness to access treatment.

The majority of clinicians endorsed individualised care due to the large variation in presentation and need seen. There were examples cited of GPs who did not feel that effective care was available, care staff that found it difficult to deal with behavioural issues, and hospital clinicians being unwilling to initiate the diagnostic process.

The current elderly demographic is stoical and less likely to seek help than younger patients; thus may be better reached by outreach and informal services. Patients were likely to want to stay in borough once diagnosed. There are mixed reports as to the impact of BME beliefs on diagnosis.

Clinicians were very keen to support dementia friendly communities and some involved in initiatives with local providers. There were challenges identified locally with a less community orientated population and difficulties in urban planning and design in a London borough.

### Support for carers

Caring for someone with dementia can cause considerable stress – support mechanisms in place should be reinforced and will need increase in the future.

### Quality of life

Factors associated with better quality of life were identified as: good support from carers and family; fewer comorbidities and ability to retain independence and hobbies.

### Demographics

Clinicians perceived that there were a large proportion of patients diagnosed at late stages in Hammersmith and Fulham, but that patients were usually picked up in early stages in Westminster and Kensington and Chelsea. Clinicians felt that their patient base was likely to increase due to ageing population, but that preventive work, better fitness levels and those of working age moving away from London may affect the impact of this.



## 9.5 Appendix E: Six Paths to a Good Life with Dementia

(Rowe et al., 2014)

Theme	Issues to address
<p><b>1. Respecting identity: ‘It’s not one size fits all’</b></p> <p>Seeing people as distinct individuals is central to having a good life with dementia. This means a genuine and determined desire to treat and respect those with dementia as unique and valuable.</p>	<p>How do we reduce fear so people feel less pressure to self-identify as ‘having dementia’?</p> <p>How do we overcome the dementia label, and the stereotypes, bad habits and compromises that flow from it?</p> <p>How do we design services that allow people’s individual identities to flourish and grow?</p>
<p><b>2. Embracing now: ‘It’s a moment-living life’</b></p> <p>The gradual disappearance of memory brings about a strong desire to focus on the thing that is being lost. While support with ‘remembering’ can be hugely valuable to people with dementia, this should be balanced with the importance of experiences in the here and now.</p>	<p>How do we empower people with dementia to make their own choices about whether to ‘consume’ memories or not?</p> <p>What more can we do to enable people to ‘live in the moment’?</p> <p>What are the implications of focusing more on what people with dementia can do, rather than what they can’t?</p>
<p><b>3. Sustaining relationships: ‘You don’t always need words’</b></p> <p>Dementia brings out different aspects of relationships. Some are beautiful, but others are tainted by prejudice, preconception and impatience. For those with dementia to thrive, sustaining meaningful relationships is essential and that responsibility extends throughout society.</p>	<p>How can we allow people with dementia to lead fulfilling social lives, on their own terms and without stigma?</p> <p>How do we create conditions that enable the meaningful continuation of important relationships?</p> <p>What can we do to normalise dementia, and ensure people do not feel ghettoised?</p>

Theme	Issues to address
<p><b>4 Valuing contrast: ‘ Good days and bad days’</b></p> <p>Happiness is complicated – a roller-coaster of highs and lows, of being able to express ourselves freely and gain contentment in whatever we choose. But this nuanced reality can be absent, or difficult to achieve, for those living with dementia.</p>	<p>How do we assess what makes someone with dementia happy?</p> <p>How can we overcome the determination to eliminate unhappiness from the lives of people with dementia?</p> <p>How do we design care environments which allow people with dementia to experience and express a full range of emotions?</p>
<p><b>5 Supporting agency: ‘ What’s there to worry about?’</b></p> <p>Letting a person with dementia take risks is hard to square with our desire to keep vulnerable people safe. But if the knowledge of certain death brings a sense of freedom and thirst for life, then to enable a good life we need to be clearer about what it is we are protecting people from.</p>	<p>How can we promote spontaneity, choice and risk as assets in a life with dementia?</p> <p>How do we design dementia services to ensure we do not restrict individuals’ freedoms by limiting them to our desired routines?</p> <p>What role can technology play in providing reassurances to carers about individuals’ safety?</p>
<p><b>6 Maintaining health: ‘My priority in life’</b></p> <p>Dementia is a serious condition which requires specialist treatment. But that focus can cause unintended disregard for other parts of an individual’s health which, if neglected, may become a source of needless suffering, or limit opportunities to live well.</p>	<p>How do we design services that have the flexibility to address every aspect of a person’s good health, regardless of their dementia?</p> <p>What more can be done to enable people with dementia to communicate their feelings in relation to health and wellbeing?</p>

