London Borough of Hammersmith & Fulham

# Health & Wellbeing Board

## Agenda

**Wednesday 9 September 2015**
**7pm**
**Courtyard Room - Hammersmith Town Hall**

## MEMBERSHIP

Councillor Vivienne Lukey, Cabinet Member for Health and Adult Social Care (Chair)
Dr Tim Spicer, Chair of H&F CCG (Vice-chair)
Councillor Sue Macmillan, Cabinet Member for Children and Education
Vanessa Andreae, H&F CCG
Liz Bruce, Executive Director of Adult Social Care
Andrew Christie, Executive Director of Children's Services
Janet Cree, H&F CCG
Trish Pashley, Local Healthwatch representative
Director of Public Health

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Date Issued: 01 September 2015

London Borough of Hammersmith & Fulham

# Health & Wellbeing Board
## Agenda

**9 September 2015**

**Item** **Pages**

**1. MINUTES AND ACTIONS** 1 - 7

To approve as an accurate record and the Chair to sign the minutes of the meeting of the Health & Wellbeing Board held on 22 June 2015.

**2. APOLOGIES FOR ABSENCE**

**3. DECLARATIONS OF INTEREST**

If a Member of the Board, or any other member present in the meeting has a disclosable pecuniary interest in a particular item, whether or not it is entered in the Authority's register of interests, or any other significant interest which they consider should be declared in the public interest, they should declare the existence and, unless it is a sensitive interest as defined in the Member Code of Conduct, the nature of the interest at the commencement of the consideration of that item or as soon as it becomes apparent.

At meetings where members of the public are allowed to be in attendance and speak, any Member with a disclosable pecuniary interest or other significant interest may also make representations, give evidence or answer questions about the matter. The Member must then withdraw immediately from the meeting before the matter is discussed and any vote taken.

Where members of the public are not allowed to be in attendance and speak, then the Member with a disclosable pecuniary interest should withdraw from the meeting whilst the matter is under consideration. Members who have declared other significant interests should also withdraw from the meeting if they consider their continued participation in the matter would not be reasonable in the circumstances and may give rise to a perception of a conflict of interest.

Members are not obliged to withdraw from the meeting where a dispensation to that effect has been obtained from the Audit, Pensions and Standards Committee.

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This report sets out the proposal to appoint a co-opted member, representing the voluntary sector to the Health & Wellbeing Board.

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**6. JSNA UPDATE AND IMPACT REVIEW** 171 - 193

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To note the submission made to NHS Engalnd.

## 8. JOINT STRATEGIC NEEDS ASSESSMENT STEERING GROUP 207 - 210

To note the minutes of the meeting held on 27 July 2015.

## 9. DATES OF NEXT MEETINGS

The Board is asked to note that the dates of the meetings scheduled for the municipal year 2015/2016 are as follows:

9 November 2015
9 February 2016
21 March 2016

London Borough of Hammersmith & Fulham

# Health & Wellbeing Board

## Minutes

### Monday 22 June 2015

**PRESENT**

**Committee members:**
Councillor Vivienne Lukey, Cabinet Member for Adult Social Care (Chair)
Dr Tim Spicer, H&F CCG (Vice-chair)
Councillor Sue Macmillan, Cabinet Member for Children and Education
Vanessa Andreae, H&F CCG
Liz Bruce, Executive Director of Adult Social Care
Andrew Christie, Executive Director of Children's Services
Janet Cree, H&F CCG
Stuart Lines, Interim Director of Public Health

**Nominated Deputies:** Councillors Sharon Holder and Rory Vaughan

**NHS England:** Cecile Henderson and Johan Van Wijgerden

**Officers:** Colin Brodie, Public Health Knowledge Manager and Sue Perrin, Committee Co-ordinator

## 1. MINUTES AND ACTIONS

The minutes of the meeting held on 23 March 2015 were approved as an accurate record and signed by the Chair.

## 2. APOLOGIES FOR ABSENCE

Apologies for absence were received from Trish Pashley.

## 3. DECLARATIONS OF INTEREST

There were no declarations of interest.

## 4. APPOINTMENT OF A VICE-CHAIR

Dr Tim Spicer was appointed as Vice-chair.

## 5. INTEGRATION OF HEALTHCARE

Mrs Bruce presented the update on the new integrated Community Independence Service (CIS), which was the most significant joint work in terms of anticipated benefits, with health services and the Better Care Fund (BCF). The focus was to avoid hospital admission of elderly people.

The three CCGs and local authority Cabinets had agreed a business case for investment in a single, integrated CIS, serving all three boroughs. In 2015/16, it was not possible to create one organisation to provide the whole of the CIS. Instead, the BCF planned to invest in improvements in front-line services through two lead provider roles, one for health services and the other for social services.

Imperial College Healthcare NHS Trust and partners had been appointed as lead health provider. There would be specific targets across the three boroughs in terms of avoidable admissions.

The report provided an update on the pilot, which would test a new approach to hospital discharge and alignment between hospital discharge and in-reach functions. The new approach would enhance the timelines and quality of hospital discharges. Patients would be clear about the support which could be expected and their estimated discharge date.

The pilot would be evaluated to provide recommendations and options for wider roll-out and potentially to neighbouring boroughs such as Ealing and Hounslow. Current work was focused on older people with multiple long term conditions. It was suggested that Brent should be included in potential discussions.

Mrs Bruce stated that the next steps included the development of recommendations and an options paper for wider implementation. Modelling work was currently being undertaken, with a view to preparing a business case for the West London Chief Executives, the lead health provider and CCGs.

It was noted that the BCF included an agreement for mutual investment and sharing benefits and risks. In respect of hospital discharges, the benefits would be pooled across the systems. There would be common protocols. Works would be extended to include families and mental health.

Dr Spicer noted that the work was beneficial because a small percentage of patients accounted for a significant percentage of spending. A coherent approach for a child with multiple needs for example would provide a better deal for residents and the health and care economy.

Mrs Bruce stated that CIS would take health care out of the formal environment of hospitals and into the community.

**RESOLVED THAT:**

The HWB noted the progress made with the BCF schemes.

## 6. PUBLIC HEALTH STRATEGY

Mr Lines introduced the ten year Public Health Strategy for the three boroughs. It was intended that the strategy would help create sustained and focused action on the key areas that it was believed would improve public health and reduce health inequalities. The report set out the vision and the mission and the six shared priorities, which reflected the challenges common across all three boroughs:

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- Reducing levels of obesity in children
- Reducing smoking rates
- Improving sexual health
- Reducing levels of substance misuse
- Improving mental wellbeing
- Improving preventative services

In addition, the three boroughs had chosen an individual priority which was most important to them. For Hammersmith & Fulham, this was reducing the health inequalities associated with childhood poverty.

A series of high level outcomes would be monitored annually and reviewed every three years to monitor progress towards achieving the 2025 vision.

The underpinning principles were: Using the Evidence; Working in Partnership; Investing in Prevention; and A Life Stage Approach.

Mr Lines then responded to a query that information would be provided in respect of improving the Public Health presence on the website.

**Action: Stuart Lines**

Councillor Vaughan queried how the impact of the strategy would be measured and how Public Health would know what worked effectively and share good practice amongst the different teams. Mr Lines responded that there would be an annual report against progress in improving the relevant outcomes. There were a number of indicators for each priority. This information would be benchmarked against neighbouring boroughs and national data.

Mr Lines stated that local authorities had a number of statutory responsibilities, such as the weighing and measuring of children in reception class and Year 6. Evidence from a pilot in Kensington & Chelsea would be shared with the other boroughs and inform future work.

Mr Christie commented that the turnover rate in the borough was so high that the data would not reflect the same population.

Mrs Bruce noted the significant challenges in the transfer of public health responsibilities from the NHS to Local Authorities. There needed to be communication around sign posting and external facing message from each of the three Council websites, which could help to change behaviour.

Dr Spicer stated that one example of where communication could influence behaviour was schools' eating policy and food availability.

**RESOLVED THAT:**

1. The Public Health Strategy be noted.
2. A report on childhood obesity be added to the work programme.

## 7. EXCESS WINTER DEATHS

Mr Lines introduced the report, which presented the 12 recommendations set out in the guidance from the National Institute for Health and Care Excellence (NICE) as to how local authorities through their HWBs and key delivery partners should mitigate and reduce the risk of death and ill health associated with living in a cold home.

The report set out the actions to date and potential gaps. A number of the recommendations focused around making every contact count. Data indicated that older people were more vulnerable.

Dawn Stephenson, Chief Executive, Age UK considered that the key issue was not just about health, but about choices. The guidelines were a real opportunity for Adult Social Care and Health to work in a more holistic way.

The Chair suggested that it might be possible to support and enhance the 'Healthier homes, healthier people initiative'. Mr Lines agreed to provide further detail.

**Action: Stuart Lines**

Dr Spicer suggested that building awareness of people at risk and what to advise could be built into care plans.

**RESOLVED THAT:**

A further report in respect of taking forward the actions should be added to the work programme.

## 8. PREVENTATIVE HEALTH

Ms Henderson updated on NHS England's (NHSE) priorities for the coming year. NHSE intended to be more transparent and forthcoming. An action plan would be reviewed with all stakeholders. NHSE would try not to duplicate work being done elsewhere and would work directly and engage more with the 31 GP practices.

There would be a full clinical audit of immunisations. The data would be reviewed and NHSE would work with those practices in need of help. The MMR2 vaccination would be a priority because of the high number of children who had not received this vaccination.

Members welcomed the planned pro-active work with practices and support for those not performing optimally.

Dr Spicer stated that Central London Community Healthcare (CLCH) was moving to SystemOne, the system used by all GPs. The single data set would provide more confidence for clinicians in terms of the veracity of the data.

Dr Spicer noted the collective responsibility between health and social care and suggested that NHSE should look at the breadth of outlets with which people came into contact.

Councillor Macmillan queried whether there was a wide discrepancy in MMR uptake between practices. Ms Henderson responded that there were likely to be some discrepancies. In the previous year, there had been a reactionary approach. NHSE would publicise the vaccination in a more integrated way.

Members suggested that the key message that the vaccination was not an injection should be communicated in every contact.

Councillor Holder queried whether there was benchmark data by groups such as children, the elderly and the workforce. It was believed that the CCG data from two years previously was the most recent. In respect of the flu vaccinations, data was collected from pharmacies and this could be benchmarked, but data was not readily available for children.

Councillor Holder queried how performance could be improved if there was no benchmark data. Johan Van Wijgerden responded that historic data could provide trends. However, it tended to be CCG locality specific.

Ms Andreae stated that the work which the CCG had undertaken with Public Health some two years previously in respect of screening, immunisation and health checks had shown that no practice was good at everything. This information should still be available.

Hammersmith & Fulham CCG had previously selected the MMR1 vaccination as a priority, and there were concerns that the MMR2 vaccination could only be targeted at those who had already received the MMR1 vaccination.

There had been no information in respect of the availability of the MenB vaccination from September 2015, before it had been publicised on BBC 1. (Information had subsequently been received by Hammersmith & Fulham practices.)

Councillor Vaughan referred to the vaccination pilots planned for that winter for children up to age six, and queried how this would be communicated to parents and whether high risk children would be targeted.

Ms Andreae responded that Leads had been identified in different organisations and that she was the CCG Lead. GPs would send parents at least three texts and there would be walk-in clinics. The vaccination would be publicised in schools, social care, the voluntary sector and children's centres. Mrs Bruce was the executive Lead for the Council. A joint message and actions would be agreed by the Council, CCG and CLCH, which was responsible for school nurses.

**RESOLVED THAT:**

The update be noted.

## 9. EARLY YEARS

The update on the transition arrangements for the transfer of health visiting and family nurse partnership services was noted.

## 10. JSNA 2015/2016

Colin Brodie introduced the update report on the current work programme and specifically the JSNAs for Dementia, Childhood Obesity, End of Life Care and Housing JSNA. Two proposals for 2015/16 had been submitted: Evidence Hub and Excess Winter Deaths and Food Poverty.

Mrs Bruce stated that the End of Life Care JSNA linked to information in respect of elderly people dying in acute beds, which contributed to inappropriate demand in acute settings.

Mrs Bruce commented that the Evidence Hub was a good way of making information usable and accessible. Mr Brodie confirmed that the hub would be publically available.

**RESOLVED THAT:**

The report be noted.

## 11. 2015-2016 OPERATING PLAN, QUALITY PREMIUM - OPERATIONAL PLAN

Ms Cree introduced the Operating Plan, which had been submitted to NHS England in May 2015, following discussion and agreement with the HWB Chair. The Operating Plan had been brought to the HWB to review and ratify the decision.

The local priorities were MMR2 and increasing the number of diabetes care plans. The Quality Premium was based on measures which covered a combination of national and local priorities and these were set out in the report.

The CCG would have its quality premium payment reduced if the providers from which it commissioned services did not meet the NHS Constitution requirements.

**RESOLVED THAT:**

The HWB endorsed the Chair’s action in agreeing the plans.

## 12. NATIONAL HEATWAVE PLAN

The HWB received the Heatwave plan for England intended to protect the population from heat-related harm to health.

Dr Spicer stated that the report set out the stages at which various risks occurred, and the recommended action, and identified the specific groups most at risk.

## 13. DATES OF NEXT MEETINGS

9 September 2015
9 November 2015
9 February 2016
21 March 2016

Meeting started: 6.00 pm
Meeting ended: 8.00 pm

Chair ..........................................................

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Agenda Item 4

# London Borough of Hammersmith & Fulham

**HEALTH & WELLBEING BOARD**
**9 September 2015**

**TITLE OF REPORT: Membership and Terms of Reference**

**Report of the Head of Governance and Scrutiny**

**Open Report**

**Classification - For Decision**

**Key Decision: No**

**Wards Affected:** All

**Accountable Executive Director:** Nigel Palace, Chief Executive

| | |
|---|---|
| **Report Author:** Sue Perrin, Committee Co-ordinator | **Contact Details:**<br>Tel: 020 8753 2094<br>E-mail:<br>sue.perrin@lbhf.gov.uk |

## 1. EXECUTIVE SUMMARY

1.1. This report sets out the proposal to appoint a co-opted member, representing the voluntary sector to the Health & Wellbeing Board.

## 2. RECOMMENDATIONS

2.1. The Board is asked to agree the appointment of a co-opted member, representing the voluntary sector for the remainder of the municipal year.

2.2. The Board is asked to agree the appointment of Ian Lawry, Chief Executive, sobus

## 3. INTRODUCTION

3.1. The Annual Council Meeting on 20 May 2015, approved the Health & Wellbeing Board's Constitution and Terms of Reference, as shown in Appendix 1.

3.2. The terms of reference permit the Board to appoint additional persons.

## 4. PROPOSAL AND ISSUES

4.1 It is proposed that a co-opted member, representing the voluntary sector is appointed to the Health & Wellbeing Board.

4.2 The co-opted member's period of office will expire at the end of the municipal year, and the Board will then decide whether this position will be reappointed for a further year.

4.3 The Board is asked to agree the appointment of Ian Lawry, Chief Executive, sobus.

4.4 Information in respect of sobus is provided as Appendix 2.

## LOCAL GOVERNMENT ACT 2000
## LIST OF BACKGROUND PAPERS USED IN PREPARING THIS REPORT

| No. | Description of Background Papers | Name/Ext of holder of file/copy | Department/ Location |
|---|---|---|---|
| 1. | None | | |

**Appendix 1: Constitution and Terms of Reference**
**Appendix 2: sobus: About Us**

**Appendix 1**

# London Borough of Hammersmith & Fulham

## HEALTH AND WELLBEING BOARD

## CONSTITUTION AND TERMS OF REFERENCE

**Members:**
The Board shall comprise 9 voting members as follows:
The Cabinet Member for Health and Adult Social Care
The Chair and 2 representatives of the H&F Clinical Commissioning Group
The Cabinet Member for Children and Education
A Local Healthwatch representative
The Tri-borough Executive Director of Adult Social Care
The Tri-borough Executive Director of Children's Services
The Tri-borough Director of Public Health

Each nominating body will nominate a primary representative and a deputy, both of whom will be permanent appointments. The deputy will have the authority to make decisions in the event that the Board member is unable to attend a meeting.

**Quorum**
Four voting members, including one Councillor

**Co-opted Members:**
The HWB may appoint additional persons to the Board.

### 1. Constitution

1.1 The Health and Social Care Act 2012 requires that every relevant local authority establishes a Health and Wellbeing Board (HWB). The Act establishes and treats Health and Wellbeing Boards as though they are Committees appointed by the Council in accordance with the Local Government Act 1972.

1.2 The Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 dissapply certain provisions of local government law from HWBs. This enables non-Councillor members to vote alongside the Councillor members unless the Council directs otherwise and disapplies the requirement to impose a political balance in relation to seats on the Board.

## 2. Voting

2.1 The Board will seek to work by consensus. Where consensus cannot be reached, all members of the Board have voting rights unless the Council (following consultation with the Board) decides otherwise. In the event of an equality of votes the Chair shall have the casting vote.

## 3. Chair

3.1 The Chair shall be appointed by the Full Council. Members shall elect a Vice-Chair from among the Board's membership.

## 4. Procedures

4.1 The Board will meet 5 times during each municipal year.

4.2 Council Standing Orders (as applicable to Committees) shall apply at meetings of the Board. In the event of a conflict between these procedures and any guidance or law then the latter will prevail.

## 5. Terms of Reference

5.1 In accordance with the statutory duties and powers given to the HWB by the Health and Social Care Act 2012, the terms of reference of the Board are as follows:

(i) To provide organisational leadership by agreeing the vision and strategic priorities for health and wellbeing in Hammersmith & Fulham, as part of the Joint Health & Wellbeing Strategy.

(ii) To ensure commissioning decisions are based on clear evidence for improving outcomes and integrating services.

(iii) To drive the development and implementation of the Joint Health & Wellbeing Strategy (JHWS) and take joint action to facilitate progress.

(iv) To oversee the development and use of the Joint Strategic Needs Assessment (JSNA) by the Council and H&F Clinical Commissioning Group.

(v) To oversee the development and maintenance of the Pharmaceutical Needs Assessment (PNA).

(vi) To ensure effective public and patient engagement and involvement in the development and provision of health and wellbeing services.

(vii) Wherever possible, to promote the effective integration of health and social care services across the three boroughs of Hammersmith & Fulham, Kensington & Chelsea and Westminster.

AMENDED JULY 2013, JANUARY 2014

**Appendix 2**

# sobus: About Us

## Sobus provides a range of services which support voluntary and community sector organisations with the expected impact for those organisations:

- Capacity of VCS to support beneficiaries increasing
- Organisations reporting improved financial stability
- Organisations more able to demonstrate impact.
- Increase in partnership working
- Improved governance of organisations
- Greater success rate for commissioning contracts and grant funding

## Sobus will know if it has been successful when we are:

- Able to demonstrate the impact its activities have to trustees and staff
- The first organisation contacted about the VCS in H&F by the local authority, CCG and private companies
- Very efficient and effective with the resources it has
- Generating an annual surplus to put into a building sinking funding, organisational reserve, staffing reserve and invest in future opportunities
- Generating enough unrestricted income to cover the cost of core functions
- Working with a broad range of trusted partners to offer and develop services, activities, events and new resources
- Having regular two way engagement with all VCS in H&F
- Highly rated by the VCS and partners in H&F
- Demonstrating the above with recognised quality standards

**Our Services fit into four areas:**

**Brokering**

being a broker between Voluntary & Community Sector (VCS) organisations and statutory, private and other VCS

**Information and Intelligence**

gathering, analysing and sharing information and intelligence on the VCS and needs of H&F

**Capacity building**

providing locality based capacity building

**Affordable premises**

being a provider of high quality and affordable premises for VCS and start up enterprises

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## Our Vision is

*Leading the transformation of Voluntary Organisations into a thriving and significant sector which better identifies and supports the needs and aspirations of our communities.*

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**sobus** is a new Community Development Agency for Hammersmith & Fulham. It has been created through the merger of the Community and Voluntary Sector Association Hammersmith & Fulham (CaVSA) and the Fulham Community Partnership Trust (FCPT).

**sobus** operates across the Borough and works with community and voluntary organisations, social enterprises and business startups, residents and statutory agencies.

The name **sobus** has been created by combining the words ‘social’ and ‘business’ and was first used as the ‘brand’ for a joint Transforming Local

Infrastructure Project between CaVSA, HAFAD (now Action on Disability) and FCPT. The name closely reflects a core operating principle for **sobus** which is to develop and promote enterprise as a means to supporting community and voluntary organisations to achieve greater social impact.

## CaVSA

CaVSA Hammersmith & Fulham was the Council for Voluntary Services (CVS) organisation in Hammersmith & Fulham. The organisation was established in 1997 and over the years has provided a range of services based on two core areas of work:

- Capacity building support to community and voluntary sector groups and organisations, including training, information, advice and practical support with governance, fundraising, project development, monitoring and evaluation, Trustee recruitment etc
- Facilitating and supporting networking between groups and engagement with statutory and private sector partners.

## FCPT

Fulham Community Partnership Trust (FCPT) was established to champion civic engagement and to keep the legacy of the New Deal for Communities alive in North Fulham. New Deal for Communities (NDC) was a national, decade-long government programme targeted at a number of disadvantaged parts of the UK, including North Fulham, empowering local people to design their own solutions to a huge range of difficult problems: poor health, crime rates, high unemployment, and low educational attainment. The programme ended in March 2010.

***Source: sobus.org.uk***

Agenda Item 5

# London Borough of Hammersmith & Fulham

**HEALTH & WELLBEING BOARD**

**9th September 2015**

**TITLE OF REPORT – Dementia JSNA and Commissioning intentions**

**Report of the Executive Director of Adult Social Care and Public Health**

**Open Report**

**Classification - For Decision**

**Key Decision: No**

**Wards Affected:** All

**Accountable Executive Director:** Liz Bruce

**Report Author:** Lisa Cavanagh / Colin Brodie

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## 1. EXECUTIVE SUMMARY

1.1. This report presents the key findings and recommendations from the Joint Strategic Needs Assessment (JSNA) on dementia, and outputs of the ‘Like Minded’ North West London (NWL) Strategic Review of Dementia and how these will be used to inform future commissioning intentions to address the challenges presented by the expected increase in dementia in our local population.

## 2. RECOMMENDATIONS

2.1. The Health and Wellbeing Board are requested to consider and approve the dementia JSNA for publication.

2.2. The Health and Wellbeing Board are requested to note how the dementia JSNA and the NWL dementia strategy will be used to inform the future commissioning intentions.

## 3. REASONS FOR DECISION

3.1. To ensure that in the future there is the right type and configuration of health and care support services in place to support people diagnosed with Dementia and their carers to live well and to meet the increasing forecasted demand within resources.

3.2. The North West London (NWL) Mental Health & Wellbeing Strategic Implementation and Evaluation Board approved the report of the strategic review of Dementia 15th May 2015, and agreed that individual CCGs would

3.3. consider the outputs and outcomes as part of their service review and development process for 2015/16.

3.4. The Health and Social Care Act 2012 placed the duty to prepare a JSNA equally and explicitly on local authorities (LAs), Clinical Commissioning Groups (CCGs) and the Health and Wellbeing Boards (HWB). Local governance arrangements require final approval from the Health and Wellbeing Board prior to publication.

## 4. INTRODUCTION AND BACKGROUND

4.1. The number of people with dementia is increasing, which will have a significant impact on our population, particularly for older people and their families and carers.

4.2. As referenced in the full report diagnosis rates are increasing, figures for Hammersmith and Fulham show a formal GP diagnosis rate of 68% of estimated prevalence as of March 2015. Local estimates indicate that the number of people aged 65+ with dementia in Hammersmith and Fulham will rise from 1200 in 2015 to just under 1800 in 2030 (a 50% increase)

4.3. This increase will inevitably impact on the local health and social care economies and will require increasing investment in services to detect, treat, and support people with dementias and their carers.

4.4. To inform the strategic approach and future commissioning arrangements required to tackle this challenge locally, two pieces of work have been undertaken:

- A deep dive JSNA on dementia for Hammersmith and Fulham, Kensington and Chelsea, and Westminster
- The North West London Strategic Review of Dementia for Brent, Harrow, Hillingdon, Ealing, Hammersmith & Fulham, Hounslow, Central London and West London Clinical Commissioning Groups.

4.5. The JSNA provides a comprehensive evidence base and information about the local population to support the development of future commissioning intentions for dementia services across the three boroughs, in order to meet this challenge.

4.6. Information for the JSNA has been collected from a variety of sources including audit, relevant policy and research as well as local data provided by stakeholders, providers and service users. This evidence has been analysed to identify gaps and solutions and forms the basis of the recommendations that are described in the JSNA report.

4.7. An Executive Summary and a full report of the JSNA are included as Background Papers.

4.8. In 2014 the former Mental Health Programme Board agreed to undertake a strategic review in relation to dementia for the eight CCG groups that fall within the NWL CCG collaboration. The review commenced in August 2014, it included; mapping of prevalence of dementia, mapping of progress towards achievement of 67% diagnosis rate in each area and delivery of a series of themed workshops. The outcomes and outputs of the review are included as Background Papers and summarised as follows:

- *An outcome focussed Framework specification that uses the Dementia 'I' statements as the basis for a suite of outcome measures, these are accompanied by set of carers outcomes measures, developed by a carer*
- *A dementia exemplar framework developed during the review, and informed by feedback and comments from people with dementia and their carers.*
- *A high level clinical care pathway developed and agreed by a virtual clinical leads group, and is included within the framework specification*
- *A set of individual/we/group and organisational commitment statements have been produced via the workshops.*

4.9. In July 2015 officers from Public Health, the CCGs and local authority met to review the JSNA recommendations with the outputs of the NWL Strategic Review of Dementia and begin planning next steps in light of the key findings of the JSNA and NWL strategy. The outputs of this session are shown in Appendix 1.

4.10. This exercise identified that the majority of the JSNA recommendations that are RAG rated based on identified service gaps/ opportunities align with the proposed service aims identified through the NWL work.

## 5. KEY THEMES OF THE JSNA

5.1 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 JSNA, several priority themes have been highlighted. These are described in the table below.

| | |
|---|---|
| 1. Numbers of people locally **who have dementia** will increase over the next few decades (around 55% in next 15 years across the 3 boroughs), primarily due to a greater number of older people (aged 80+) | We need **adequate resource** to deal with this challenge and we need to provide services more **efficiently** and **sustainably** |
| 2. **Dementia diagnosis rates** have been **rising** in each of the three boroughs | This has to be followed by an equal input into **post-diagnostic care** to ensure people are **living well** with dementia |
| 3. Most of the cost of supporting those with dementia falls on **unpaid carers** and **adult social care**. With more care provided at home, pressure on carers may increase | We need to **support, advise and empower carers** 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 **appropriate escalation of care** when needed | There may be a need for **increased training** for paid and unpaid carers residential care staff, and other appropriate professionals |
| 5. Dementia services are provided by a **range of agencies** - acute and primary care, mental health services, social care and third sector | Better **cohesion and collaboration** 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 **mental and physical** health needs | People with dementia need to receive **parity of access** across mental and physical health services |

## 6. KEY THEMES OF THE NWL STRATEGIC REVIEW OF DEMENTIA

6.1 The key themes from the NWL review highlighted the importance of achieving timely diagnosis for all those who need it balanced against support being available post-diagnosis and having one named person that people with dementia and their carers can call upon.

6.2 Other recommendations to support service improvements in dementia care are:

- The voices of people with dementia and their carers continue to be heard
- Commitments be given to utilize the dementia framework
- The dementia commitment statements should reinforce the importance of continuing to improve dementia services across North West London
- The need to work in partnership to achieve implementation of local plans.

## 7. NEXT STEPS

7.1 In Hammersmith and Fulham there are two key pieces of work underway to further improve and develop Dementia health and care services to meet the needs of people with memory impairment/dementia and their carers as follows;

I. Hammersmith and Fulham Clinical Commissioning Group (HFCCG) are re-commissioning memory assessment services. The proposal is to commission a multi-disciplinary, primary care focused memory assessment and post diagnostic support service to provide opportunities to increase dementia diagnosis rates with Hammersmith & Fulham and provide integrated and holistic post diagnostic support to enable people to live well with dementia and ensure that carers are well supported. The Procurement process is expected to take place during the period January 2016 – September 2016 with a view to awarding a contract and a new service in place October 2016.

II. The CCGs and LAs have started a three borough strategic review of jointly commissioned dementia day and community services to explore options to improve and develop services to include a Dementia Resource Centre service model in light of central and local strategic drivers and developments across health and social care. This review will include engagement with stakeholders including people with dementia and their carers to inform future commissioning intentions; the procurement timeline is also expected to take place January 2016 – September 2016 with new services in place October 2016.

7.2 The CCGs and LA will need to ensure people with dementia and their carers continue to be heard via patient/user/carer group forums to help shape dementia friendly environments and accessible health, social care and voluntary sector services that are vital in supporting people with dementia and their carers.

7.3 Both of these pieces of work afford commissioners an excellent opportunity to remodel/design and align services across the dementia care pathway to meet the growing demand and better meet the needs of local service users and their carers and enable them to live well with dementia

7.4 The JSNA recommendations and NWL outputs will be key to shaping services going forward and we will use these to benchmark against proposed service models.

## 8. CONSULTATION

8.1 In developing the JSNA a draft report was circulated to a range of stakeholders for consultation, including Local Authority colleagues, CCGs, Community and Voluntary Sector, and Healthwatch. Response to the consultation was good and a large number of comments received and incorporated into the final version. The views of local people with dementia and their carers were gathered from the Adult Carers Survey and work undertaken by Healthwatch.

8.2 In the process of undertaking the strategic review of dementia services across NWL an exemplar dementia framework was developed in co-production with people with dementia and their carers. A series of themed workshops were held engaging and involving key stakeholders and this work was undertaken with input and the support of Innovations in Dementia and Age UK Kensington and Chelsea.

## 9. EQUALITY IMPLICATIONS

9.1 JSNAs must consider the health, wellbeing and social care needs for the local area addressing the whole local population from pre-conception to end of life.

9.2 The “local area” is that of the borough, and the population living in or accessing services within the area, and those people residing out of the area for whom CCGs and the local authority are responsible for commissioning services

9.3 The “whole local population” includes people in the most vulnerable circumstances or at risk of social exclusion (for example carers, disabled people, offenders, homeless people, people with mental health needs etc.)

9.4 Equality implications will be further considered based on the outcome of the 3 borough dementia service review and future re-commissioning and re- procurement intentions and will be cleared by the relevant Equality Officer.

## 10. LEGAL IMPLICATIONS

10.1 The JSNA was introduced by the Local Government and Public Involvement in Health Act 2007. Sections 192 and 196 Health and Social Care Act 2012 place the duty to prepare a JSNA equally on local authorities (LAs), Clinical Commissioning Groups (CCGs) and the Health and Wellbeing Boards (HWB).

10.2 Section 2 Care Act 2014 imposes a duty on LAs to provide or arrange for the provision of services that contribute towards preventing, delaying or reducing care needs.

10.3 Section 3 Care Act 2014 imposed a duty on LAs to exercise its Care Act functions with a view to ensuring the integration of care and support provision with health provision to promote well-being, contribute to the prevention or delay of care needs and improve the quality of care and support.

10.4 JSNAs are a key means whereby LAs work with CCGs to identify and plan to meet the care and support needs of the local population, contributing to fulfilment of LA s2 and s3 Care Act duties.

10.5 Implications verified/completed by: Kevin Beale, Principal Social Care Lawyer, 0208 753 2740

## 11. FINANCIAL AND RESOURCES IMPLICATIONS

11.1 There are no financial implications arising from this report, any future financial implications identified as a result of the review and re-commissioning projects will be presented to the appropriate board & governance channels in a separate report.

11.2 Implications verified/completed by: (Prakash Daryanani, Head of ASC Finance, Telephone: 0208-753-2523.)

## 12. RISK MANAGEMENT

12.1 Public Health risks are integrated into the Council's Strategic Risk Management framework and are noted on the Shared Services risk register, risk number 5. Market Testing risks, achieving high quality commissioned services at lowest possible cost to the local taxpayer is also acknowledged, risk number 4. Statutory duties are referred to in the register under risk 8, compliance with laws and regulations. Risks are regularly reviewed at Business Board and are referenced to in the periodic report to Audit, Pensions and Standards Committee. Any risks identified during the 3 borough dementia service review and any subsequent re-procurement of services will be captured as they arise and incorporated if significant on the Shared Services risk register.

12.2 Risk Management implications verified by Michael Sloniowski, Shared Services Risk Manager, telephone 020 8753 2587.

## 13. PROCUREMENT AND IT STRATEGY IMPLICATIONS

13.1 Any future contractual arrangements and procurement proposals identified as a result of the 3 borough dementia service review and re-commissioning projects will be cleared by the relevant Procurement Officer.

## LOCAL GOVERNMENT ACT 2000
## LIST OF BACKGROUND PAPERS USED IN PREPARING THIS REPORT

| No. | Description of Background Papers | Name/Ext of holder of file/copy | Department/ Location |
|---|---|---|---|
| 1. | Dementia JSNA and Executive Summary | Colin Brodie | Public Health |
| 2 | Dementia Report 06.05.15 | Barbara Edwards & Debbie Mayor | CLCCG |
| 3 | NWL Strategic Review of Dementia 15.06.15 | Barbara Edwards & Debbie Mayor | CLCCG |
| 4. | Dementia Framework Service Specification | Barbara Edwards & Debbie Mayor | CLCCG |

**LIST OF APPENDICES:**

Appendix 1 – JSNA and NWL outputs

**Appendix 1: Hammersmith and Fulham**

In the JSNA, services were RAG rated against National Strategy Objectives, NICE Guidance, views expressed by people with dementia and their carers, qualitative research with clinicians, and supporting evidence. From this RAG rating, gaps were identified and recommendations developed. The table below highlights the recommendations which were developed from the areas highlighted as Red or Amber in the JSNA and those that align with the service aims from the North West London Service Framework Specification (NWL Strategic Review of Dementia May 2015)

| | Gap/Opportunity | Recommendation(s) | Links to NWL Strategic Review |
|---|---|---|---|
| **Memory Service Care** | *A. Memory service care varies between provider: in some cases the patient may not have access to timely diagnostic or adequate community support.*<br>*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.* | 1. Develop a single point of access to diagnostic assessment and ensure all patients across all three Boroughs have equitable access<br>2. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme | Aim 6: To promote a positive experience of services to people with dementia and family/carers |
| | *C. Diagnosis rates still do not meet estimated prevalence and can be further improved*<br>*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* | 3. Improve screening and diagnosis in care home and Extra Care residents<br>4. Consider training to increase referral from or support diagnosis in primary care, in line with NWL strategy<br>5. Audit completion of diagnostic assessment for those first identified in hospital and address accordingly<br>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 | Aim 2: To provide high quality advice and support for other Providers, especially Primary Care, on assessment and management interventions for dementia<br>Aim 5: To support the development of the workforce and volunteers providing the Service with the right attitudes and skill mix |

| | Gap/Opportunity | Recommendation(s) | Links to NWL Strategic Review |
|---|---|---|---|
| **Community Care** | *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*<br>*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.*<br>*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.* | 7. 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<br>8. Provide adequate infrastructure and training for care staff.<br>9. Ensure people are supported to access the care appropriate to them through the use of personal budgets<br>10. Ensure that there are sufficient Dementia Advisers to coordinate access to services. | Aim 4: To promote support and inclusion for people with dementia and family/carers using the Service<br>Aim 5: To support the development of the workforce and volunteers providing the Service with the right attitudes and skill mix<br>Aim 6: To promote a positive experience of services to people with dementia and family/carers |
| | *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)* | 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 | Aim 4: To promote support and inclusion for people with dementia and family/carers using the Service |

| | Gap/Opportunity | Recommendation(s) | Links to NWL Strategic Review |
|---|---|---|---|
| **Residential Care** | *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.* | 12. Address supply of local care home beds in future local authority and CCG commissioning intentions, including those specifically for dementia care. | |
| | *J. Little is known about the quality of dementia care in care homes locally* | 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.<br>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.<br>15. Ensure either all staff in intermediate care have appropriate training for looking after people with dementia or a specialist service is provided. | Aim 5: To support the development of the workforce and volunteers providing the Service with the right attitudes and skill mix<br>Also links to Aim 3 |

|  | Gap/Opportunity | Recommendation(s) | Links to NWL Strategic Review |
|---|---|---|---|
| **General Medical Care** | *K. Little is known about adequate use of antipsychotics – an audit is due to take place in Chelsea and Westminster Hospital.* | 16. Audit and address accordingly use of antipsychotics in hospitals and community prescriptions | Aim 3: To prevent or minimise the inappropriate use of anti-psychotic medication, including advice on alternative strategies for people with dementia living at home, in care homes or in other residential settings |
|  | *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.*<br>*M. Opportunities for reducing escalation of problems and care need have been identified through early targeted hospital care.* | 17. Ensure adequate monitoring, assessment and provision of care for other physical and mental health needs for people with dementia.<br>18. Ensure timely identification and targeted care of those with dementia in hospital<br>19. Provide dementia friendly environment within hospitals<br>20. Ensure adequate provision of liaison psychiatry and dementia nurses, consider expanding remit | Aim 1: To provide commissioners with confidence that service specifications and operational standards are consistently met<br>Aim 2: To provide high quality advice and support for other Providers, especially Primary Care, on assessment and management interventions for dementia<br>Aim 6: To promote a positive experience of services to people with dementia and family/carers |

| | Gap/Opportunity | Recommendation(s) | Links to NWL Strategic Review |
|---|---|---|---|
| **Whole Systems Care** | *N. There are few easy channels of communication between different providers of dementia care* | 21. All patients, carers and clinicians should have consistent and comprehensive information with clear signposting of care pathways<br>22. The current fragmentation in care provision would be addressed through centralised coordination and improved communication/collaboration between services | Aim 2: To provide high quality advice and support for other Providers, especially Primary Care, on assessment and management interventions for dementia<br>Aim 6: To promote a positive experience of services to people with dementia and family/carers |
| | *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.* | 23. Ensure adequate training and support across all services for staff and carers looking after people with dementia<br>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.<br>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. | Aim 1: To provide commissioners with confidence that service specifications and operational standards are consistently met<br>Aim 5: To support the development of the workforce and volunteers providing the Service with the right attitudes and skill mix |
| | *P. The Dementia Strategy in Kensington and Chelsea will end in 2016. The Westminster and* | 26. There should be a joint health and social care dementia programme board for the three | Aim 1: To provide commissioners with confidence that service specifications |

| | Gap/Opportunity | Recommendation(s) | Links to NWL Strategic Review |
|---|---|---|---|
| | *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* | boroughs to facilitate implementation of the North West London dementia strategy in alignment with findings and recommendations from this JSNA.<br>27. Local services are active stakeholders with wider initiatives to ensure strategy is sensitive to local needs | and operational standards are consistently met |
| | *Q. Housing, environment and planning strategies do not specifically mention dementia or carers of people with dementia* | 28. 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 | Aim 2: To provide high quality advice and support for other Providers, especially Primary Care, on assessment and management interventions for dementia |

| | Gap/Opportunity | Recommendation(s) | Links to NWL Strategic Review |
|---|---|---|---|
| **Patient and Carer's Rights** | *R. Lack of sufficient resource to support with end of life care across the three boroughs.*<br>*S. Lack of defined carer support pathway.*<br>*T. Support is needed for advocating peoples' best interests and awareness of the Mental Capacity Act 2005*<br>*U. There is little supporting infrastructure available to provide help to self-funders to "micro-commission" care as mandated by the Care Act 2014.* | 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.<br>30. 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.<br>31. Patients and carers should be aware of advance directives and power of attorney and how to initiate them.<br>32. Ensure there is adequate infrastructure to support self-funders to access care | Aim 1: To provide commissioners with confidence that service specifications and operational standards are consistently met<br>Aim 6: To promote a positive experience of services to people with dementia and family/carers |

# Dementia

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

## Executive Summary

[July 2015]   www.jsna.info

# 1 Executive Summary

## 1.1 Purpose of the JSNA

The purpose of this Joint Strategic Needs Assessment (JSNA) 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, the North West London strategic approach to dementia and guidance.

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
- Review guidance and evidence to inform best practice locally
- Make recommendations to align 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.

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

The full version of this report is available at (insert link here)

## 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 **who have dementia** 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 **adequate resource** to deal with this challenge and we need to provide services more **efficiently** and **sustainably** |
| **2. Dementia diagnosis rates** have been **rising** in each of the three boroughs | This has to be followed by an equal input into **post-diagnostic care** to ensure people are **living well** with dementia |
| **3.** Most of the cost of supporting those with dementia falls on **unpaid carers** and **adult social care**. With more care provided at home, pressure on carers may increase | We need to **support, advise and empower carers** 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 **appropriate escalation of care** when needed | There may be a need for **increased training** for paid and unpaid carers residential care staff, and other appropriate professionals |
| **5.** Dementia services are provided by a **range of agencies** - acute and primary care, mental health services, social care and third sector | Better **cohesion and collaboration** 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 **mental and physical** health needs | People with dementia need to receive **parity of access** 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 the full report (insert link) in Appendix A: RAG rating of local assets.

**Table 2: Recommendations**

| | Gap/Opportunity | Recommendation(s) |
|---|---|---|
| **Memory Service Care** | *A. Memory service care varies between provider: in some cases the patient may not have access to timely diagnostic or adequate community support.*<br>*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.* | 1. Develop a single point of access to diagnostic assessment and ensure all patients across all three Boroughs have equitable access<br>2. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme |
| | *C. Diagnosis rates still do not meet estimated prevalence and can be further improved*<br>*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* | 3. Improve screening and diagnosis in care home and Extra Care residents<br>4. Consider training to increase referral from or support diagnosis in primary care, in line with NWL strategy<br>5. Audit completion of diagnostic assessment for those first identified in hospital and address accordingly<br>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 |

|  | Gap/Opportunity | Recommendation(s) |
|---|---|---|
| **Community Care** | *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*<br>*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.*<br>*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.* | 7. 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<br>8. Provide adequate infrastructure and training for care staff.<br>9. Ensure people are supported to access the care appropriate to them through the use of personal budgets<br>10. Ensure that there are sufficient Dementia Advisers to coordinate access to services. |
|  | *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)* | 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 |

| | Gap/Opportunity | Recommendation(s) |
|---|---|---|
| **Residential Care** | *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.* | 12. Address supply of local care home beds in future local authority and CCG commissioning intentions, including those specifically for dementia care. |
| | *J. Little is known about the quality of dementia care in care homes locally* | 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.<br>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.<br>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** | *K. Little is known about adequate use of antipsychotics – an audit is due to take place in Chelsea and Westminster Hospital.* | 16. Audit and address accordingly use of antipsychotics in hospitals and community prescriptions |
| | *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.*<br>*M. Opportunities for reducing escalation of problems and care need have been identified through early targeted hospital care.* | 17. Ensure adequate monitoring, assessment and provision of care for other physical and mental health needs for people with dementia.<br>18.Ensure timely identification and targeted care of those with dementia in hospital<br>19. Provide dementia friendly environment within hospitals<br>20. Ensure adequate provision of liaison psychiatry and dementia nurses, consider expanding remit |

| | Gap/Opportunity | Recommendation(s) |
|---|---|---|
| **Whole Systems Care** | *N. There are few easy channels of communication between different providers of dementia care* | 21. All patients, carers and clinicians should have consistent and comprehensive information with clear signposting of care pathways<br>22. The current fragmentation in care provision would be addressed through centralised coordination and improved communication/collaboration between services |
| | *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.* | 23. Ensure adequate training and support across all services for staff and carers looking after people with dementia<br>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.<br>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. 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* | 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.<br>27.Local services are active stakeholders with wider initiatives to ensure strategy is sensitive to local needs |
| | *Q. Housing, environment and planning strategies do not specifically mention dementia or carers of people with dementia* | 28. 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 |

|  | Gap/Opportunity | Recommendation(s) |
|---|---|---|
|  |  | environment |
| Patient and Carer's Rights | *R. Lack of sufficient resource to support with end of life care across the three boroughs.*<br>*S. Lack of defined carer support pathway.*<br>*T. Support is needed for advocating peoples' best interests and awareness of the Mental Capacity Act 2005*<br>*U. There is little supporting infrastructure available to provide help to self-funders to "micro-commission" care as mandated by the Care Act 2014.*<br>*V.* | 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.<br>30. 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.<br>31. Patients and carers should be aware of advance directives and power of attorney and how to initiate them.<br>32. Ensure there is adequate infrastructure to support self-funders to access care |

## 1.4 About dementia

Dementia is a condition that affects about 800,000 people in the UK[1]. 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. There are several different causes of dementia, the most common being Alzheimer's (62% of cases) and vascular dementia (17% of cases).

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.

People with dementia are likely to have significant physical and mental comorbidities, such as depression, hypertension and diabetes. Average life expectancy ranges from 6.5 years for those diagnosed between the ages of 60-69; to 1.8 years for those diagnosed at age 90 and older.

The main risk factor for dementia is growing older and ageing. While the evidence base on the prevention of dementia is not yet fully developed (and will be informed by a number of current studies), research has indicated that most success lies with modifying cardiovascular risk factors.

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

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[1] Alzheimer's Society http://www.alzheimers.org.uk/statistics

Carers play a vital role in supporting people with dementia. Unpaid care contributes more in financial terms than contributions from any other agency (45% of the total, with social care providing 40%). Carers are often old themselves, more likely to be women, and are likely to be providing a substantial number of hours of support.

Carers for people with dementia often experience poorer physical and mental health, social isolation, fewer opportunities to employment or education, or having time to themselves or with friends. For young carers, it can often mean life chances are severely limited.

At any one time, a quarter of acute hospital beds are in use by people with dementia (Royal College of Psychiatrists, 2013). The recent introduction of dementia CQUIN payments (Commissioning for Quality and Innovation) has led to increased provision of dementia specialist nursing and better identification of dementia.

Nationally, 1/3rd of people identified as having dementia are resident in a care home[2], and local audits have identified at least two thirds of older people newly admitted to care homes had dementia. Care home provision is therefore an important factor in dementia.

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. For the most complex cases, annual costs of c. £70k have been reported[3].

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

**Table 3: 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 |
| **Total** | **161,000,000** |

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[2] Alzheimer's Society Statistics http://www.alzheimers.org.uk/statistics

[3] London Dementia Needs Assessment 2011, NHS London

## 1.5 Dementia in our population

Current estimates of the number of people with dementia in the local population are approximately 1200 in Hammersmith and Fulham (LBHF); 1500 in Kensington and Chelsea (RBKC) and 1800 in Westminster (WCC). About half of these people are aged 85+. The total across the three boroughs is estimated to rise from 4,500 in 2015 to 7,000 in 2030 for those aged 65+, if the current prevalence rates in the population remain the same. Prevalence rates do fluctuate and recent estimates may indicate a reduction in prevalence due to an improvement in general health in recent years.

Current published diagnosis rates – the numbers known by GPs to have dementia - are 63% of the estimated prevalence rates in Hammersmith and Fulham Clinical Commissioning Group (LBHF), 65% in West London CCG (RBKC plus Queens Park and Paddington) and 65% in Central London CCG (WCC minus QPP,) based on old prevalence rates[4]. This compares to 60% across London. There are unpublished results that are included in section **Error! Reference source not found.**

> *'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**

Through the aging of the population alone, we can estimate a 55% increase in the number of people across the three boroughs with dementia over the next 15 years: 50% for Hammersmith & Fulham; 70% for Kensington & Chelsea; and 45% for Westminster. Diagnostic, treatment and care service provision may need to expand proportionately to meet this increasing need.

Across the three Boroughs there are approximately 39,000 residents who identify themselves as providing unpaid care. According to the Survey of Adult Carers in 2014/15 in the three boroughs, around a quarter of carers responding to the survey 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

> *'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**

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[4] Prevalence rates are discussed in more detail in the full report in section 3.5

## 1.6 Dementia services and asset mapping

Basic pathways of care involve diagnosis in a Memory Service; either led by mental health or by general medical services. Patients are referred to this service via their GP, although some will be identified through hospital admission or adult social care. The voluntary sector is also often well placed to notice early signs of dementia in their service users. On-going care is provided initially by the Memory Service then via GP, social care and the voluntary sector.

Memory Services are shared between RBKC and WCC. A Living Well service for on-going care is also being developed jointly between RBKC and WCC. LBHF has Memory Services provided by West London Mental Health NHS Trust and Imperial College Healthcare NHS Trust. A detailed map of service provision has been created and is available in Chapter 5.

> *'Having the same referral strategy across whole trust is important'*
>
> **Local Clinician, 2014**

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. Core services provided are home care, memory cafés, and day services.

People who need adult social care services will be allocated a personal budget which can be used to fund a range of support including information and advice, home adaptations, assistive technology, rehabilitation or reablement, or moves to extra care sheltered housing or residential care where necessary. Adult Social Care also commission services to support carers, such as respite care, to prevent carers from developing their own needs for care and support.

Published rates of care home bed provision have identified a national rate of 114.1 beds per 1,000 aged 75+. Provision across the three boroughs is less than half of this at 45.5 per 1000; 59.3 in LBHF, 46.6 in RBKC and 35.7 in WCC (the lowest in England). Surrounding boroughs also have lower provision of beds than the national average. A local audit of those identified as having dementia indicates 60% are placed outside of their original borough of residence.

There is a strong local emphasis on caring for people at home for longer and delaying entry to care homes when that person can be supported in the community. It is important to ensure that patients are receiving adequate support whether at home or via residential care regardless of capacity and availability of care, and that external placement where possible do not go against the wishes of patients.

> *'Voluntary services are huge and play a massive role'*
>
> **Local Clinician, 2014**

The voluntary sector plays a key role for people living with dementia in the community, including providing day services, activities and befriending schemes.

Our needs assessment has collated feedback from local clinicians and service users. Through this we have identified several areas for improvement regarding quality, supply and cohesion of services. These are addressed in the gaps and recommendations.

## 1.7 Views of people with dementia and their carers

Research shows 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.

Patient and carer's choices over type of support and care they receive may be influenced by cultural background, beliefs and their relationship and communication with professionals. Some may find it difficult to engage with advance care planning.

This is reflected locally where users and carers have identified that they particularly value respite care, practical (financial and legal) advice, memory cafes and day centres. Areas for improvement include staff training, access to and cohesion of services, consistency of support and personal control when choosing services

> *'…(x) is great; she organises a book clubs… reads books out loud, …royal academy workshop discusses paintings - once a month'*
>
> **Service User**

## 1.8 Review of evidence and models of care

Management of dementia centres around medication for symptoms of cognitive impairment and distressing behaviour, and care that includes stable staffing, calm environments and appropriate stimulation (NICE, 2006). The Prime Minister's Challenge has prioritized research into finding a cure for dementia or solutions to delay the progress of symptoms, and sharing best practice for service delivery.

There is increasing emphasis on the creation of 'dementia friendly communities' and dementia friendly environments, supported by the Dementia Action Alliance and Prime Minister's Challenge[5].

Technologies such as remote tracking, alarms and telecare may aid in diagnosis of dementia and management of problems such as wandering, however need to be supported by surrounding infrastructure.

> *'Caring communities are difficult in an urban inner city'*
>
> **Local Clinician, 2014**

The Blackfriars Consensus[6] recognises the overlap between risk factors for vascular disease and dementia, and the potential for effective approaches to prevent non-communicable diseases, such as cardiovascular disease, to be effective in the prevention of dementia.

Key routes to reducing the risk of dementia are:

- modifying cardiovascular risk
- maintaining mental stimulation
- social engagement
- physical activity
- treating depression.

Three large research studies are currently taking place in Europe and the results will inform the case for preventive intervention. NICE is currently developing guidelines referring to midlife prevention of dementia.

New models of care may enable provision of better quality and more streamlined, cost effective services. The North West London dementia strategy highlights a primary-care based diagnostic approach. Scotland's national Dementia Strategy outlines the '8 Pillars' model with care centred around a 'dementia practice coordinator'. Watford's Dual Frailty ward and Delirium Recovery Programme may reduce incidence of escalation to residential care.

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[5] Prime Minister's challenge on dementia 2020 https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020 (accessed 1 July 2015)

[6] Public Health England/UK Health Forum. *Blackfriars Consensus* http://nhfshare.heartforum.org.uk/RMAssets/Dementia/Blackfriars%20consensus%20%20_V19b.pdf

## 1.9 Conclusion

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.

This JSNA provides a comprehensive evidence base and information about the local population 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.

# Dementia

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

FINAL DRAFT

[July 2015]     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, Andrew Rixom, and Neha Shah.

## Acknowledgements

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# 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
- Review guidance and evidence to inform best practice locally
- Make recommendations to align 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 at (insert link here)

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 **who have dementia** 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 **adequate resource** to deal with this challenge and we need to provide services more **efficiently** and **sustainably** |
| **2. Dementia diagnosis rates** have been **rising** in each of the three boroughs | This has to be followed by an equal input into **post-diagnostic care** to ensure people are **living well** with dementia |
| **3.** Most of the cost of supporting those with dementia falls on **unpaid carers** and **adult social care**. With more care provided at home, pressure on carers may increase | We need to **support, advise and empower carers** 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 **appropriate escalation of care** when needed | There may be a need for **increased training** for paid and unpaid carers residential care staff, and other appropriate professionals |
| **5.** Dementia services are provided by a **range of agencies** - acute and primary care, mental health services, social care and third sector | Better **cohesion and collaboration** 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 **mental and physical** health needs | People with dementia need to receive **parity of access** 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** | *A. Memory service care varies between provider: in some cases the patient may not have access to timely diagnostic or adequate community support.*<br>*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.* | 1. Develop a single point of access to diagnostic assessment and ensure all patients across all three Boroughs have equitable access<br>2. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme |
| | *C. Diagnosis rates still do not meet estimated prevalence and can be further improved*<br>*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* | 3. Improve screening and diagnosis in care home and Extra Care residents<br>4. Consider training to increase referral from or support diagnosis in primary care, in line with NWL strategy<br>5. Audit completion of diagnostic assessment for those first identified in hospital and address accordingly<br>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 |

| | Gap/Opportunity | Recommendation(s) |
|---|---|---|
| **Community Care** | *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*<br>*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.*<br>*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.* | 7. 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<br>8. Provide adequate infrastructure and training for care staff.<br>9. Ensure people are supported to access the care appropriate to them through the use of personal budgets<br>10.Ensure that there are sufficient Dementia Advisers to coordinate access to services. |
| | *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)* | 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 |

| | Gap/Opportunity | Recommendation(s) |
|---|---|---|
| **Residential Care** | *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.* | 12.Address supply of local care home beds in future local authority and CCG commissioning intentions, including those specifically for dementia care. |
| | *J. Little is known about the quality of dementia care in care homes locally* | 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.<br>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.<br>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** | *K. Little is known about adequate use of antipsychotics – an audit is due to take place in Chelsea and Westminster Hospital.* | 16.Audit and address accordingly use of antipsychotics in hospitals and community prescriptions |
| | *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.*<br>*M. Opportunities for reducing escalation of problems and care need have been identified through early targeted hospital care.* | 17.Ensure adequate monitoring, assessment and provision of care for other physical and mental health needs for people with dementia.<br>18.Ensure timely identification and targeted care of those with dementia in hospital<br>19.Provide dementia friendly environment within hospitals<br>20.Ensure adequate provision of liaison psychiatry and dementia nurses, consider expanding remit |

| | Gap/Opportunity | Recommendation(s) |
|---|---|---|
| **Whole Systems Care** | *N. There are few easy channels of communication between different providers of dementia care* | 21.All patients, carers and clinicians should have consistent and comprehensive information with clear signposting of care pathways<br>22.The current fragmentation in care provision would be addressed through centralised coordination and improved communication/collaboration between services |
| | *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.* | 23.Ensure adequate training and support across all services for staff and carers looking after people with dementia<br>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.<br>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. 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* | 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.<br>27.Local services are active stakeholders with wider initiatives to ensure strategy is sensitive to local needs |
| | *Q. Housing, environment and planning strategies do not specifically mention dementia or carers of people with dementia* | 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** | *R. Lack of sufficient resource to support with end of life care across the three boroughs.*<br>*S. Lack of defined carer support pathway.*<br>*T. Support is needed for advocating peoples' best interests and awareness of the Mental Capacity Act 2005*<br>*U. There is little supporting infrastructure available to provide help to self-funders to "micro-commission" care as mandated by the Care Act 2014.* | 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.<br>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.<br>31.Patients and carers should be aware of advance directives and power of attorney and how to initiate them.<br>32.Ensure there is adequate infrastructure to support self-funders to access care |

# 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)**

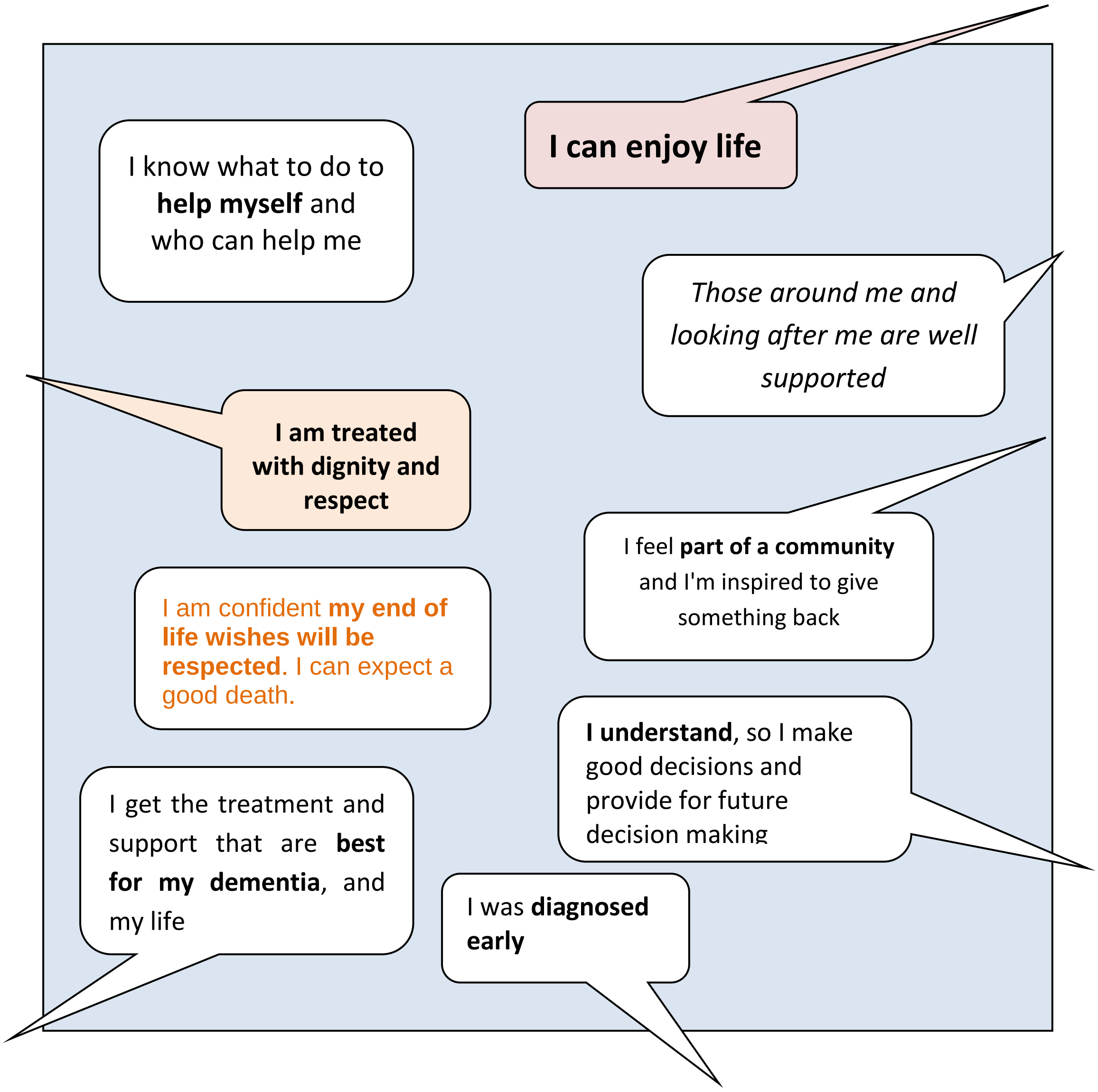
1. Improving public and professional awareness and understanding of dementia: addressing stigma
2. Good-quality early diagnosis and intervention for all: establishing a clear care pathway for people who may have dementia
3. Good-quality information for those with diagnosed dementia and their carers
4. 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**'[1]. 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**



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[1] Department for Health https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213811/dh_119828.pdf

Prime Minister's challenge of dementia 2020[2] 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.

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[2] 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**[3] 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**[4] 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 £1milion 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.

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[3] HM Government. Care Act 2014 http://www.legislation.gov.uk/ukpga/2014/23/contents

[4] 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"[5] 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[6]
- *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.

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

[6] 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[7]. 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.[8]

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[9]:

- 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,

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[7] Alzheimer's Society http://www.alzheimers.org.uk/statistics

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

[9] 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 finding are contrary to existing research and that further research is required to better understand the consequences of these findings.

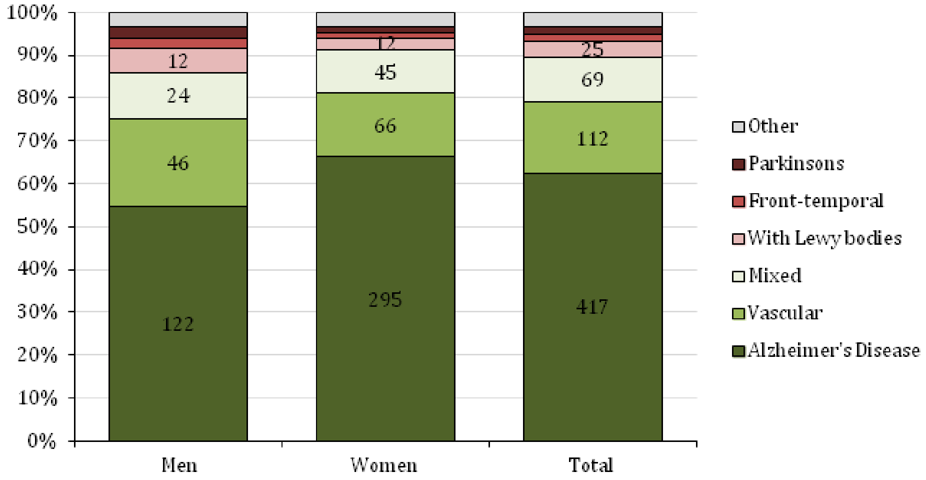
The risk of developing Alzheimer's disease and Vascular Dementia is reduced by a normal healthy lifestyle; good nutrition, no more than recommended alcohol consumption, and adequate physical activity.

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[10]. 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%

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

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[11] (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

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[11] 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

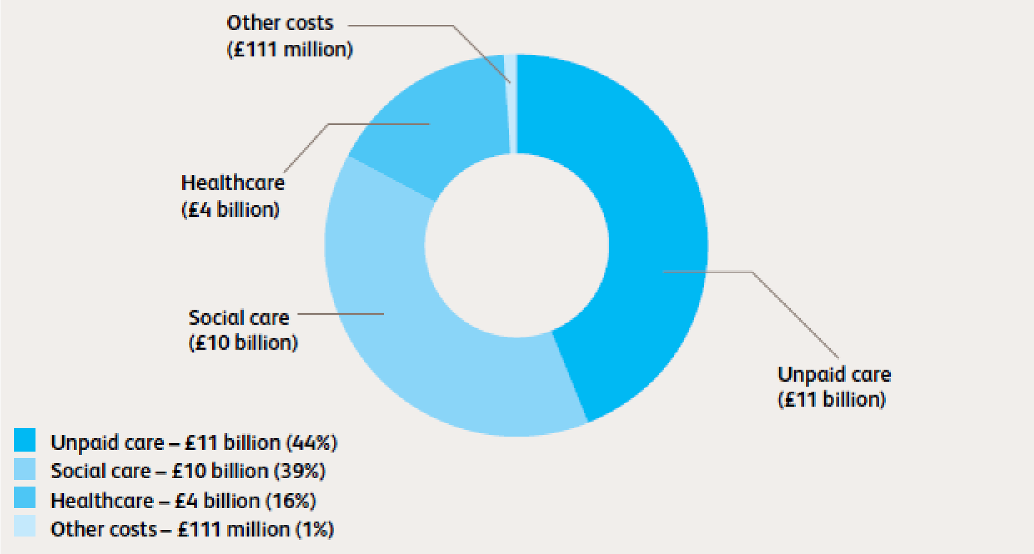
## The cost of dementia

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[12], other service costs and land prices. For the most complex cases, annual costs of c.£70k have been reported[13].

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 |
| **Total** | 161,000,000 |

## 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.

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

[13] 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, CFASI was conducted in 1989-1994 and was repeated as CFASII in 2008-2011 in exactly the same way. Dementia prevalence in those 65+ in 2008-2011 was predicted to be 8.3% by CFASI but was actually found to be 6.5% in CFASII - 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.

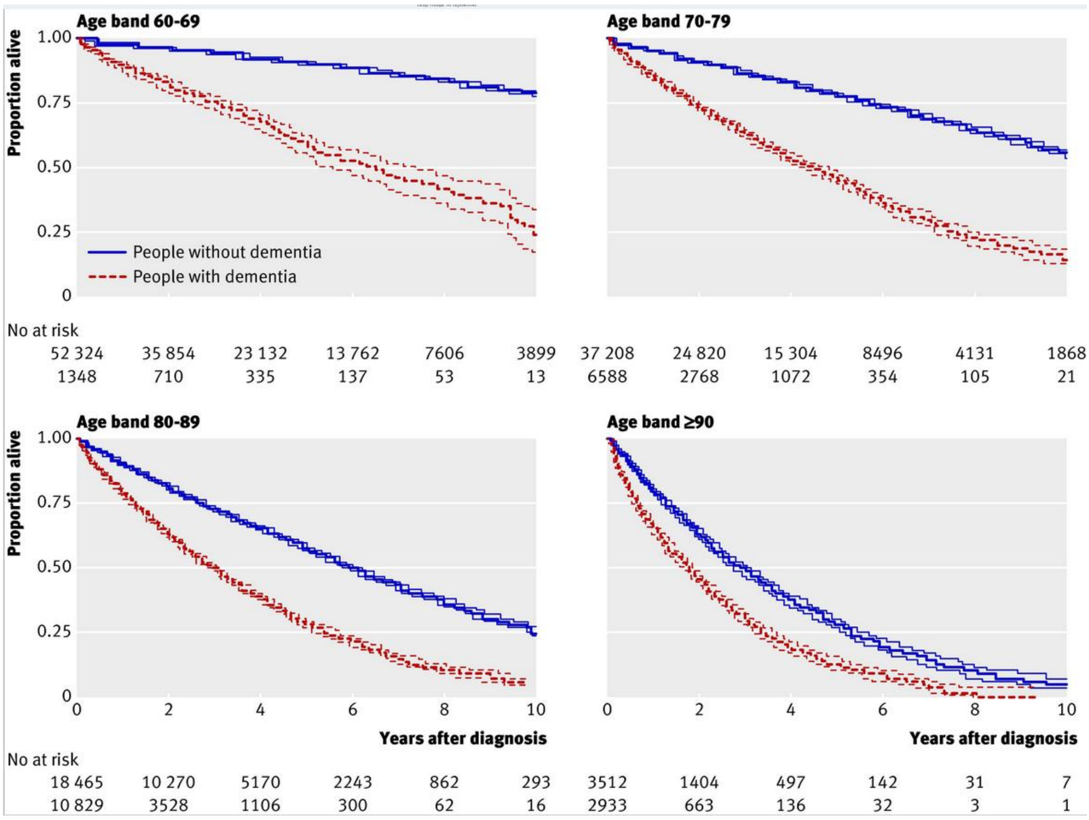
Table 7: Median number of years survival in study following a diagnosis of dementia (red line) and for those that do not get dementia (blue line) with inter quartile range (25% dying and 75% dying. The values for "all" are taken from the ONS life tables

| 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 is 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.

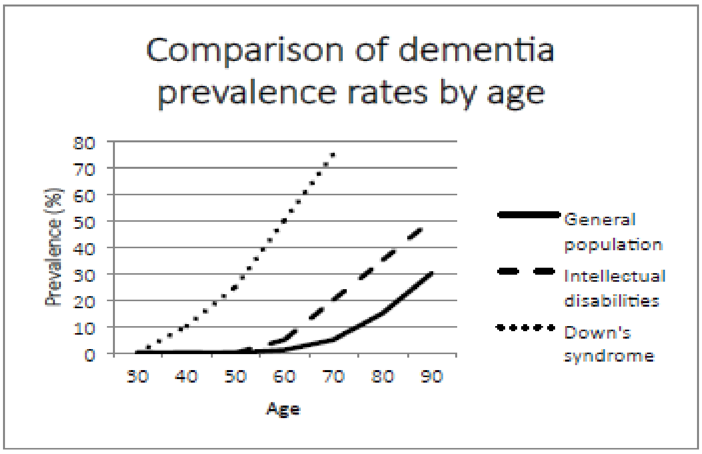
## 3.9 Dementia and people with learning disabilities

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[14]. 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

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[14] Alzheimer's Society
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*."

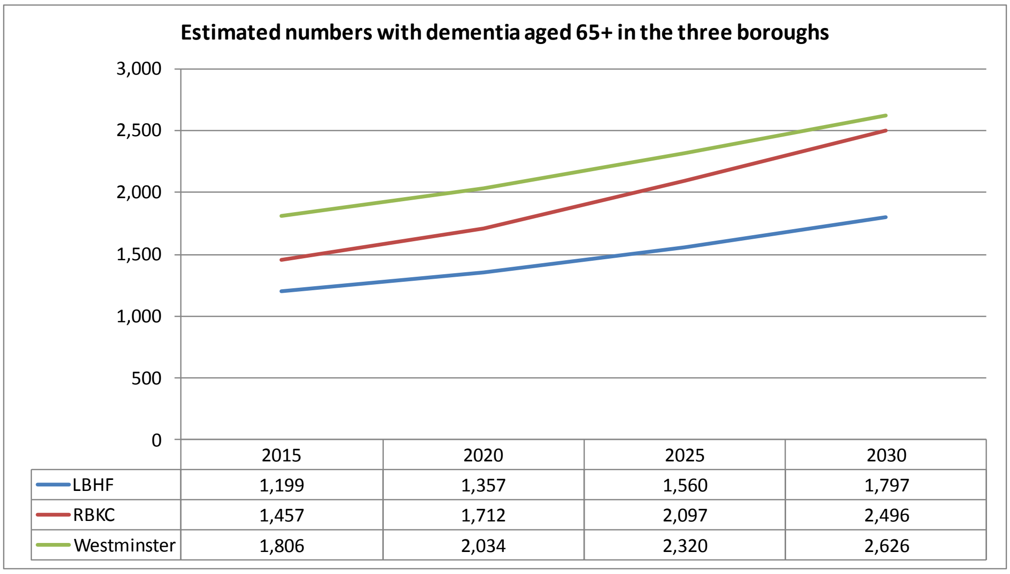
# 4 Dementia in our local population

## 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[15]. 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



| | 2015 | 2020 | 2025 | 2030 |
|---|---|---|---|---|
| LBHF | 1,199 | 1,357 | 1,560 | 1,797 |
| RBKC | 1,457 | 1,712 | 2,097 | 2,496 |
| Westminster | 1,806 | 2,034 | 2,320 | 2,626 |

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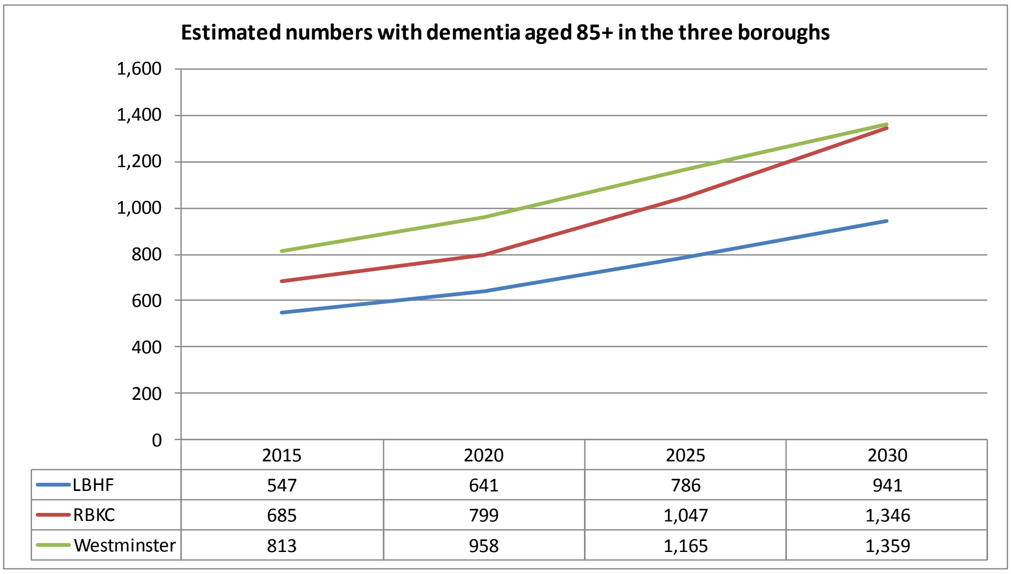
[15] GLA Population Projections http://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables (accessed 1 July 2015)

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



| | 2015 | 2020 | 2025 | 2030 |
|---|---|---|---|---|
| LBHF | 547 | 641 | 786 | 941 |
| RBKC | 685 | 799 | 1,047 | 1,346 |
| Westminster | 813 | 958 | 1,165 | 1,359 |

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.

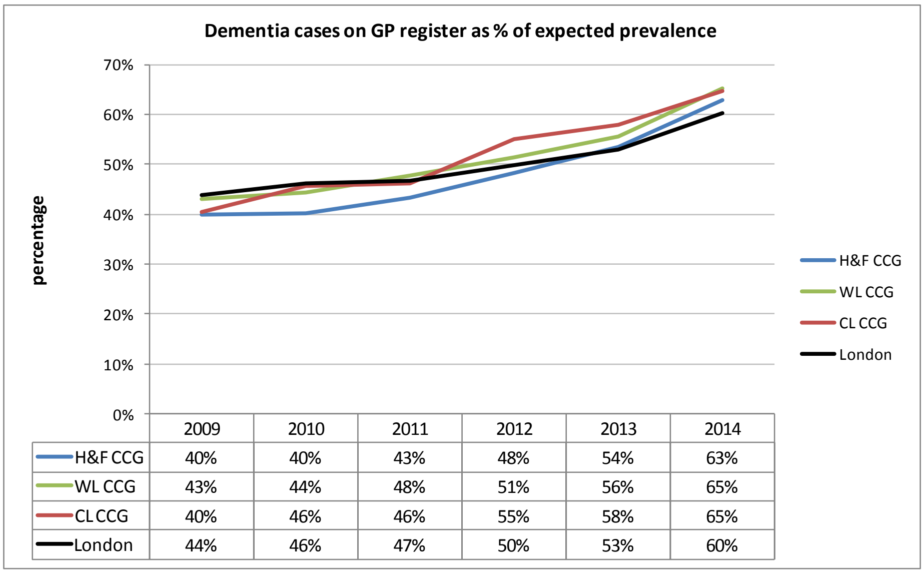
**As indicated above (see 3.5), there is evidence that prevalence has changed from the figures currently used nationally. Whatever the estimated prevalence rates are taken to be, if the actual current age and gender specific rates remain constant, then the aging population will produce a 55% increase 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



| | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 |
|---|---|---|---|---|---|---|
| H&F CCG | 40% | 40% | 43% | 48% | 54% | 63% |
| WL CCG | 43% | 44% | 48% | 51% | 56% | 65% |
| CL CCG | 40% | 46% | 46% | 55% | 58% | 65% |
| London | 44% | 46% | 47% | 50% | 53% | 60% |

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). 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.

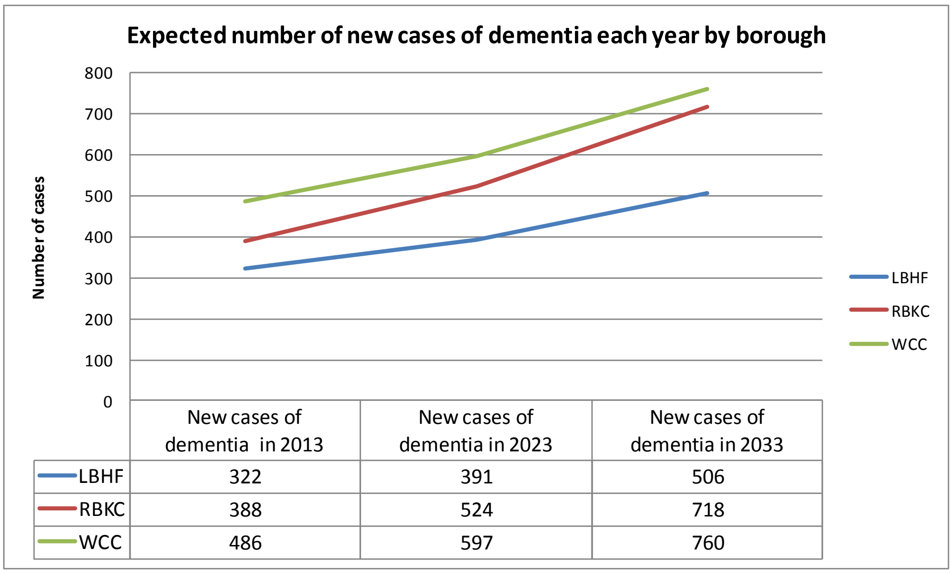
## 4.3 Estimated incidence of dementia

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% |
| Total | **1,196** | **1,513** | **1,985** | **26%** | **66%** |

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



| | New cases of dementia in 2013 | New cases of dementia in 2023 | New cases of dementia in 2033 |
|---|---|---|---|
| LBHF | 322 | 391 | 506 |
| RBKC | 388 | 524 | 718 |
| WCC | 486 | 597 | 760 |

Figure 11: Clinicians perspectives 2

**CLINICIANS' PERSPECTIVES**

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

- Clinicians did not feel that their patient base was different to surrounding areas. Perceptions were that in Hammersmith and Fulham people tended to be seen and diagnosed at more advanced stages, whereas in Kensington, Chelsea and Westminster people were diagnosed early.
- A significant proportion of people who were seen in hospital were thought to have cognitive impairment

  *'1/3 of my inpatients have dementia diagnosis, 2/3 should have a diagnosis of dementia.'*
- In general, it was agreed that numbers were to increase in the coming years secondary to an ageing population in general, although some interviewees felt that the impact would be less than expected due to:
  - Increasing preventative work around cardiovascular disease
  - Increased fitness levels in those that do survive longer
  - Possible new drugs and treatments for dementia
  - A shift of current working age adults out of central London due to rising house prices and living costs or to seek a quieter environment for retirement

## 4.4 Unpaid Care

Across the three Boroughs there are approximately 39,000 carers[16]. According to the Survey of Adult Carers[17] 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**

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[16] JSNA Carers Evidence Pack http://www.jsna.info/document/carers-evidence-pack

[17] 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 who 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.

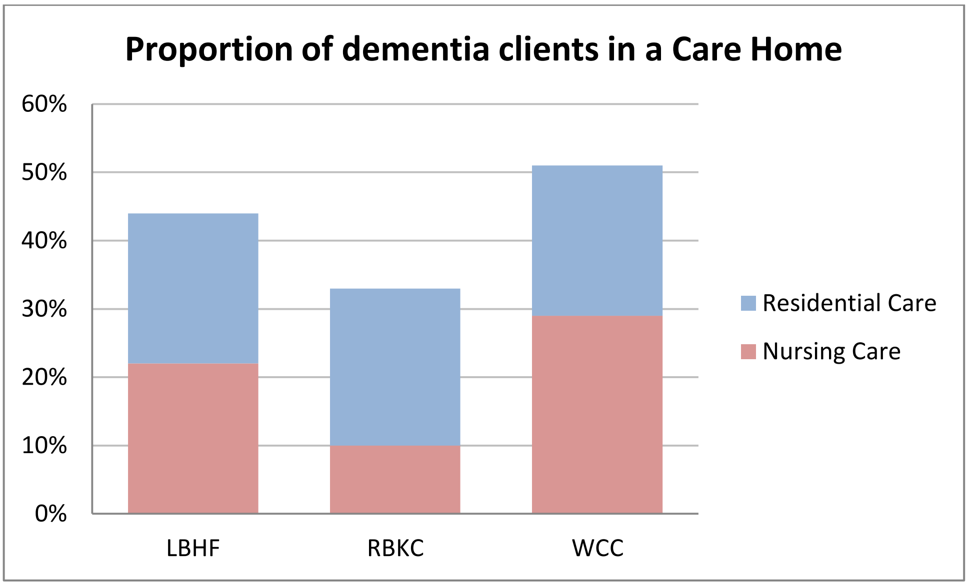
## Accommodation

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 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

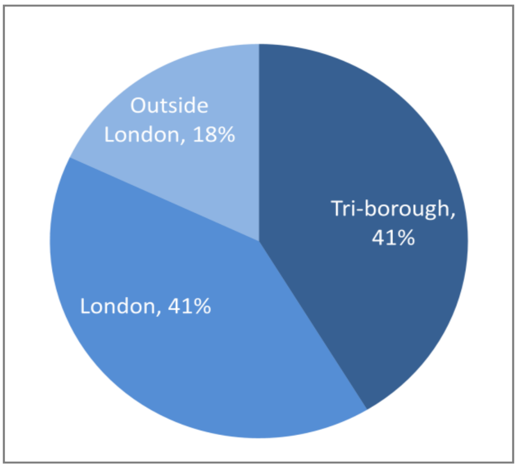
Adult Social Care provide services on the basis of need and not diagnosis, and may see different people to the GP. Accurate diagnoses are therefore not necessarily coded in records, particularly as there is no access to medical records. It was possible to extract the dementia type in 52 (66%) of the 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 I 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[18]. Collectively they are also the lowest at 1/3rd 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 (1/3rd 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 2/3rds 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.

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[18] End of Life Care Profiles 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% |
| **Total** | **1,488** | **398** | **1,886** | **65.2** | **1,193** | **41.2** | **63%** |

**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 Profiles2011/12*

**** 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.[19] 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 1/3rd. 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.

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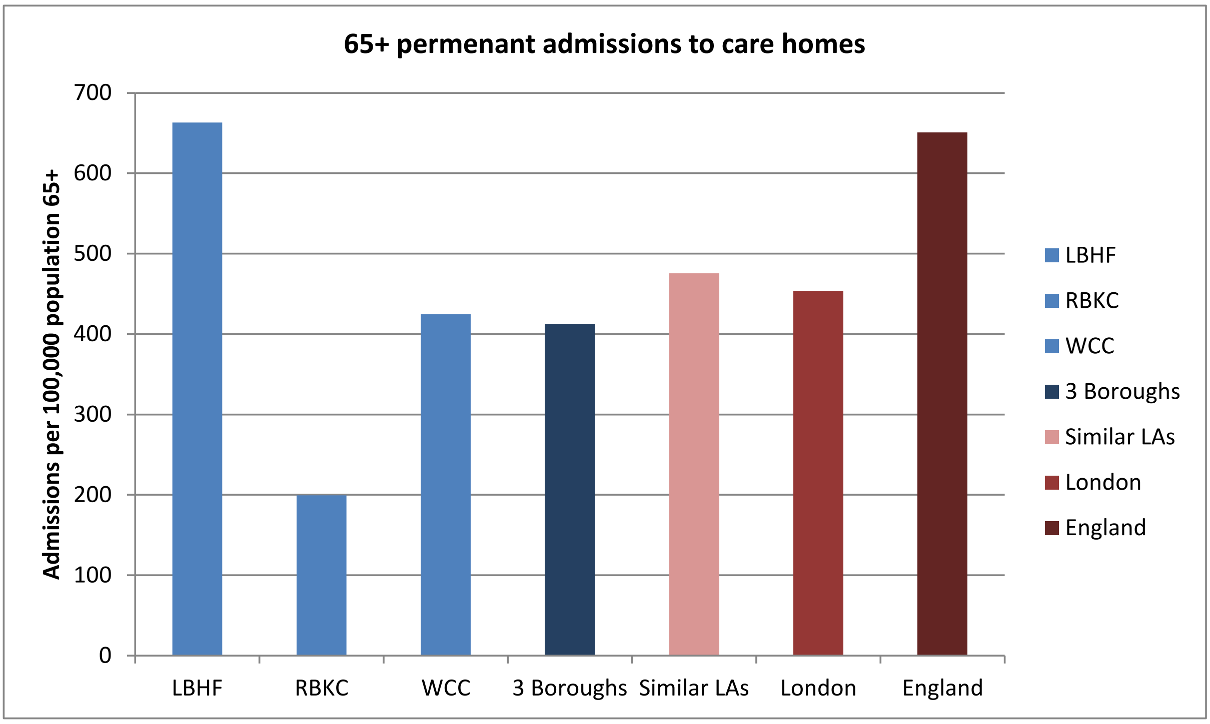
[19] Adult Social Care Outcome Framework http://ascof.hscic.gov.uk/Outcome/713/

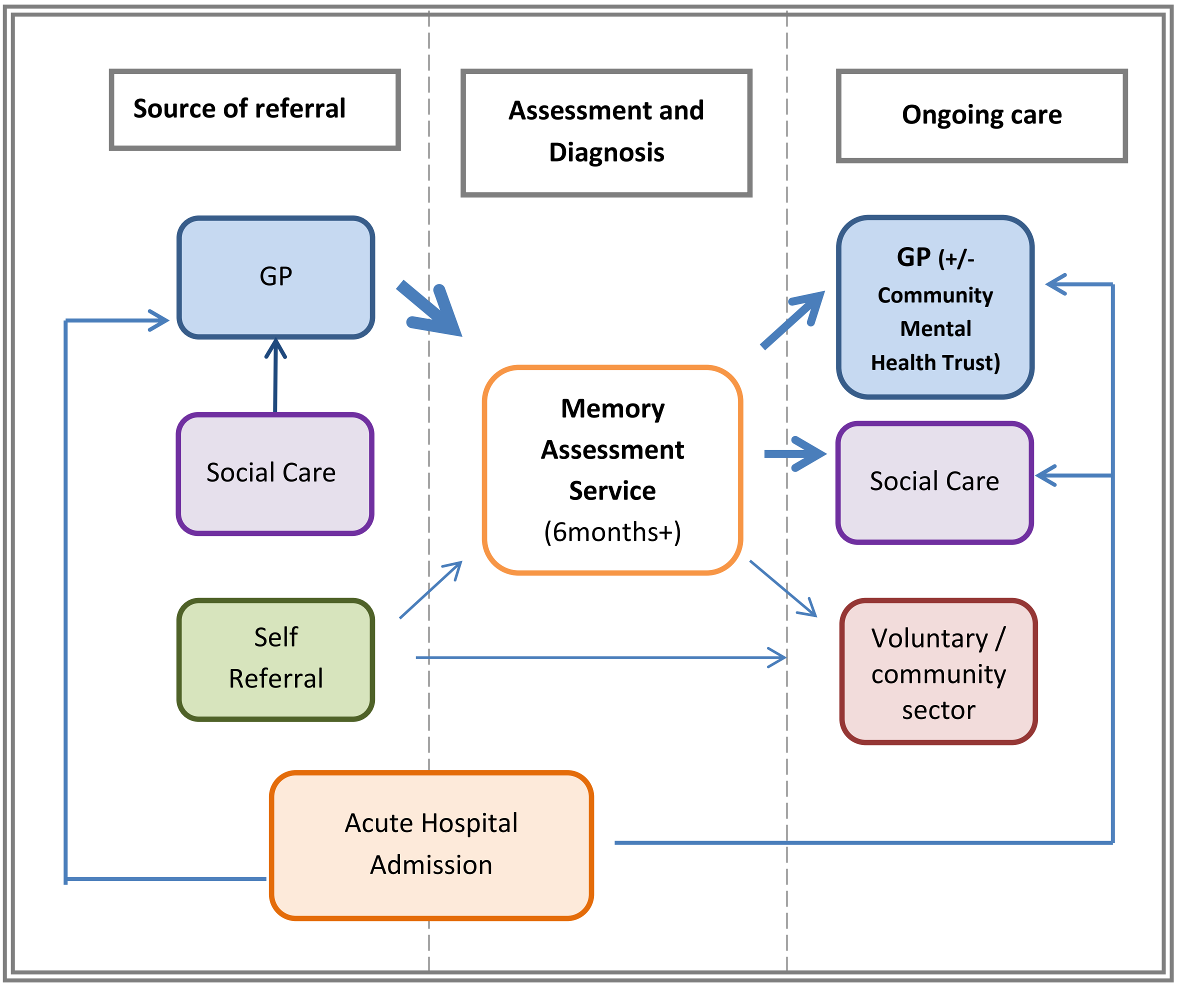
Figure 14: Number of permanent admissions to care homes in 65+ age group per 100,000 aged 65+ from ASC Outcomes Framework



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** | **'One stop shop' memory assessment service** (led by neurology at Charing Cross/Hammersmith hospitals) specialises in Early Onset Dementia takes ref. from all NWL<br>**H&F memory service** (led by community mental health team (West London Mental Health Trust) | **K&C memory assessment service** (led by Central North West London Mental Health Trust)<br>**Diagnostic Dementia Clinic** at Chelsea and Westminster hospital | **Westminster memory assessment service** (led by Central North West London Mental Health Trust) |
| | Multidisciplinary team decision (MDT) for every referral<br>Cognitive stimulation therapy 6 months post diagnosis – called 'Mind Gym' in KCW<br>**Dementia advisor service** (to signpost to community services)<br>**Admiral nursing service** (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; **oversubscribed service** | 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 **memory service** for diagnosis and assessment<br>After 6 months GP resumes ongoing management<br>**Coordinate My Care** - 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;<br>'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 |

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

| | LBHF | RBKC plus QPP | Westminster minus QPP |
|---|---|---|---|
| Voluntary and community services (See sources for full guides) | Independent Mental Health Advocacy for older people (across three boroughs) | | |
| | Dementia Action Alliance (DAA) Group recently closed<br>**Age UK** : information and advice<br>**Open Age:** various activities and link-up project to support vulnerable/isolated older people access activities<br>**Alzheimer's society**: Memory café, day services, outreach, carer's training via CRISP programme<br>**Arts/activities**: Nubian life day service for African-Caribbean Elders; Music 4 Life; Housing 21; Resonate Arts; Singing for the Brain<br>**Home support**: Bishop-Creighton Centre outreach and support services; Housing 21 provide community outreach services | Primary care navigation service (collaborative with primary care)<br>Admiral nursing[20] | |
| | | **Age UK**: memory café's and support groups; outreach services and activities; Dementia Volunteer Coordinator<br>**Open Age:** link-up project to support vulnerable/isolated older people access activities<br>**Arts/activities**: 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<br>**Home care**: Home stead; Health Vision<br>**Culture specific**: Persian care Centre<br>**Memory cafes** x 2(Age UK) | **Advocacy+** as part of advocacy project (will be Tri-B)<br>**Arts/activities**: 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<br>**Home support**: Age concern Westminster; Housing 21<br>**Diet:** Westminster health trainers<br>**Culture specific**: Jewish Care, Chinese Community Centre; Marylebone Bangladesh Society, British Arab resource Centre<br>**Octavia foundation**: outreach and befriending services<br>**Memory cafe** x2 (Housing 21) |

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[20] 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.

| | LBHF | RBKC plus QPP | Westminster minus QPP |
|---|---|---|---|
| Carers' services | 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<br>RBKC social services line<br>Crossroads care<br>Carer's emergency Card scheme; contact4me scheme | Carer's training; therapeutic massage by dementia pathfinder/London school of beauty therapy; CNWL recovery college courses an 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 update 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[21] 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[22].
- 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.

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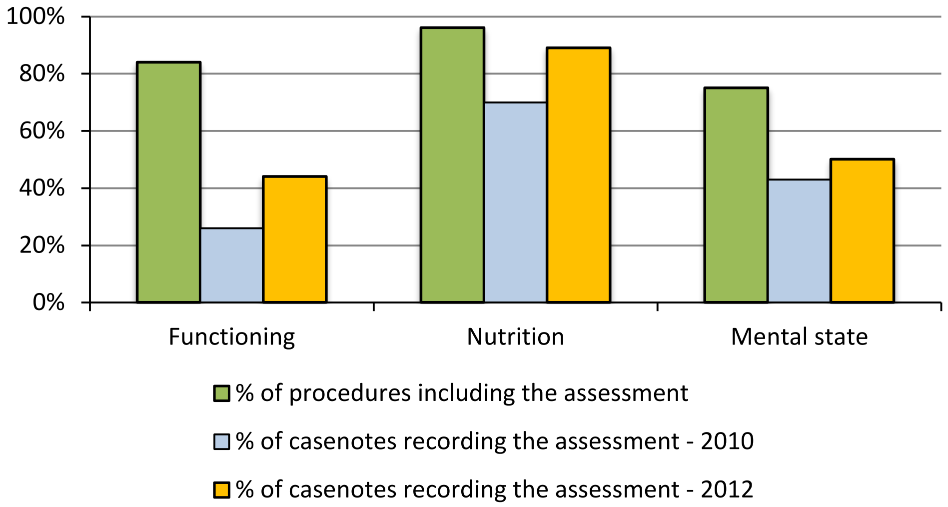
[21] Hospital Episode Statistics from HSCIC

[22] 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*[23] 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 reablemet 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

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[23] 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*[24]

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.

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[24] 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 | Research undertaken by the Alzheimer's society (Quince, 2013) found:<br>• There are low expectations about the quality of life of people with dementia in care homes.<br>• Positive views on the quality of care for people living with dementia in care homes<br>• Finding information on care homes can be challenging.<br>• 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.<br>• Family members and staff were positive about how homes worked with doctors and family members<br>• Views on opportunities for trips out and how the home worked with volunteers were less positive.<br>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 & Orrell, 2008). |
| Services | Palliative care | A recent review (Raymond et al., 2014) of carers' and professionals' views on end of life care made the following observations:<br>• 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.<br>• Cultural backgrounds, beliefs and experiences of professionals may influence choices over what kind of support and care is desired<br>• Advance care planning may be helpful to all parties, but may not always be desired<br>• 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<br>• 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 |

| 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 | Research from the UK and Israel (Landau, Werner, Auslander, Shoval, & Heinik, 2010; McCabe & 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.<br>Users of the tracking devices, their carers, and professionals should be involved in the design of the devices in discussions regarding their use. |
| Interventions | Crisis interventions | One study (Toot et al., 2013) reported the following to address crises for people with dementia:<br>• People with dementia preferred support from family and friends, access to mobile phones and home adaptations to reduce risks<br>• Carers were keen on assistive technology and home adaptations<br>• Both carers and staff valued carer training and education, care plans and well-coordinated care.<br>• Staff emphasized more intensive interventions such as emergency home respite and extended hours services.<br>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. |

| Theme | Description | Evidence |
|---|---|---|
| Vulnerable groups | People with a visual impairment and dementia | One study (Lawrence, Murray, Banerjee, & Ffytche, 2008) considered the implications for people with dementia and visual impairment. Six themes were identified from a number of case studies:<br>• Disorientation, including the inability to orientate oneself due to a lack of memory and visual cues.<br>• Loss of independence<br>• Accepting multiple losses, with acceptance identified as a key coping strategy<br>• Risk of isolation. Day centres and one-to-one interaction were both highly valued<br>• Hallucinations, with over a third of the older adults interviewed experiencing visual hallucinations<br>• Challenges to services. Professionals reported difficulties in coping with patients who developed dementia, and a lack of training. |

## 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

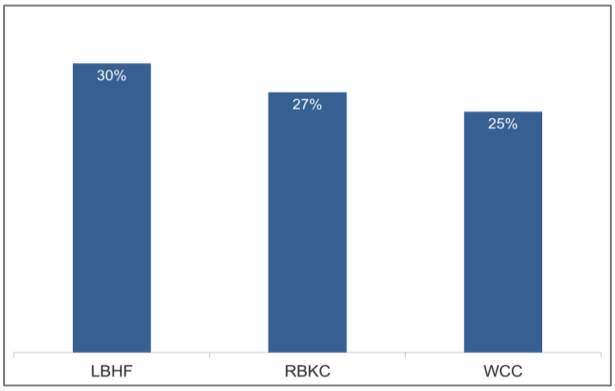


Figure 20: Carers quality of life score (out of 12) – for all carers and those caring for someone with dementia

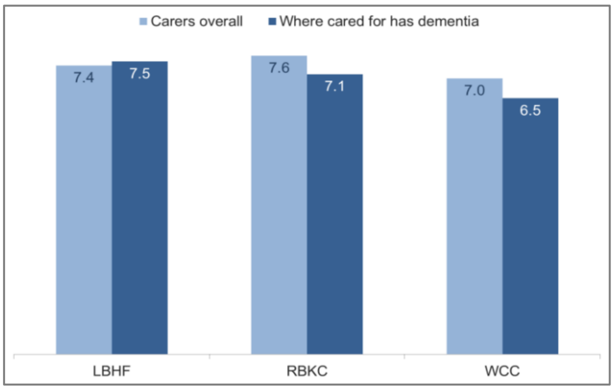
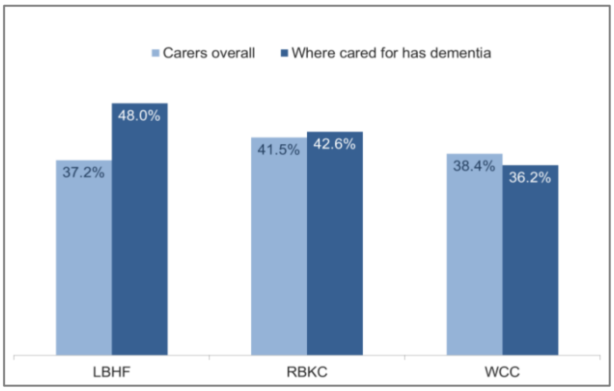


Figure 21:Carers satisfaction score (extremely and very satisfied) – for all carers and those caring for someone with dementia



## 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[25]. 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).

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

NICE are currently developing guidelines referring to midlife prevention of dementia.[26] 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

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[26] 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[27] 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 that 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.’

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[27] 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[28]. 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

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[28] 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[29] 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

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[29] 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, & Droes, 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[30]. 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[31] :

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

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

[31] Alzheimer's Society 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[32] 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[33]. 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.

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[32] Scottish Government http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316

[33] http://www.gnosallsurgery.co.uk/website/M83070/files/Gnosall_Memory_Clinic_-_The_Basics_April_2013.pdf

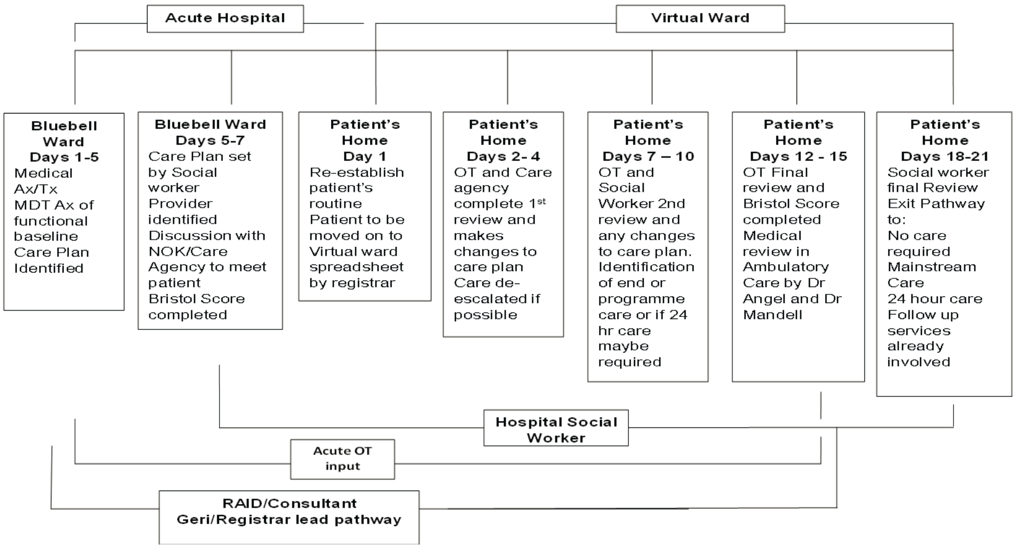
## Dual frailty ward and delirium recovery programme

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.**[34] 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.

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[34] 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

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# 9 Appendices

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

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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 |
|---|---|---|
| | **National Dementia Strategy Key Objectives**<br>**NICE Priorities**<br>**Care Act 2014 Responsibilities** | **Healthwatch HF areas for improvement**<br>**Healthwatch CNWL areas for improvement**<br>**Clinicians' Qualitative analysis** |
| 1 | Improving public and professional awareness and understanding of dementia: addressing stigma<br>Non-discrimination in access to all care and services for people with dementia | 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. |
| 2 | Good-quality early diagnosis and intervention for all: establishing a clear care pathway for people who may have dementia<br>Structural imaging for diagnosis | Confidence in GP ability to effectively screen for dementia<br>Confidence in GP ability to effectively screen for dementia<br><br>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 |
| 3 | Good-quality information for those with diagnosed dementia and their carers<br>Valid consent; Carers<br>Information and advice is to be made available to support considered and informed choices regarding care early on | Information on how to access services especially for self-funders<br>Information on how to access services especially for self- funders<br>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 & 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. |

| RAG Rating | | | Identified Gaps | Recommendation |
|---|---|---|---|---|
| LBHF | RBKC | WCC | | |
| 🟧 | 🟧 | 🟧 | 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)<br>*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.* | 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.<br>2. Ensure adequate monitoring, assessment and provision of care for other physical and mental health needs for people with dementia. |
| 🟥 | 🟩 | 🟩 | 1. Diagnosis rates still do not meet estimated prevalence and can be further improved;<br>2. There are few easy channels of communication between different providers of dementia care; at different levels of intensity.<br>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.<br>*Please see section 4.2 for information on diagnosis rates. Please see section 5.3 for information regarding service cohesion.* | 1. Develop a single point of access to diagnostic assessment and ensure all patients across all three Boroughs have equitable access.<br>2. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme.<br>3. Improve screening and diagnosis in care home and Extra Care residents.<br>4. Consider training to increase referral from or support diagnosis in primary care, in line with NWL strategy.<br>5. Audit completion of diagnostic assessment for those first identified in hospital. |
| 🟥 | 🟩 | 🟩 | 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.<br>*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.* | 1. All patients, carers and clinicians should have consistent and comprehensive information with clear signposting of care pathways.<br>2. Patients and carers should be aware of advance directives and power of attorney and how to initiate them. |

| | National Guidance | Local observatio |
|---|---|---|
| | **National Dementia Strategy Key Objectives**<br>**NICE Priorities**<br>**Care Act 2014 Responsibilities** | **Healthwatch HF areas for improvement**<br>**Healthwatch CNWL areas for improvement**<br>**Clinician's Qualitative analysis** |
| 4 | Enabling easy access to care, support and advice following diagnosis: providing a dementia advisor<br>Memory services | Regularity of care reviews – GP and social services every year/15 months?<br>Regularity of care reviews – GP and social services every year/15 months?; Personal control when choosing services<br>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. |
| 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<br>Coordination and integration of health and social care; Behaviour that challenges<br>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. | Integration of health and care services<br>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. |
| 7 | Implementing the Carers' Strategy: needs assessments and respite breaks for carers<br>Carers<br>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 | Support for carers; Respite<br>Support for carers; Respite<br>Consider ways of providing extra support for carers |

| **RAG Rating** | | | **Identified Gaps** | **Recommendation** |
|---|---|---|---|---|
| LBHF | RBKC | WCC | | |
| 🟧 | 🟧 | 🟧 | (1) Memory service care varies greatly between provider: in some cases the patient may not have access to timely diagnostic or adequate community support;<br>(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.<br>*Please see section 5 for information on* service provision and cohesion. | 1. The current fragmentation in care provision should be addressed through centralised coordination and improved communication/collaboration between services. |
| 🟥 | 🟧 | 🟧 | Peer support is now being commissioned as part of Living Well service in Westminster and K&C, however there is lack of resource in H&F.<br>*Please see section 5 for information on service provision.* | 1. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme. |
| 🟧 | 🟧 | 🟧 | 1. There is little supporting infrastructure available to provide help to self-funders to "micro-commission" care as mandated by the Care Act 2014.<br>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.<br>*Please see section 2.1 for information on the Care act 2014.* | 1. Ensure there is adequate infrastructure to support self-funders to access care.<br>2. Ensure people are supported to access the care appropriate to them through the use of personal budgets.<br>3. Provide adequate infrastructure and training for care staff and carers.<br>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. |
| 🟧 | 🟧 | 🟧 | 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.<br>*Please see section 5.2 and 5.3 for information on service provision and cohesion.* | 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. |

| | National Guidance | Local observation |
|---|---|---|
| | National Dementia Strategy Key Objectives<br>NICE Priorities<br>Care Act 2014 Responsibilities | Healthwatch HF areas for improvement<br>Healthwatch CNWL areas for improvement<br>Clinician's Qualitative analysis |
| 8 | Improved quality of care for people with dementia in general hospitals<br>Mental health needs in acute hospitals | Inpatient care including discharge planning<br>Inpatient care including discharge planning<br>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<br>Coordination and integration of health and social care | Integration of health and care services<br>Integration of health and care services<br>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 | Living well with dementia in care homes: defined care pathways, specialist in-reach services and inspections<br>Coordination and integration of health and social care | Quality and confidence in care homes and home care, particularly staff.<br>Integration of health and care services<br>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 | | |
| 🟧 | 🟧 | 🟧 | (1) Little is known about adequate use of antipsychotics – an audit is due to take place in Chelsea and Westminster Hospital.<br>(2) Support is needed for the person to prevent avoidable admission, but to ensure the right intervention at the right time.<br>*Previous audits in the 3 boroughs have shown a fall in the use of antipsychotics.* | 1. Audit and address accordingly use of antipsychotics in hospitals and community prescriptions<br>2. Ensure timely identification and targeted care of those with dementia in hospital<br>3. Provide dementia friendly environment within hospitals<br>4. Ensure adequate provision of liaison psychiatry and dementia nurses, consider expanding remit to improve admission related support. |
| 🟥 | 🟥 | 🟩 | 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.<br>*Please see section 5 for information on service provision*. | 1. Ensure either all staff in intermediate care have appropriate training for looking after people with dementia or a specialist service is provided. |
| 🟥 | 🟥 | 🟥 | Housing and environment strategies do not specifically mention dementia or carers of people with dementia | 1. The increasing numbers and needs of people with dementia and their carers are taken into account in wider local authority and health strategies, especialy housing and environment<br>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 |
| 🟥 | 🟥 | 🟥 | 1. The supply of care homes currently does not match need therefore a significant proportion of residents are moved out of borough;<br>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.<br>*Please see section 4.6 for discussion on supply of care homes and figure 14 on quality of care in care homes.* | 1. Address supply of local care home beds in future local authority and CCG commissioning intentions, including those specifically for dementia care.<br>2. Address findings from Care Quality Commission (CQC) national report; audit to provide assurance of quality of care in care homes.<br>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. |

| | **National Guidance** | **Local observation** |
|---|---|---|
| | **National Dementia Strategy Key Objectives**<br>**NICE Priorities**<br>**Care Act 2014 Responsibilities** | **Healthwatch HF areas for improvement**<br>**Healthwatch CNWL areas for improvement**<br>**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<br>Valid consent; Carers; Coordination and integration of health and social care | Integration of health and care services<br>Integration of health and care services<br>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<br>Training | Staff training (inc. GPs, support staff, hospital staff)<br>Staff training (inc. GPs, support staff, hospital staff)<br>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<br>Coordination and integration of health and social care<br>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<br>Integration of health and care services<br>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<br>Coordination and integration of health and social care<br>Increased oversight for quality and financial security of services; protection of care provided when service users move borough | Integration of health and care services<br>Integration of health and care services;<br>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.<br>*This is addressed in the End of Life JSNA* | 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<br>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<br>*Please see figure 14 and section 5.1 for information of quality of care in care homes.* | 1. Address findings from CQC report on care homes (awaiting publication);<br>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.<br>*Please see section 4.1 on prevalence.* | 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 |
|---|---|
| **Non-discrimination** | 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. |
| **Valid consent** | 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. |
| **Carers** | 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.<br>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. |
| **Coordination and integration of health and social care** | 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.<br>2. Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve:<br>• 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<br>• assignment of named health and/or social care staff to operate the care plan<br>• endorsement of the care plan by the person with dementia and/or carers<br>• 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 |
| **Memory services** | 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 |
|---|---|
| **Structural imaging for diagnosis** | 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. |
| **Behaviour that challenges** | 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:<br>• the person's physical health<br>• depression<br>• possible undetected pain or discomfort<br>• side effects of medication<br>• individual biography, including religious beliefs and spiritual and cultural identity<br>• psychosocial factors<br>• physical environmental factors<br>• behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.<br>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. |
| **Training** | 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. |
| **Mental health needs in acute hospitals** | 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** | **55 (70%)** | **24 (30%)** | **79** |
| **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** | **205 (72%)** | **79 (28%)** | **284** |
| **<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 catagorised as "Black" among ASC clients matches the proportion in the relevant population. Collectively so do those catagorised as "Asian" and "Other", but it is possible that "Asians" are under-represented.

## Dementia type

### *Service Audit*

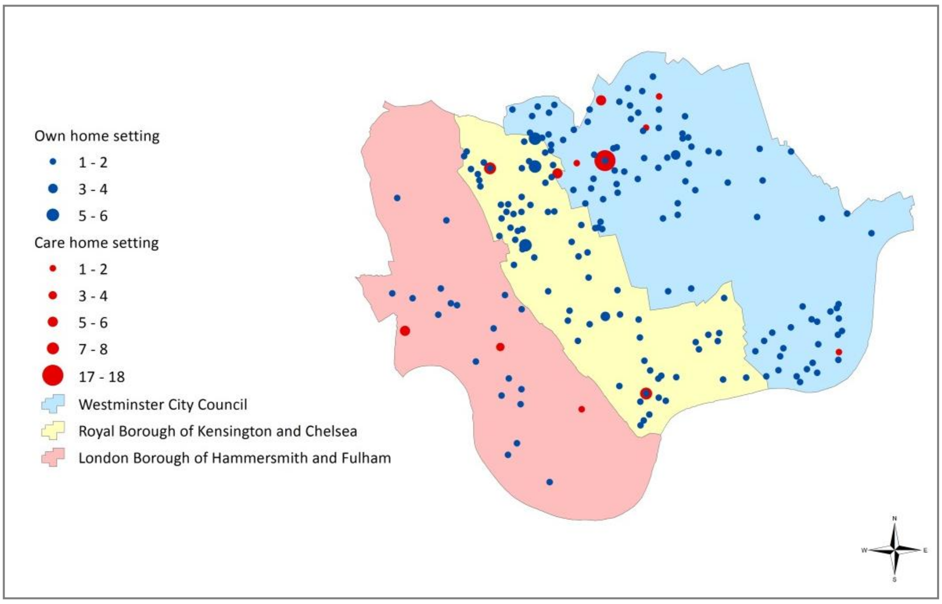
Table 14: Number (%) of ASC clients by dementia type recorded

| 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

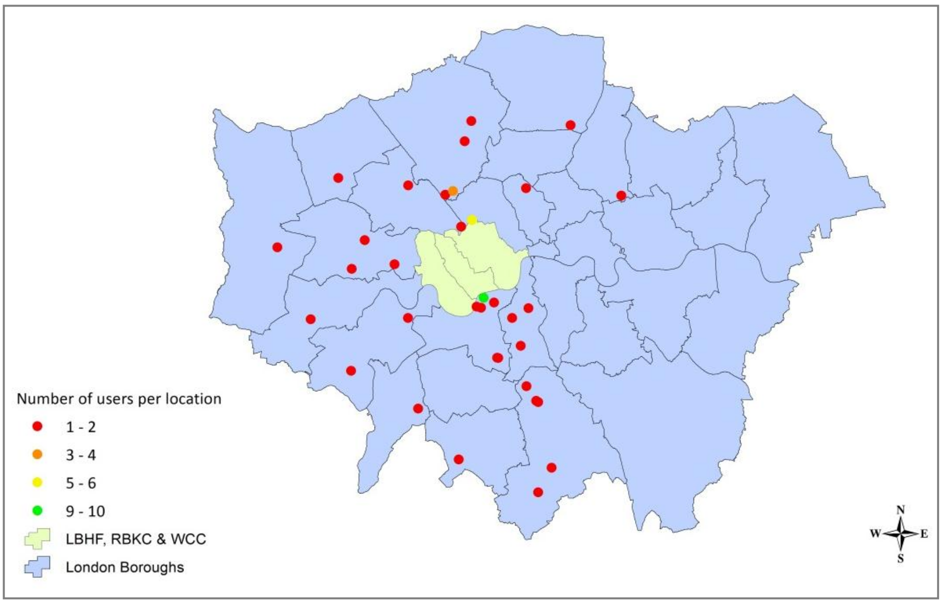
### *Framework I audit*

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



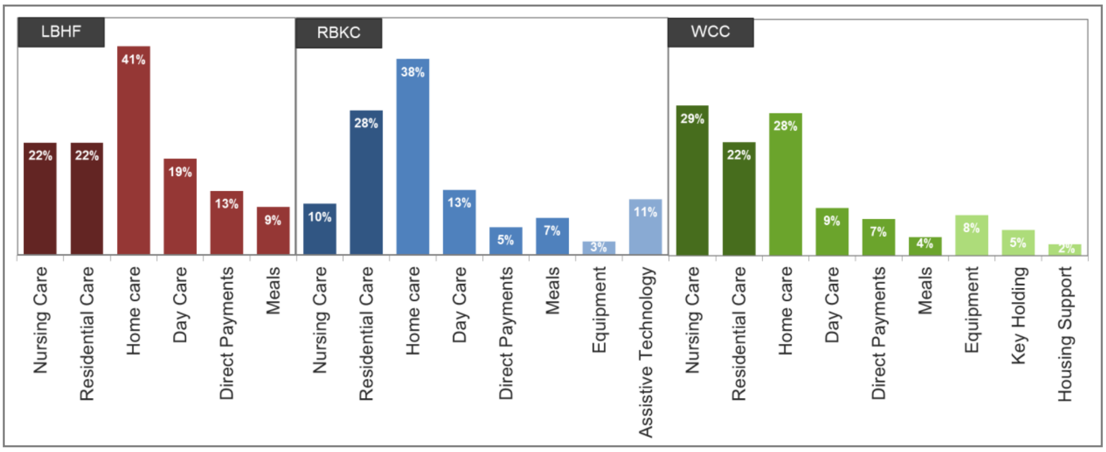
The map highlights the different level or recording of dementia, the split between care homes and own home, as well as the location of care homes in the three boroughs.

**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

The full report can be found at xxxxxxxxxxx. The summary in the report 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 |
|---|---|
| **1. Respecting identity: ‘ It’s not one size fits all’**<br>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. | How do we reduce fear so people feel less pressure to self-identify as ‘having dementia’?<br>How do we overcome the dementia label, and the stereotypes, bad habits and compromises that flow from it?<br>How do we design services that allow people’s individual identities to flourish and grow? |
| **2. Embracing now: ‘ It’s a moment-living life’**<br>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. | How do we empower people with dementia to make their own choices about whether to ‘consume’ memories or not?<br>What more can we do to enable people to ‘live in the moment’?<br>What are the implications of focusing more on what people with dementia can do, rather than what they can’t? |
| **3. Sustaining relationships: ‘ You don’t always need words’**<br>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. | How can we allow people with dementia to lead fulfilling social lives, on their own terms and without stigma?<br>How do we create conditions that enable the meaningful continuation of important relationships?<br>What can we do to normalise dementia, and ensure people do not feel ghettoised? |

| Theme | Issues to address |
|---|---|
| **4 Valuing contrast: ' Good days and bad days'**<br>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. | How do we assess what makes someone with dementia happy?<br>How can we overcome the determination to eliminate unhappiness from the lives of people with dementia?<br>How do we design care environments which allow people with dementia to experience and express a full range of emotions? |
| **5 Supporting agency: ' What's there to worry about?'**<br>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. | How can we promote spontaneity, choice and risk as assets in a life with dementia?<br>How do we design dementia services to ensure we do not restrict individuals' freedoms by limiting them to our desired routines?<br>What role can technology play in providing reassurances to carers about individuals' safety? |
| **6 Maintaining health: 'My priority in life'**<br>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. | How do we design services that have the flexibility to address every aspect of a person's good health, regardless of their dementia?<br>What more can be done to enable people with dementia to communicate their feelings in relation to health and wellbeing? |

# North West London Mental Health & Wellbeing Strategic Implementation and Evaluation Board

*Excellent, integrated mental health services to improve mental and physical health, secured through collaboration and determination to do the best for the population of North West London*

## Item 3: Strategic Review of Dementia
## 15th May 2015

| | |
|---|---|
| **Date: 6 May 2015** | **Presenter: Dr Serena Foo** |
| **Author(s): Barbara Edwards & Debbie Mayor** | |
| **Appendices:** 1 Strategic Review; 2: Framework Service Specification 3: Exemplar Framework & Statements | |

| **Purpose** | **Action Required** |
|---|---|
| The purpose of this paper is to provide an update of the outcome of the strategic review of dementia services across NWL. | Discussion, comment, noting and implementation |

**Executive Summary/Key Issues**

This executive summary and more detailed report (see appendix 1) reflects:

- background to the strategic review of dementia
- processes undertaken
- co-production and collaboration
- outputs and outcomes from the review
- recommendations for taking the review forward

### Background

The former Mental Health Programme Board agreed to undertake a strategic review of dementia in 2014. This process commenced in August 2014. Dementia continues to remain a high national and local priority.

### Process

**The process undertaken has included**

- Mapping of local levels of current and projected need and dementia prevalence across NWL.
- Mapping of progress towards achievement of dementia diagnosis rate of 67% for prevalent local population.
- Delivery of a series of three stakeholder workshops, which have fully informed the outputs of the process including a framework service specification, set of dementia commitment statements and dementia exemplar framework.

**Co-production and Collaboration**

- People with dementia and their carers were involved and engaged in the workshops, and in different individual and group meetings over the autumn/winter.
- Innovations in Dementia, working alongside Age UK, facilitated a separate session with a group of people with dementia about the review. The group presented their views and findings at the final workshop in February.

**Outputs and outcomes**

- Framework specification is outcomes focussed, and uses the Dementia 'I' statements, as the basis for a suite of outcome measures.
- These are accompanied by set of carers outcomes measures, developed by a carer.
- A dementia exemplar framework was developed over the course of the review, and informed in particular by feedback and comments from people with dementia and their carers. Two CCGs are intending to use this, against which to benchmark their current dementia service pathways and provision.
- A high level clinical care pathway was developed and agreed by a virtual clinical leads group, and is included within the framework specification.
- A set of individual/we/group and organisational commitment statements have been produced via the workshops.

**Taking the Review Forward**

- Seeking 'sign off' from the Board.
- Ensuring key stakeholders are fully aware of the output documents, and their purpose . Key documents including the framework service specification and commitment statements have been circulated to all former workshop attendees.
- Ensuring that these are utilised to support on-going service improvement and development in dementia care and services within NWL.
- Individual CCGs to consider as part of their service review and development process for 15/16.

**Decisions/Actions Required**

The Board is asked to consider, discuss the contents of the report and to support CCGs and Local Authorities to utilise the outputs of the process in future commissioning of dementia services.

**Identification of Risks** (& any Mitigation) **in the next period.**

None identified

# SCHEDULE 2 – THE SERVICES

## A. Service Specifications

Mandatory headings 1 – 4: mandatory but detail for local determination and agreement
Optional headings 5-7: optional to use, detail for local determination and agreement.

All subheadings for local determination and agreement

| | |
|---|---|
| **Service Specification No.** | |
| **Service** | Dementia/cognitive impairment service |
| **Commissioner Lead** | |
| **Provider Lead** | |
| **Period** | |
| **Date of Review** | |

## 1. Population Needs

Research conducted for Dementia UK: second edition[1] shows that, in 2013, there were 815,827 people with dementia in the UK. 773,502 of these people with dementia were aged 65 years or over. This represents one in every 79 (1.3%) of the entire UK population and 1 in every 14 of the population aged 65 years and over. In 2015, there will be 856,700 people with dementia in the UK in 2015 at the current rate of prevalence.

If current trends continue and no action is taken, the number of people with dementia in the UK is forecast to increase to 1,142,677 by 2025 and 2,092,945 by 2051, an increase of 40% over the next 12 years and of 156% over the next 38 years.

The total cost of dementia in the UK is £26.3 billion.

The NHS picks up £4.3 billion of the costs and social care £10.3.

Of the £10.3 billion in social care costs, £4.5 billion is attributed to Local Authority social services for state funded care. The remaining £5.8 billion is what people with dementia and their families pay out annually for help with everyday tasks that are provided by professional care workers, such as washing, dressing and eating.

Two thirds of the cost of dementia (£17.4 billion) is paid by people with dementia and their families, either in unpaid care (11.6 billion) or in paying for private social care.

Dementia is a syndrome caused by a number of illnesses in which there is a progressive functional decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may also develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering. These cause problems in themselves, complicate care, and can occur at any stage of the illness.

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[1] Dementia UK: second edition. Alzheimer's Society (2014)

Although the risks of developing dementia increase with age, it is not an inevitable part of ageing.[2]

There are different types of dementia, these include:

- Alzheimer's disease (60% of all cases in people aged over 65)
- Vascular dementia (15–20% of all cases of people aged over 65)
- Dementia with Lewy bodies (15–20% of all cases of people aged over 65)
- Frontotemporal dementia (more common among younger people)

Many cases of dementia may have mixed pathology (for example, Alzheimer's disease and Vascular dementia or Alzheimer's disease and Dementia with Lewy bodies). Such cases should be managed according to the condition that is considered to be the predominant cause of dementia

An estimated 15,000 people of all ages from black and minority ethnic groups have dementia, and 6% of this group will have young onset dementia, compared with 2% in the wider UK population. People with learning disabilities and Down's Syndrome are at higher risk of dementia. People with Down's syndrome have an increased genetic risk. Higher risk of dementia is also associated with stroke and some other neurological conditions. Between 30% and 70% of people with Parkinson's disease develop dementia, depending on duration of the condition and age.

In 2009, the Government published 'Living Well with Dementia: A National Dementia Strategy (DH, 2009).[3]

The national strategy set out 17 recommendations that the government wants the NHS, Local Authorities and others to take to improve dementia care services. The recommendations are focused on three key themes of:

- Raising awareness and understanding
- Early diagnosis and support
- Living well with dementia

In addition this specification takes account of the following national policy and guidance:

- Prime Minister's Challenge (March, 2012[4]): including focus on improving diagnosis rates by 2015, and developing dementia friendly communities.
- Dementia: A state of the nation report on dementia care and support in England (DH November 2014)
- Improving diagnosis was further highlighted as a key DH priority with all Clinical Commissioning Groups (CCG's) set an aspirational target was set to achieve 67% diagnosis rates by 31/3/15.
- The Care Act 2014 (DH, October 2014)
- The Prime Ministers Challenge, 2020 (DH, 21st February, 2015)

## 1.1 Local Context

According to the Primary Care Web Tool [5](data as at March 2015 ) the current diagnosis

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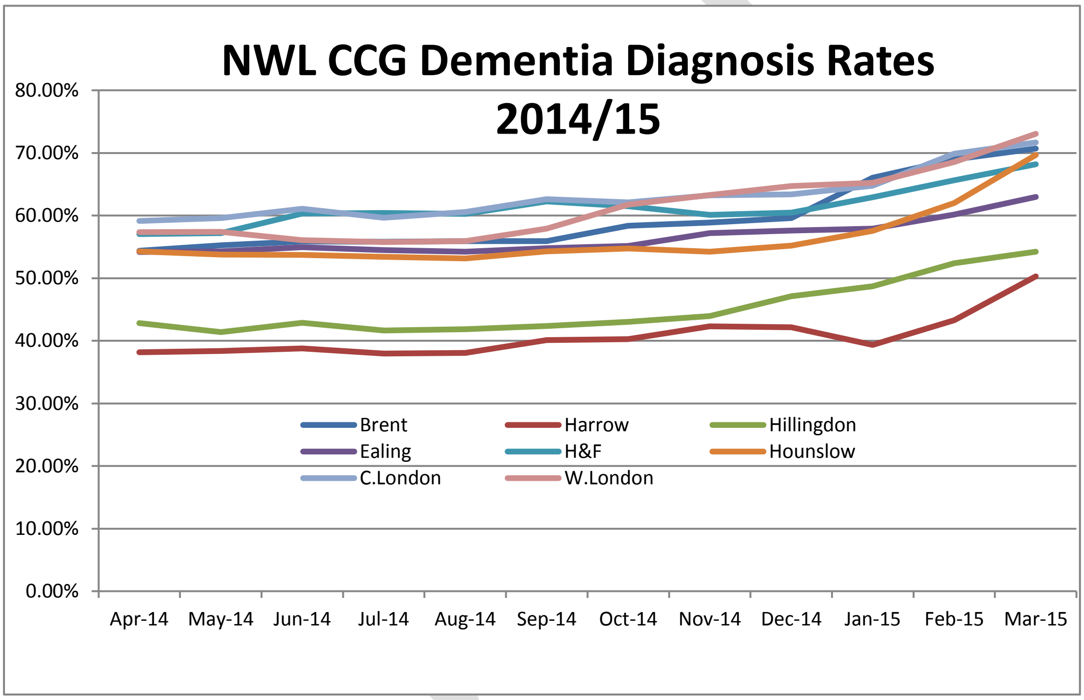
[2] Joint Commissioning Panel for Mental Health (2012). Guidance for commissioners of dementia services Volume Two: Practical mental health commission. London: JCP-MH www.jcpmh.info NICE (2010). *Dementia Quality Standards.* NICE Implementation. Directorate Quality Standards Programme. London: Department of Health.

[3] Living Well with Dementia; A National Strategy (DH 2009)

[4] Prime Minister's challenge on dementia :Delivering major improvements in dementia care and research by 2015 (DH 2012)

rate for the NWL CCG's is shown below together with the trend  (APRIL 14 – March 15)

| CCG | Diagnosis rate at 30.03.15 |
|---|---|
| Brent | 70.70% |
| Harrow | 50.30% |
| Hillingdon | 54.23% |
| Ealing | 62.98% |
| H&F | 68.18% |
| Hounslow | 69.68% |
| C.London | 71.68% |
| W.London | 73.06% |
| | |
| Source: Primary Care Web Tool  accessed 20.4.15 | |



**Note : In terms of local need at a CCG level this section is for completion by the individual CCG.**

## 2. Outcomes

### 2.1 NHS Outcomes Framework Domains & Indicators

| | | |
|---|---|---|
| **Domain 1** | **Preventing people from dying prematurely** | |
| **Domain 2** | **Enhancing quality of life for people with long-term conditions** | √ |

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[5] https://www.primarycare.nhs.uk/private/dpc/dpc_main.aspx

| | | |
|---|---|---|
| **Domain 3** | **Helping people to recover from episodes of ill-health or following injury** | |
| **Domain 4** | **Ensuring people have a positive experience of care** | √ |
| **Domain 5** | **Treating and caring for people in safe environment and protecting them from avoidable harm** | √ |

## 2.2 Local defined outcomes for people with dementia

In developing locally defined outcomes for people with dementia, these have been linked to the dementia 'I' statements with clear objectives, outcomes and proposed outcome measures. The 'I' statements have been cross referenced with the relevant national quality standards which are set out in section 4.1 of this schedule. There are two sets of outcomes:

- One for people with dementia
- One for carers of people with dementia

| **Vision Statement** | **Objective** | **Outcome** | **Measure** |
|---|---|---|---|
| I was diagnosed in a timely way | Improve the local diagnosis rate | Increased number of individuals will receive a timely diagnosis | Increase in referrals to memory assessment services.<br>Increased number of people on dementia registers<br>Data from electronic patient information systems /ICD 10 codes<br>Increased number of people with a Learning Disability on dementia registers |
| I understand so I make good decisions and provide for future decision making | Living well with dementia | People with dementia, their families and carers receive high quality and meaningful information, advice and support.<br>The patient and carer will be supported by a care navigator, dementia advisor or care co-ordinator from diagnosis and at all stages of the care pathway<br>Information should be presented clearly and in different formats as required | Individuals and carers report that they are approp riately supported e.g use of patient and carer surveys. |
| I get the treatment and support which | Living well with dementia | Clear pathway for individuals. | Reduction in the number of people prescribed |

| | | | |
|---|---|---|---|
| are best for my dementia and my life | | Increase in number of referrals to psychological therapies if required (e.g.IAPT services)<br>For people with dementia this may be to manage problems such as fear, anxiety, practical and financial issues, using non-pharmacological management as a first port of call.<br>Raised awareness and access to information and advice<br>Support along the patient and carer journey from a named care navigator, dementia advisor or care co-ordinator | antipsychotic medication.<br>Cross reference to IAPT provider and relevant contract data<br>Individuals and carers report that they are provided with relevant and timely information e.g use of patient and carer surveys.<br>Patient and carer feedback |
| I am treated with dignity and respect | Living well with dementia | All staff have access to appropriate training in dementia.<br>Range of opportunities to engage and listen to people with dementia and their carers are identified and acted upon. | Individuals and their carers report they are treated with dignity and respect |
| I know what I can do to help myself and who else can help me | Living well with dementia | There is a clear person centered plan in place for every individual known to the service. | Number of people with a copy of own care plan.<br>The care plan will be updated at every review stage so the patient and carer are fully informed. |
| I can enjoy life | Living well with dementia | People with dementia have access to a choice of activities and services | Individuals and their carers report that they have access to a range of activies and services to meet their needs. |
| I feel part of a | Living well | People with dementia are | All CCG's in |

|  |  |  |  |
|---|---|---|---|
| community and I am inspired to give something back | with dementia | empowered to have high aspirations and feel confident that people in the local community treat them with dignity and respect<br>The service ensures that all people with dementia and their carers are offered the opportunity to register their interest in participating in research | partnership with local authorities, providers and communities achieve dementia friendly status |
| I am confident my end of life wishes will be respected | End of Life Care | The dementia pathway from late stage dementia to EOL is clear and well communicated | Number of people with dementia with advance directives in place |

2.3 Local defined outcomes for carers of people with dementia : with **acknowledgement and grateful thanks to Barbara Benedek**

| Vision Statement | Objective | Outcome | Measure |
|---|---|---|---|
| I was listened to by the GP when I said that my relative had some memory/behavioral problems | Improve the local diagnosis rate and reduce stress on family carer who knows there is a problem but no one listens | Increased number of individuals will receive a timely diagnosis<br>Increased number of people referred early to dementia support groups | Increase in referrals to memory assessment services.<br>Increased number of people on dementia registers<br>Increased number of patients and carers getting timely support at the early stages of dementia in order to put in place POA and address other legal and financial issues |

| | | | |
|---|---|---|---|
| I understand so I make good decisions and provide for future decision making in my caring role | Reducing stress and its consequences for family carers | Family carers receive high quality and meaningful information, advice and support.<br>The patient and carer will be supported by a care navigator, dementia advisor or care co-ordinator from diagnosis and at all stages of the care pathway<br>Information should be presented clearly and in different formats as required – carer training programmes | Individuals and carers report that they are appropriately supported |
| I get the support and ongoing guidance to help me care for my relative | Helping me to continue to care for my relative and allowing me to lead my own life to some extent | Clear support and guidance for individual carers for the entirely of the journey<br>Guidance and advice on all the practical issues of caring for someone with dementia<br>Referral to psychological therapies if required (IAPT services)<br>Raised awareness and access to information and advice<br>Support along the patient and carer journey from a named care navigator, dementia advisor or care co-ordinator | Reduction in carers no longer being able to care- Method and measures to be agreed with commissioner, carer rep and provider<br>Robust information sharing systems in place<br>Reduction in carer illness and psychological problems<br>Patient and carer feedback |
| I am treated with dignity and respect and my views are listened to by clinicians, social workers and other support workers | Reducing the stress of my caring role and providing me with support and help in making decisions | All staff have access to appropriate training in dementia.<br>Range of opportunities to engage and listen to family carers. Issue raised are identified and acted upon. | Individuals are treated with dignity and respect ( based on consistent method of gathering feedback) |
| I know what I can do to help myself and who else can | Reducing stress and helping me lead a fulfilling | There is a clear person centred plan in place for every carer known to the | Number of people with named carer support worker |

| | | | |
|---|---|---|---|
| help me | life | service. | |
| I can enjoy life and am helped to have the necessary respite from caring | Reducing stress and helping me lead a fulfilling life | Carers for people with dementia have access to a choice of appropriate activities and services which provide stimulation for the person with dementia and respite for carers | Choice of access is evidenced from consistent method if gathering feedback |
| I have enough support and respite in my caring role that I have time and energy to participate in engagement activities as well and life enhancing ones (theatre, friends etc) | Provide invaluable input from family carers who have knowledge from years of experience caring for people with dementia | Clinical and social service support becomes more person centred and is able to respond more appropriately to the needs of the person with dementia and their carers | Good practice evidenced from consistent method if gathering feedback |
| I don't have sole responsibility for end of life conversations with the person I care for. Clinical services are able to engage the person with dementia in this conversation – as it is very hard for close relative to do this | End of Life Care plans made with the person with dementia – reducing the stress and anxiety of the carer who may not know what the person they care for really wants | The dementia pathway from late stage dementia to EOL is clear and well communicated to family carer and clinicians | Number of people with dementia with advance directives in place |

## 3. Scope

### 3.1 Aims and objectives of service

**Aim1: To provide commissioners with confidence that service specifications and operational standards are consistently met. The Provider demonstrates the Service is underpinned by the following values and principles:**

**For people with dementia and their family/carers to:**

- Feel valued and respected
- Be fully informed and engaged in all aspects of their care, via care co-ordination/care management

- Live a normal life as far as possible, be safe and feel secure
- Be included in local community and activities
- Not be stigmatised or discriminated against on any grounds
- Have easy access to up to date and accurate information
- Have options in the choice of care available locally

### Be supported with services that:

- Are flexible, holistic and responsive to individual levels of need
- Adopt the principle of ‘one person, one plan’
- Are built around the needs and wishes of each individual and their family/carers
- Look after people who live alone and offer community support.
- Promote and enable wellbeing
- Take into account people’s safety

### Aim 2: To provide high quality advice and support for other Providers, especially Primary Care, on assessment and management interventions for dementia through:

- Effective knowledge transfer
- Development of joint shared care protocols across organisations
- Education on good clinical care
- Contribution to training and organisation service development
- Providing links and sharing of information, that can support independent living and wellbeing
- Advice and signposting on other available support

### Aim 3: To prevent or minimise the inappropriate use of anti-psychotic medication, including advice on alternative strategies for people with dementia living at home, in care homes or in other residential settings, through:

- Following the NICE/SCIE guidance on Supporting people with dementia and their family/carers in health and social care (CG42), specifically section 1.7, Interventions for Non-Cognitive Symptoms and Challenging Behaviour in People with Dementia,
- Ensuring that people who are prescribed anti-psychotic medication have been fully assessed and are subject to regular and agreed medication reviews
- Ensuring family/carers are fully involved in the decisions about medication
- Ensuring there are therapeutic alternatives for people with behaviours that are considered to be ‘challenging’

### Aim 4: To promote support and inclusion for people with dementia and family/carers using the Service through:

- Care orientated to the individuality, life experiences, strengths and abilities while attending to difficulties and disabilities to support people with dementia and family/carers
- Providing access and/or support into purposeful, stimulating and appropriate engagement, activities and connections
- Promoting people's continued connections with their families, friendships, communities and local neighbourhoods
- Identifying and supporting the cultural and faith groups/spiritual needs of each

person.

- Having access to translators and interpreters to meet the needs of the people using the service (: consider needs associated with language, learning disability, sensory impairment, etc.)
- Identifying any reasonable adjustments necessary at the point of referral and taking appropriate steps to meet individual needs
- Providing written information about the memory service is distributed to GP surgeries and other public places in languages and formats that can be understood by local people
- Proactively addressing the stigma of dementia and other mental health issues and proactively identifying issues of social isolation
- Developing a form of expert carer programme for family/carers of people with dementia and uptake that is in line with predicted need, based on the NWL demographics

## Aim 5: To support the development of the workforce and volunteers providing the Service with the right attitudes and skill mix by ensuring that:

- The provider develops and promotes a culture of continuing learning and improvement throughout the whole Service and across providers
- Staff receive the training and supervision they need in relation to both current good practices and customer service approaches paying particular attention to the needs of the person with dementia and their family/carers
- Workforce capacity and capability are sufficient to deliver the expected outcomes
- The Provider involves people with dementia and family /carers in the dementia training of staff and volunteers, taking a co-production approach
- There is a good quality evidence based programme of training for volunteers to promote a sense of empathy with people with dementia and family/carers
- Staff are familiar with and alert to the benefits of assistive technology and Telecare for people with dementia.
- Dementia care training should include, “the importance and use of communication skills for working with people with dementia’ (Francis report 2013)

## Aim 6: To promote a positive experience of services to people with dementia and family/carers through:

- Integrated care pathway services and integration across other Providers where all the component parts are clear and well-co-ordinated and used as required through the person’s lifetime, including the development of person-centred holistic care plans
- in collaboration/formal partnership arrangements with other Providers
- Ensuring the service is delivered in a considered and co-ordinated manner
- Effective systems and processes in place to enable people with dementia and family/carers to have the opportunity to take part in high quality research studies
- Putting in place procedures, protocols, governance and audit arrangements to support the delivery of good health care

- Effective communication systems between front-line staff and managers and between members of the staff team and across organisations providing support to an individual
- Management and supervision appropriate to the delivery of good quality care
- Enabling a peer support model of care to be put in place, recognising that the experience of dementia (particularly in the early phases) may mean that the person can actively and valuably contribute to post-diagnostic support (in a paid sessional or voluntary capacity)

## Aim 7: To promote a positive experience of services to people with dementia and family/carers through:

- Integrated care pathway services and integration across other Providers, where all the component parts are clear and well-co-ordinated by a named care co-ordinator/care navigator, and used as required through the person's lifetime, including the development of person-centred holistic care plans
- Collaboration/formal partnership arrangements with other Providers
- Ensuring the service is delivered in a considered and co-ordinated manner
- Effective systems and processes in place to enable people with dementia and family/carers to have the opportunity to take part in high quality research studies
- Putting in place procedures, protocols, governance and audit arrangements to support the delivery of good health care
- Effective communication systems between front-line staff and managers and between members of the staff team and across organisations providing support to an individual
- Management and supervision appropriate to the delivery of good quality care
- Enabling a peer support model of care to be put in place, recognising that the experience of dementia (particularly in the early phases) may mean that the person can actively and valuably contribute to post-diagnostic support (in a paid sessional or voluntary capacity)

## Aim 8: To provide commissioners with confidence that service specifications and operational standards are consistently met. The Provider demonstrates the Service is underpinned by the following values:

## For people with dementia and their family/carers to:

- Feel valued and respected
- Be fully informed and engaged in all aspects of their care
- Live a normal life as far as possible, be safe and feel secure
- Be included in local community and activities
- Not be stigmatised or discriminated against on any grounds
- Have easy access to up to date and accurate information
- Have options in the choice of care available locally

## Be supported with services that:

- Are built around the needs of each individual and their family/carers
- Look after people who live alone and offer community support.

- Promote and enable wellbeing
- Take into account people's safety

## 3.2 Service description/care pathway

### 3.2.1 Key Service Principles

The provider will ensure that people with memory problem/dementia have fair access to assessment , care and treatment on the basis of need, irrespective of age, gender, social or cultural background, and are not excluded from services because of their diagnosis, age or co-existing disabilities/medical problems.

People with memory problems/dementia will receive a service that is person centred and takes into account their unique and changing personal, psychosocial and physical needs.

### 3.2.2 Service Model

The service model may vary by CCG with some CCG's commissioning a primary care based model, such as Gnosall, or a secondary care assessment and treatment service. Whatever model is adopted, the service should be part of an integrated pathway for the assessment, diagnosis and management of patients with dementia and cognitive impairment.

The remit of the service is to assess, diagnose and treat with appropriate interventions, including carer support and initiation of medication, until the patient is eligible for discharge into any shared care arrangements that may be agreed with primary care.
As people with dementia progress through the care pathway the need for specialist input is likely to increase. Therefore for patients who are at middle or late stafge of the care pathway the managemet of the patient is likely to sit with specialist care.

The service must be NICE compliant and either have, or work towards, MSNAP accreditation.

The Memory Assessment Service (MAS) is supported by the following key principles,

- The person with dementia and family/carers are at the centre of the model and key to making decisions about care.
- For people with dementia who live alone and have no immediate carer support the service will identify these patients at assessment and work with local partners to ensure the patient is supported throughout the pathway.
- To provide a co-ordinated and integrated approach between health, social care, voluntary and community sectors6 to provide a person-centred holistic pathway.
- A service that recognises that each person is an individual.
- A service which delivers an integrated response that can meet the needs of people's other co-morbid mental health conditions
- A flexible and sustainable service that delivers the proposed model by co-ordinating the integration of care across all agencies involved and supporting General Practitioners - from diagnosis, active support for self-management through to end of life care.
- To develop shared care arrangements between primary and secondary care providers to ensure that people with significant impairment and challenging needs can be 'Fast tracked' to specialist services when required and GP's supported to manage this cohort of patients in the community for as long as possible.
- Seeing dementia as everybody's business, not just as "health or "social care" issues. Mainstream services and facilities that work towards becoming more inclusive of

and accessible to people with dementia and their families, in line with the “Dementia Friendly Communities” national work stream.

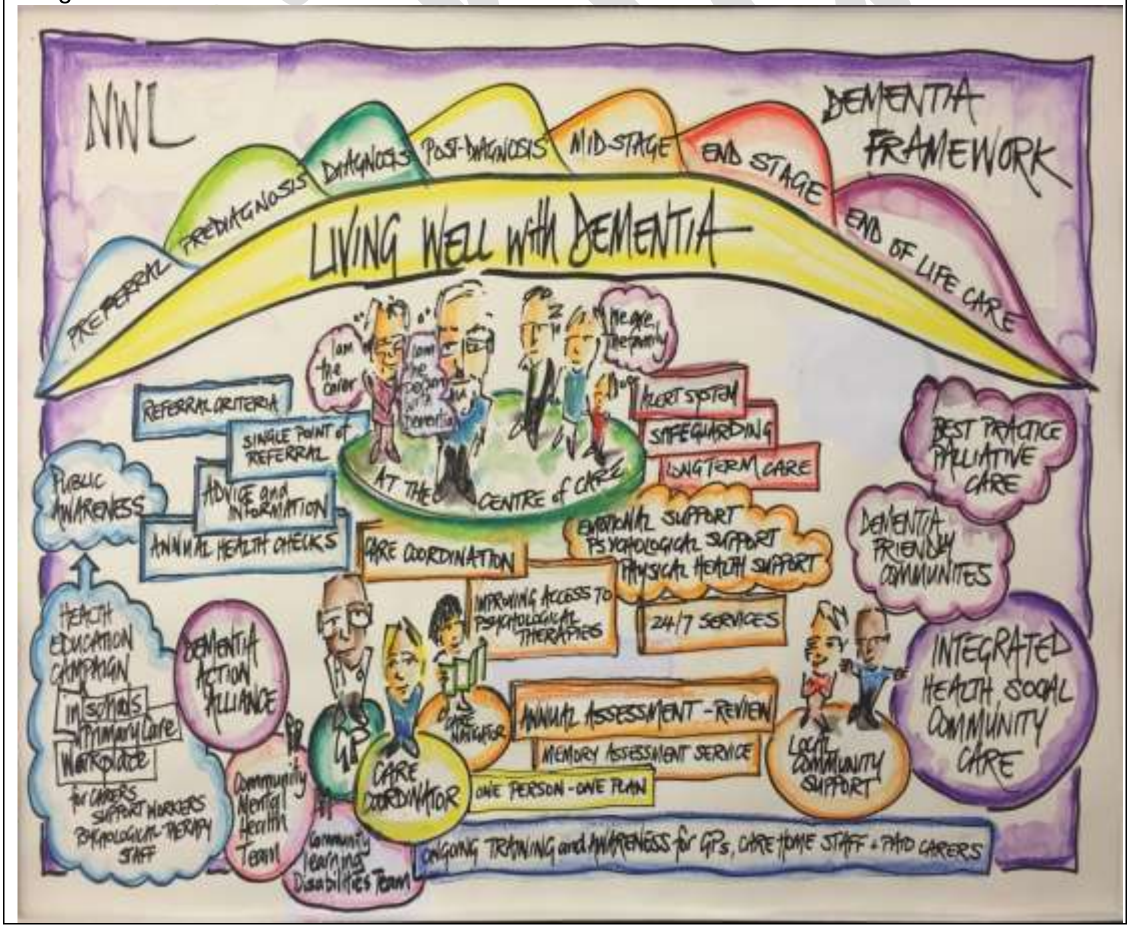
- Care that is actively delivered in collaboration or formal partnership arrangements with other Providers and ensures that agencies communicate and work together effectively along the care pathway
- A service that affords people a high level of dignity and respect, which is sensitive to their social and cultural background, and which maintains the highest standards of quality practice
- A service where people with dementia are understood as part of wider systems (families, carers, neighbourhoods, communities, friendship groups) and must always be worked with in relation to this key understanding

### 3.2.3 Dementia Framework

As part of the engagement and co-production process with key stakeholders including people with dementia and carers a dementia framework has been developed which underpins the clinical care pathway and outcome measures. The framework began as a high level dementia pathway and was discussed and debated at various forums including themed workshops and most importantly seen through the eyes of people with dementia and carers. The message was clear from people with dementia and carers in that the original format was ‘bbusy and confusing’ and there was a need for a simplified framework that would support and underpin the clinical care pathway.

The following dementia framework (diagram 1) is therefore a visual framework which contains all the key stages of living ell with dementia from pre referral to end of life stage.

Diagram 1



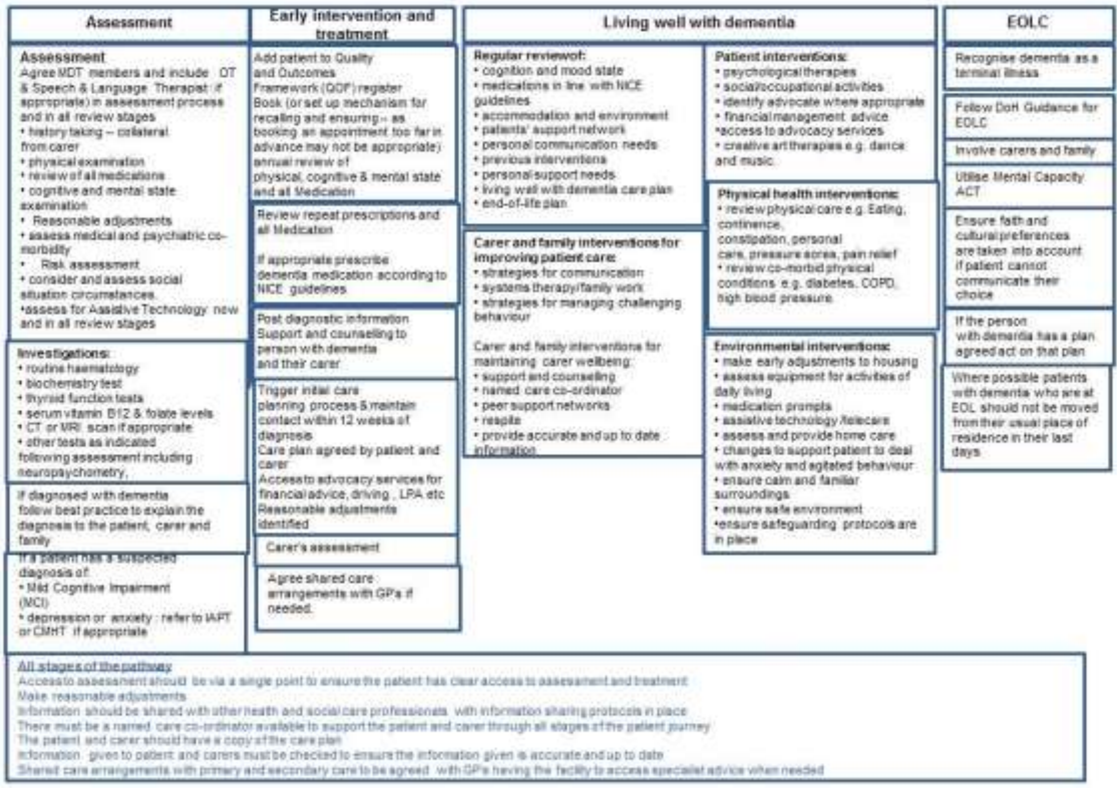
## 3.2.4

## High Level Clinical Care Pathway

The clinical care pathway will be specific to the appropriate model of care. There are however, some elements of the pathway that will be constantregardless of the service model.

The following high level pathway ( diagram 2) has also been developed from the dementia framework which underpins the the model of care. The pathway has been produced via a process of collaboration and co-production via the themed workshops and virtual discussion by the clinical leads and is aimed to be used and adapted as appropriate as the role of the clinician will be defined depending on agreed individual CCG model service model.

Diagram 2



**Assessment**

**Assessment**
Agree MDT members and include OT & Speech & Language Therapist ( if appropriate) in assessment process and in all review stages
- history taking – collateral from carer
- physical examination
- review of all medications
- cognitive and mental state examination
- Reasonable adjustments
- assess medical and psychiatric co-morbidity
- Risk assessment
- consider and assess social situation circumstances.
- assess for Assistive Technology new and in all review stages

**Investigations:**
- routine haematology
- biochemistry test
- thyroid function tests
- serum vitamin B12 & folate levels
- CT or MRI scan if appropriate
- other tests as indicated following assessment including neuropsychometry,

If diagnosed with dementia follow best practice to explain the diagnosis to the patient, carer and family

If a patient has a suspected diagnosis of:
- Mild Cognitive Impairment (MCI)
- depression or anxiety : refer to IAPT or CMHT if appropriate

**Early intervention and treatment**

Add patient to Quality and Outcomes Framework (QOF) register
Book (or set up mechanism for recalling and ensuring – as booking an appointment too far in advance may not be appropriate) annual review of physical, cognitive & mental state and all Medication

Review repeat prescriptions and all Medication

If appropriate prescribe dementia medication according to NICE guidelines

Post diagnostic information
Support and counselling to person with dementia and their carer

Trigger initial care planning process & maintain contact within 12 weeks of diagnosis
Care plan agreed by patient and carer
Access to advocacy services for financial advice, driving , LPA etc
Reasonable adjustments identified

Carer's assessment

Agree shared care arrangements with GP's if needed.

**Living well with dementia**

**Regular reviewof:**
- cognition and mood state
- medications in line with NICE guidelines
- accommodation and environment
- patients' support network
- personal communication needs
- previous interventions
- personal support needs
- living well with dementia care plan
- end-of-life plan

**Carer and family interventions for improving patient care:**
- strategies for communication
- systems therapy/family work
- strategies for managing challenging behaviour

Carer and family interventions for maintaining carer wellbeing:
- support and counselling
- named care co-ordinator
- peer support networks
- respite
- provide accurate and up to date information

**Patient interventions:**
- psychological therapies
- social/occupational activities
- identify advocate where appropriate
- financial management advice
- access to advocacy services
- creative art therapies e.g. dance and music

**Physical health interventions:**
- review physical care e.g. Eating, continence, constipation, personal care, pressure sores, pain relief
- review co-morbid physical conditions e.g. diabetes, COPD, high blood pressure

**Environmental interventions:**
- make early adjustments to housing
- assess equipment for activities of daily living
- medication prompts
- assistive technology /telecare
- assess and provide home care
- changes to support patient to deal with anxiety and agitated behaviour
- ensure calm and familiar surroundings
- ensure safe environment
- ensure safeguarding protocols are in place

**EOLC**

Recognise dementia as a terminal illness

Follow DoH Guidance for EOLC

Involve carers and family

Utilise Mental Capacity ACT

Ensure faith and cultural preferences are taken into account if patient cannot communicate their choice

If the person with demardia has a plan agreed act on that plan

Where possible patients with dementia who are at EOL should not be moved from their usual place of residence in their last days

All stages of the pathway
Access to assessment should be via a single point to ensure the patient has clear access to assessment and treatment
Make reasonable adjustments
Information should be shared with other health and social care professionals with information sharing protocols in place
There must be a named care co-ordinator available to support the patient and carer through all stages of the patient journey
The patient and carer should have a copy of the care plan
Information given to patient and carers must be checked to ensure the information given is accurate and up to date
Shared care arrangements with primary and secondary care to be agreed with GP's having the facility to access specialist advice when needed

## Assessment

In line with NICE guidelines (2013), valid consent should always be sought from the person being assessed. This should entail informing the person of the options and checking that he or she understands and that there is no coercion, and he or she continues to consent through time and the process.

People who are assessed for the possibility of dementia should be asked if they wish to know the diagnosis, and with whom this should be shared, and documented accordingly.

If the person lacks the capacity to make a decision, the provisions of the Mental Capacity

Act 2005 must be followed.

The assessment process should include input from other health professionals e.g OT and Speech and Language Therapist if appropriate.

Prticualr consideration and flexibility needs to be exercised for people who live alone and may need support to attend for an assessment.

## Diagnosis

If a primary care model of care is in place it is expected that an increasing number of straightforward cases of Alzheimer’s Disease or Vascular Dementia will be diagnosed in primary care without needing to be referred to specialist services.

In some cases, General Practitioners will be supported to make a diagnosis of dementia themselves. In other cases, the General Practitioner will refer a person for the diagnosis to a secondary care service for a diagnosis to be made.

The provider will have an important role in supporting General Practitioners to make a diagnosis, providing timely access to advice and guidance and providing training as appropriate. The Service will put in place a shared care protocol that has been agreed jointly by Providers and Commissioners to ensure that this is delivered in a clinically safe and appropriate way.

The Provider will allocate a named appropriately skilled worker to each practice to facilitate this. The Provider should ensure that there is a shared care protocol in place, (written by the commissioning clinical leads, GPs and the Provider,) for the prescription of cholinesterase inhibitors, as recommended in NICE technology appraisal 217.

## Access

The Service will aim to operate a Single Point of Access (SPA), that will be integrated within the existing SPA system and process.

A SPA will eliminate duplication,streamline the referral process and reduce the number of times the patient or carer will need to relate their story.

The SPA will be able to initiate first assessment by the service (following GP referral), provide advice and support for people who have a diagnosis and family/carers and/or professionals who require information, and fast track people back in to the Service who have not been actively using it.

It is important that this component of the service has a signposting role to help people access other services that will be able to provide support,information and advice.

## Advice, Education and Training

Professionals can access telephone and e-mail advice from the Service; this will include advice/support for Primary Care to make a diagnosis of dementia and to manage clinical issues.

The Department of Health’s Mandate to Health Education England (HEE), published in April 2013, set out the work programme for HEE to develop in partnership with the relevant stakeholders, a national roll-out plan for foundation level dementia training for all NHS staff.

The agreed definition of Foundation level dementia training is familiarising staff with recognising and understanding dementia, interacting with those with dementia, and training them to be able to signpost patients and carers to appropriate support. By doing this:

- Staff will have greater awareness and confidence to support patients affected by dementia.
- There will be better diagnosis, treatment and care of those with dementia
- NHS staff will be able to identify the early symptoms of dementia
- NHS staff will be more aware of the needs of patients affected by dementia and their families and carers, to enable them to provide safe, dignified and compassionate care
- GPs will be able to identify and work with patients affected by dementia
- The training will signpost staff to the most appropriate care
- The training will raise awareness of the increased likelihood of mental health problems presenting in those with Long Term Conditions

A Tier 2 intermediary dementia training and Tier 3 advanced dementia training is being developed and will be rolled out in 2014/15

## 3.3 Referral Route

The Provider shall respond to all requests relating to adults who meet the eligibility criteria for assessment and diagnosis.

- The Provider shall respond to referrals/referrers and ensure Initial contact is made with all people who are newly referred within three weeks of referral, as per MSNAP guidance [6]
- The assessment process should begin no later than six weeks from referral
- The provider will have a policy to follow up people who do not attend appointments

Where a face-to face assessment with a person suspected or diagnosed with dementia is required, the Provider will undertake the assessment in the place that is most appropriate for the person, which might be in a clinic, at home or in a care home. The Provider shall respond to requests for advice by telephone.

The Provider shall respond to requests for assessment or general advice by telephone from Primary Care within an agreed response time for urgent and non urgent requests non-urgent requests. ( Individual CCG to agree with service providers)

Where an urgent response is required, the Provider shall undertake the assessment within the same working day, if within the operating times of the Service, or if appropriate signpost any urgent referrals to the most appropriate service.

## 3.4 Population covered

- All adults), who are registered with a CCG within NWL at the time of referral and who may be in the early stages of dementia.
- This will include people with mild Learning Disability

### 3.5 Any acceptance and exclusion criteria and thresholds

- Those who do not meet the referral criteria

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[6] Memory Services National Accreditation Programme (MSNAP) Standards for Memory Services (2014) 4th edition

### 3.6 Interdependence with other services/providers

In addition, the service will support whole system relationships and develop agreed protocols and interfaces with:

- NWL CCG'S and Member Practices
- Local Departments of Adult Social Services
- Care and Residential Homes
- Alzheimer's Society and other voluntary sector organisations
- Acute Hospital Trusts
- Community Health professionals
- Community Geriatricians

**Manage interdependencies with:**

- GPs
- CMHTs
- Primary Care Mental Health Services
- Social Services Departments
- Local Authorities
- Allied Health Professionals
- District Nursing and Community Matrons
- Carer groups
- Patient and Public Forums
- Acute Trusts
- Community Hospitals
- Care Homes
- Young/Early Onset Dementia Service including ARBD
- Assistive Technology
- Learning Disability Services
- Domiciliary Care Providers
- Housing Providers
- Advocacy Services

## 4. Applicable Service Standards

### 4.1 Applicable national standards (e.g. NICE)

- NICE Technology Appraisal TA217 Alzheimer's disease - donepezil, galantamine, rivastigmine and memantine (2012)
- NICE Clinical Guideline CG42 Supporting people with dementia and their carers in health and social care (2011)
- NICE Quality Standard for Dementia (2010)
- Quality Outcomes for people with Dementia: building on the work of the National Dementia Strategy. (DH, 2010)
- Public Health Outcomes Framework (s 4.16)
- NHS Outcomes Framework ( s.1.5. 2.1, 2.4)
- Adult Social Care Outcomes Framework ( s.1b,1d & 3d)

### 4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

- Royal College of Psychiatrists Memory Services National Accreditation Programme Standards for Memory Services Assessment and Diagnosis

### 4.3 Applicable local standards

- Initial contact is made with all people who are newly referred within three weeks of referral as per MSNAP [7]
- The assessment process should begin no later than six weeks of referral

### 4.4 Safeguarding

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

### 4.5 Information Sharing

There will be a policy in place regarding the sharing of information between identified personnel and agencies in accordance with the Data Protection Act and Mental Capacity Act and their codes of practice/Guidance.

The provider will ensure that patients are aware that personal information about them will be shared within the health care team, unless they object, and of the reasons for this. It is essential and important that the provider checks that patients understand what will be disclosed in the event that identifiable information is shared with anyone employed by another organisation or agency who is contributing to their care.

## 5. Applicable quality requirements and CQUIN goals

### 5.1 Applicable Quality Requirements (See Schedule 4 Parts [A-D])

### 5.2 Applicable CQUIN goals (See Schedule 4 Part [E])

## 6. Location of Provider Premises

**The Provider's Premises are located at:**

## 7. Individual Service User Placement

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[7] Memory Services National Accreditation Programme (MSNAP) Standards for Memory Services (2014) 4th edition

Agenda Item 6

# London Borough of Hammersmith & Fulham

HEALTH AND WELLBEING BOARD

**9 September 2015**

## JSNA Update and Impact Review

**Report of the Acting Director of Public Health**

**Open Report**

**Classification - For Information**
(delete as appropriate)
**Key Decision: No**

**Wards Affected:** All

**Accountable Executive Director:** Liz Bruce, Executive Director of Adult Social Care

| | |
|---|---|
| **Report Author:**<br>Jessica Nyman, JSNA Manager<br>Colin Brodie, Public Health Knowledge Manager | **Contact Details:**<br>Tel: 020 7641 8461<br>E-mail:<br>jnyman@westminster.gov.uk |

AUTHORISED BY: ....................................

……………………………………………….

DATE: ………………………………………..

## 1. EXECUTIVE SUMMARY

1.1. This paper provides a short update on the current stage of delivery of the Joint Strategic Needs Assessment (JSNA) products agreed by the Health and Wellbeing Board for the 2014/15 work programme.

1.2. The report includes a demonstration of the proof of concept developed for the online interactive JSNA ("Evidence Hub") discussed at the previous meeting to provide an insight into the work to date, visualise how the online tool might look and to help show the value that it might add.

1.3. This report also includes progress made to date against evidence set out in deep dive JSNAs published in 2013-2014 (as an appendix), and considers how the future JSNA work programme can support the Health and Wellbeing Board priorities and Joint Health and Wellbeing Strategy.

## 2. RECOMMENDATIONS

2.1. The Health and Wellbeing Board are asked to consider progress on the scope and development of the Evidence Hub/online JSNA Highlights Report.

2.2. The Health and Wellbeing Board is invited to consider how the JSNA can best support the priorities and work programme of the Health and Wellbeing Board?

2.3. The Health and Wellbeing Board is invited to consider the report on progress made from the JSNA Work Programme 2013/14 (i.e. Physical Activity JSNA; Employment Support JSNA; Learning Disabilities JSNA; Child Poverty JSNA; and Tuberculosis JSNA

2.4. The JSNA Programme Team recommend that future JSNA Leads, and appropriate commissioners, report to the Health and Wellbeing Board on (1) how JSNA findings and recommendations will be taken forward when the JSNA is completed, and (2) progress made on implementation one year after completion.

## 3. REASONS FOR DECISION

3.1. The Health and Wellbeing Board are invited to comment on progress with the JSNA work programme.

## 4. INTRODUCTION AND BACKGROUND

4.1. JSNAs provide a detailed picture of the health and wellbeing needs of the local population. They are developed jointly by local NHS and council partners and identify actions that local commissioning organisations will need to take to improve the design, delivery and effectiveness of services that improve the health and wellbeing of individuals and communities, and reduce health inequalities. Other partners are also involved in the process, including service providers, voluntary organisations and Healthwatch

4.2. Local authorities and Clinical Commissioning Groups (CCGs), through the Health and Wellbeing Board, have a legal duty to prepare a JSNA.

4.3. The Hammersmith and Fulham Health and Wellbeing Board has delegated the prioritisation of the JSNA workplan and the day-to-day management of the programme to a sub-group of the Health and Wellbeing Board, the JSNA Steering Group. This group consists of representatives from the CCGs, Public Health, Children's Services, Adult Social Care, Community and Voluntary Sector, and Healthwatch. The Health and Wellbeing Board remain accountable for the JSNA and are required to agree and sign-off the JSNA work programme and the final JSNA products, and monitor delivery of the programme.

4.4. The JSNA work programme currently contains two main workstreams:

(a) highlight reports for each borough, and

(b) 'deep dive' JSNAs which produce topic-specific needs assessments to inform particular commissioning questions.

4.5. There are currently four deep dive JSNAs in progress covering the following topics – Dementia, Childhood Obesity, End of Life Care and Housing.

4.6. In addition, the development of an Evidence Hub has been added to the future JSNA work programme. The Evidence Hub will provide a tool which brings together a broad base of information and which will allow access to a range of data and evidence. The aim is for this to be easy to use and understand and so will facilitate and inform the refresh of the borough-specific JSNA Highlight reports.

## 5. Current JSNA Work Programme

5.1. An update on the 4 current deep dive JSNAs was brought to the previous meeting in July 2015 and so a very brief progress report is provided below.

5.2. The **Dementia JSNA** is presented for approval at this meeting of the Health and Wellbeing Board in a separate report.

5.3. Following initial comments on an initial draft of the **Childhood Obesity JSNA** from the Tackling Childhood Obesity Team (TCOT) a revised draft is being completed which will be sent to a wider group of stakeholders for comment and feedback. A final draft is expected to be ready for consideration by the Health and Wellbeing Board in November 2015.

5.4. Work to capture the views of clinicians, commissioners, patients and their families/carers is well underway for the **End of Life Care JSNA**. This will be incorporated into the current draft report for review by the End of Life Care Steering Group at the end of September 2015. The Steering Group will take on responsibility for developing the recommendations based on the evidence from the JSNA.

5.5. A template report for the **Housing JSNA** has been developed which will describe levels of need for vulnerable residents; services to support people in their own homes; the supply of housing for vulnerable residents; and identify gaps in provision and potential solutions.

***Evidence Hub***

5.6. An initial proposal to develop an online JSNA data observatory, or Evidence Hub, was first raised at the JSNA Steering Group in January 2015. Since then work has progressed to develop the scope of the Evidence Hub in more detail, how it may look in practice, and the benefits of this project.

5.7. The aim of the Evidence Hub will be to present information drawn from a range of national and local data and evidence sources, and provide an online toolkit for users to interrogate in a more interactive and flexible way.

5.8. Building on consultation with a range of stakeholders, a proof of concept has been developed which has been presented to a number of forums such as the Public Health Integration and Transformation Board, the Public Health Leadership Forum and the JSNA Steering Group.

5.9. Following a presentation at the Shared Services Board in August 2015 it was proposed that the scope of the Evidence Hub is expanded to incorporate intelligence from across the local authority and close linking with the Business Intelligence function. This project has yet to be scoped in detail.

5.10. In the meantime the JSNA work programme will focus on the development of the proof of concept and refreshing the JSNA Highlights report as an online tool.

**5.11. The Health and Wellbeing Board are asked to consider progress on the scope and development of the Evidence Hub/online JSNA Highlights Report.**

## 6. Future JSNA Work Programme

6.1. In order to support the Health and Wellbeing Board work programme, the JSNA Steering Group discussed alignment between the JSNA work programme and Health and Wellbeing Board priorities at their meetings on the 4 June and 27 July 2015. The Steering Group have identified a number of actions to improve closer alignment with the Board and key stakeholders:

- Provide minutes of the JSNA Steering Group to Health and Wellbeing Board members
- Rotate Chair of the JSNA Steering Group (traditionally Chaired by Director of Public Health, currently chaired by CCG representative)
- Review Terms of Reference and membership of JSNA Steering Group
- Presentations to CCG governing bodies (or similar)

### *Potential topics for future deep dive JSNAs*

6.2. To date no further applications have been submitted to the JSNA Steering Group for consideration.

6.3. **The Health and Wellbeing Board is invited to consider how the JSNA can best support the priorities and work programme of the Health and Wellbeing Board?**

6.4. To inform the future JSNA work programme it is worth considering how previous JSNAs have informed commissioning, strategy and service development. The report attached at Appendix 1 has been provided by the JSNA Steering Group and JSNA Project Leads. It provides a summary of progress on the findings/recommendations of the deep dive JSNAs published in the 2013/14 work programme. These were Physical Activity; Child Poverty; Tuberculosis; Learning Disabilities and Employment Support.

6.5. **The Health and Wellbeing Board are invited to consider the report on progress made from the JSNA Work Programme 2013/14**

**6.6. The JSNA Programme Team recommend that future JSNA Leads, and appropriate commissioners, report to the Health and Wellbeing Board on (1) how JSNA findings and recommendations will be taken forward when the JSNA is completed, and (2) progress made on implementation one year after completion.**

6.7. Please see attached report at Appendix 1.

## 7. EQUALITY IMPLICATIONS

7.1. JSNAs must consider the health, wellbeing and social care needs for the local area addressing the whole local population from pre-conception to end of life.

7.2. The “local area” is that of the borough, and the population living in or accessing services within the area, and those people residing out of the area for whom CCGs and the local authority are responsible for commissioning services

7.3. The “whole local population” includes people in the most vulnerable circumstances or at risk of social exclusion (for example carers, disabled people, offenders, homeless people, people with mental health needs etc.)

## 8. LEGAL IMPLICATIONS

8.1. The JSNA was introduced in the Local Government and Public Involvement in Health Act 2007

8.2. The Health and Social Care Act 2012 placed the duty to prepare a JSNA equally and explicitly on local authorities (LAs), Clinical Commissioning Groups (CCGs) and the Health and Wellbeing Boards (HWB)

8.3. Implications verified/completed by: (Name, title and telephone of Legal Officer)

## 9. FINANCIAL AND RESOURCES IMPLICATIONS

9.1. The current JSNA projects are scoped and progressed within existing resources and capacity. The individual JSNAs largely draw on existing staff capacity from across the key departments and stakeholders involved, and from the JSNA team within the Public Health department.

9.2. The refresh of the JSNA Highlights Report as an online tool (see Evidence Hub) as set out above could be progressed within existing resources. However, the expansion of the Evidence Hub project will require further resource and capacity appropriate to the scope of the project (to be determined). The Health and Wellbeing Board may wish to consider these projects more fully at a future meeting alongside other potential draws on the Joint Strategic Needs Assessment resource.

9.3. Implications verified/completed by: (Name, title and telephone of Finance Officer).

## 11. IMPLICATIONS FOR BUSINESS

11.1 None identified in this update.

## 12. RISK MANAGEMENT

12.1 None identified in this update

21.1 Implications verified/completed by: (Name, title and telephone of Risk Officer).

## 13. PROCUREMENT AND IT STRATEGY IMPLICATIONS

13.1 None identified in this update

13.2 Implications verified/completed by: (name, title and telephone of Procurement Officer).

## LOCAL GOVERNMENT ACT 2000
## LIST OF BACKGROUND PAPERS USED IN PREPARING THIS REPORT

| **No.** | **Description of Background Papers** | **Name/Ext of holder of file/copy** | **Department/ Location** |
|---|---|---|---|
| 1. | JSNA Steering Group Minutes 27072015 | Colin Brodie/02076414632 | Public Health |

*[**Note:** Please list only those that are not already in the public domain, i.e. you do not need to include Government publications, previous public reports etc.] Do not list exempt documents. Background Papers must be retained for public inspection for four years after the date of the meeting.*

## LIST OF APPENDICES:

*(Please submit appendices with the main report. Appendices should be numbered clearly and consecutively on the top right hand corner of the page, i.e. Appendix 1, Appendix 2, etc. There needs to be a clear reference to the appendix in the body of the report.)*

Appendix 1- JSNA Deep Dive Update and Progress Review June 2015

# Appendix 1 - JSNA Deep Dive Update and Progress Review June 2015

## COMPLETED JSNA DEEP DIVES PRODUCTS 2013/14– Update on Progress

The following deep-dive JSNAs were completed and published in 2013/14. Below is a reminder of the summary of the key findings for each JSNA, and an update on progress since they were published.

1. Employment Support – August 2013
2. Learning Disabilities – January 2014
3. Tuberculosis – March 2014
4. Child Poverty – April 2014
5. Physical Activity – May 2014

| **1. Supported Employment JSNA August 2013** | |
|---|---|
| Summary | Unemployed individuals have a higher risk of poor physical and mental health compared with those in employment. The health and social impacts of a long period of unemployment can last for years.<br>Some key findings reported in the JSNA:-<br>• Unemployed people have higher levels of GP consultations and longer in-patient stays. Extrapolating from national figures, the cost of mental illness locally is approximately £300 million in H&F. Over a third of this is due to loss of economic output (over £80million per borough) and a fifth due to health and social care costs (over £5million per borough). These figures are probably underestimates due to high local prevalence of severe mental illness and a larger working age population than the national average.<br>• Clients with learning disabilities were noted to have worse employment prospects than other disability groups. The employment rate [*at time of JSNA reporting*] for disabled people nationally had risen to 48% overall but remained only 10% for those with learning disabilities. The report also noted that 65% of people with learning disabilities nationally would like a paid job .<br>• Sickness absence and presenteeism (reduced productivity at work related to ill health) are also likely to have major impacts in the three boroughs, based on what we know nationally. Mental illness is the number one cause of long-term sickness absence, closely |

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| | followed by musculoskeletal problems.<br>• There is substantial evidence that specialist employment support, tailored to the needs of clients with mental illness or disabilities, can deliver jobs. The most cost effective models of support include Individual Placement and Support (IPS) for mental health clients and Supported Employment (SE) in the disabilities field.<br>• There is also evidence to support a role for 'Very Supported' employment opportunities (such as social enterprises) for clients with very complex needs.<br>• In addition, Government policy advocates early intervention in-work support to help individuals to retain employment, to prevent the 'revolving door' of sickness absence and to avoid the negative health impacts of unemployment.<br>• Evidence shows that these approaches to employment support can deliver:<br>Improved individual health and wellbeing<br>Increased personal income<br>Reduced use of health and social care services<br>• Evidence-based employment support is, at least, cost neutral. At best it can generate significant cost savings to local commissioners. |
| Purpose | To implement a needs assessment to inform Adult Social Care and CCG planned commissioning and to implement a recommended JSNA approach advocated by the London Mental Health and Employment Group.<br>The JSNA profiled prevalence of mental illness, physical disabilities and learning disabilities; employment rates; mapped service provision, outlined evidence base and made recommendations for evidence based future service provision. |
| Recommendations | See 'Progress to date' section for synopsis. |
| Lead responsibility | Public Health; Adult Social Care; CCG Mental Health Commissioning Support |

<table>
<tr>
<td>Progress to date</td>
<td>
The JSNA outlined elements of good practice to be considered by local commissioners, please see below some examples with summary of progress to date:-
<table>
<tr><th>Elements of good practice</th><th>Progress to date</th></tr>
<tr>
<td>• <b>Evidence-based approaches</b> to employment support. For example IPS in the mental health field and SE in the disabilities field<br>• <b>Regular review of progress</b> to ensure that clients progress towards paid employment and do not get stuck at earlier stages along the pathway to work<br>• <b>A single point of referral</b> into the system and <b>clear pathways</b> within it</td>
<td>• JSNA has informed:-<br>- ASC service design and specification for new supported employment service for individuals with learning disabilities/disabilities to be commissioned<br>-Public Health Investment Fund Employability Programmes including Supported Employment Service as noted above (JSNA identified need for provision in LBHF)<br>-recent discussions relating to West London Mental Health Trailblazer (LBHF)</td>
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<tr>
<td>• <b>Partnership work and effective communication</b> between employment support providers, care managers, health care and benefits advisors<br>• <b>Co-location</b> of employment support within social and health services (e.g. IAPT). This can improve the effectiveness of support for clients and may be cost saving</td>
<td></td>
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<tr>
<td>• <b>Employer engagement</b> so that more high quality job opportunities are available to clients. Fewer people will fall out of employment when employers know what to expect when they employ individuals with mental illness or disabilities.<br>• <b>High quality work opportunities</b></td>
<td>• Public Health Investment Fund: London Healthy Workplace Charter -Environmental Health Teams working with local businesses to support healthy workplace practice and work towards achieving Charter accreditation<br>• Commissioning of Social Enterprise, designed to form part of the new model of employment support</td>
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| | | |
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| | - **Provision of early intervention support for job retention supporting employees and employers** | provision and offering supported work opportunities for individuals with disabilities and learning disabilities.<br>- One year Fit for Work Service (2013-2014), following on from DWP & DH funded 3 year pilot (2010-2013). |
| | - **The local Councils and CCGs leading by example** as employers. | |
| Future delivery | Commissioning of Supported Employment service (ASC 3 boroughs): The new service is expected into place in December 2015. | |
| Risks and issues | None identified | |
| Actions for Health and Wellbeing Board | **The local Councils and CCGs leading by example** as employers<br>Raise awareness and encourage Health and Wellbeing Board representative's organisations to:-<br>-Identify and facilitate work related opportunities within the organisation and additional opportunities that could be offered via commissioning (i.e. providers/contractors) for identified target groups<br>-Participate in the London Healthy Workplace Charter | |

| **2. Learning Disabilities JSNA January 2014** | |
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| Summary | This report assesses and develops local strategy around support for people with learning disabilities, alongside a range of other information, such as other specific needs assessments, strategies, action plans and routine monitoring.<br>Some detail has been provided in this report on services in the three Boroughs and how they are responding to local needs, but it is envisaged that this detail will predominantly be captured in resulting action plans and strategies, which will ensure that issues from this report are addressed. |
| Purpose | Describe the needs of people with learning disabilities locally and be used to assess and develop local strategy around support for people with learning disabilities. |
| Recommendations | • Ensure that cross-organisational systems are in place to **identify those with learning disabilities**, in order to tackle potential under-diagnosis in the local population, and do early assessments of those with learning disabilities likely to be transitioning into adult services, to ensure that referrals are received in a timely fashion. This will also support professionals to better plan for the young people who are assessed as not eligible and therefore will not receive a service.<br>• **Ensure that local services plan** for expected increases in numbers of complex clients in transition, as well as numbers reaching old age, and the specific requirements that these groups have, such as planning for more and more varied models of accommodation and support.<br>• To work with housing, leisure services and care providers around issues relating to the promotion of leisure facilities and the **tackling of obesity for** people with learning disabilities<br>• Continue working with GPs and hospitals to **ensure reasonable adjustments are made to enable people to access services** easily for those with learning disabilities and autistic spectrum disorders. A three borough inpatient audit into service users' experiences is currently being carried out which will help to improve the quality of the service. Work with dentistry services in the community and secondary services to make further adjustments to enable service users with complex and challenging behaviour to access the service e.g. designated slots when there are fewer patients and minimise waiting time<br>• To **address data quality issues,** around numbers attending cervical and breast screening and develop actions to improve uptake where necessary, reporting causes of death of those with learning disabilities, to give indications of possible preventability (e.g. lung problems / |

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| | epilepsy). Need to improve systems around health checks to address the recent drop in uptake.<br>• There needs to be access to **high quality care and support services and suitable accessible housing** in order to ensure that Adult Social Care departments keep people in the community rather than placing them in residential care. Examine residential care placement costs in Hammersmith and Fulham, which routine data suggests are high. Extra Care Sheltered (ECS) placements, and more accessible accommodation is likely to be needed across all the boroughs. In accordance with the Winterbourne View Concordat, those in hospital placements should be moved out of hospitals by June 2014, unless being actively treated in hospital<br>• The recent drop in existing clients **receiving a review** needs to be examined and addressed<br>• Ensure that work with general practice and hospital trusts is **addressing issues raised by local families** and review current local strategies and action plans around **carers** |
| Lead responsibility | Adult Social Care, The Joint Commissioning Team |
| Progress to date | In response to the findings from the JSNA the following information has been provided:<br>Work is well underway in both local acute trusts on **identification of people with Learning Disabilities.** Work has been undertaken to identify the numbers of people with learning disability coming through transition, each team is aware of the numbers expected and is currently mapping out specific levels of need. There has been a significant increase in primary care identification of people with learning disabilities in Hammersmith and Fulham to more than 80%.<br>Work to **tackle obesity** is being completed through primary care and the local community learning disability teams in conjunction with local leisure providers. The Health Action Plan from the annual health check identifies specific area of health need including obesity and this will drive opportunities for exercise.<br>A Secondary care Referral addendum has been developed to link flagging and identification of **reasonable adjustments** between primary and secondary care for people with learning disabilities.<br>To **address data quality issues** around numbers attending cervical and breast screening, data is collected via SystmOne reports, so there is a systematic approach, CCGs are looking at further validating this data in the coming year through the LD SAF action plan. |

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| | **Those people that are safe to move out of inpatient hospital services have been moved**. A recent report to the Adult Safeguarding Board has provided assurance. Independent care and treatment reviews (CTR) have been completed for those without discharge dates and this is now due to be used for the wider cohort of people still in these settings. Quantitative and qualitative information is reported back to CCG Quality patient Safety and Risk Committees on a quarterly basis. Hammersmith and Fulham achieved more than 80% of reviews in 2014/15.<br>**Carers** attend local hospital learning disability steering groups and people that use services and carers regularly attend and contribute to the Learning Disability Health Steering Group across the three local authority and CCG areas. This is starting to address issues raised by local families including accessible information (including appointment letters), employment, reasonable adjustments and housing. Carer primary care navigators have been piloted across the three local authority areas to help identify **carers** early vis NHS routes, putting in place systems and support to support GP practice staff to identify, signpost and support carers. |
| Future delivery | Review and recomissioning of Carer services. Learning Disability housing options such as Extra Care. |
| Risks and issues | N/A |
| Actions for Health and Wellbeing Board | N/A |

### 3. Tuberculosis JSNA

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| Summary | The main concern with regards to TB strategy and management is the lack of clarity surrounding the strategic planning of services. The TB Action group, which used to bring together commissioners and service providers is no longer in existence and there is no obvious successor.<br>The commissioning of TB services across the three boroughs now falls to the Clinical Commissioning Groups (CCGs) with input from the Health and Wellbeing Boards. This new arrangement provides opportunities for Adult Social Care, CCGs and Public Health to join up thinking and provide a TB service which addresses current issues around provision of housing for TB patients without recourse to public funds and operate across boundaries. However, currently there is no clear arrangement with regards to the TB strategy. A London TB Control Board (LTBCB) has been set up by Public Health England London and NHS England (London Region) in order to provide strategic oversight and direction and a whole systems approach. |
| Purpose | This TB needs assessment supports the development of a three borough strategy and Clinical Commissioning Group (CCG) commissioning intentions. |
| Recommendations | Recommendation 1: Pool staff, clinics and resources where appropriate<br>Recommendation 2: Consider how hospital and community services can be provided more effectively and efficiently. Strengthen the community aspect of TB management |

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| | Recommendation 3: Review current commissioning arrangements and establish specific service specification and service level agreements for TB<br>- Unbundle the components of TB service costs and establish clear service specifications and service level agreements<br>- Unify services under one provider<br>- Consider joint TB funding across regions<br><br>Recommendation 4: Establish a local pathway and programme for the management of latent and active TB<br>- Establish a latent TB screening programme<br>- Establish a clear pathway for the management of acute and latent TB in the community involving all stakeholders |
| Lead responsibility | Connie Junghans, Public Health Analyst |
| Progress to date | In response to the findings from the JSNA, the following changes have been implemented in cooperation with the CCGs and Imperial and NHS England:<br><br>(1) The tertiary service has been reorganised – the JSNA found that the arrangement of providing the tertiary service via the CLCH service in particular caused concerns in terms of clinical safety as well as efficiency. Analysis showed that providing TB clinics from St Mary's was the most advantageous for patients as well as staff and substantially reduced travel time for some patients. All services have now been reconfigured to provide TB clinics out of St Mary's as well as Chelsea and Westminster hospital, with increased cooperation between the two sites to provide economy of scale in terms of specialty clinic provisions.<br><br>(2) A primary care Latent Tuberculosis Infection (LTBI) pathway has been implemented and started running in April to systematically identify those at highest risk of having LTBI and developing active TB in the future. |
| Future delivery | Monitoring demand and supply, particularly with regards to patients with LTBI picked up in the community by the LTBI screening programme. |
| Risks and issues | It remains to be seen how the detailed funding structure of the tertiary service will meet the challenges of community service provision such as TB incident management, contact tracing and DOT provision. Additional community service capacity may be needed in the future.<br><br>The TB Action group for the three Boroughs could be re-instated for monitoring services. |

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| | There is little involvement at present from Public Health, so the opportunity for Public Health to lead on coordinating TB services across council departments, CCGs and hospitals could be missed. |
| Actions for Health and Wellbeing Board | N/A |

| **4.Child Poverty JSNA** | |
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| Summary | Evidence has shown that the foundations for virtually every aspect of human development are laid in early childhood, and that this has a lifelong impact on health and wellbeing, from obesity, heart disease and mental health through to educational achievement and economic status.<br>National research has found that child poverty in the UK results in additional public spending of £12 billion a year, 60% of which is spent on personal social services, school education, the police and criminal justice.<br>The report identified several key priorities for tackling child poverty:<br>Priority 1- Supporting families to engage with services<br>Priority 2 – Promoting parental employment<br>Priority 3 – Access to quality/affordable childcare, for all families<br>Priority 4 – Supporting the role of the school community<br>Priority 5 – Appropriate healthcare, at the right time<br>Priority 6 – All families have access to housing of a reasonable standard |
| Purpose | Discover what causes child poverty, what works in tackling child poverty, what is being done locally to alleviate the effects of it and what |

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| | further opportunities there are to support those affected, beyond what is already being done. |
| Recommendations | All recommendations are linked to above priorities. |
| Lead responsibility | Children's Services with Public Health, Economic Development and Housing |
| Progress to date | Hammersmith and Fulham council is working to incorporate the findings of the JSNA into existing policy and strategy to ensure that addressing the needs of children in low incomes families is appropriately woven throughout. A Child Poverty Strategy is currently under development in Hammersmith & Fulham HWB to ensure that actions in different sections of the council and its partners are drawn together to provide an overview and ensure cohesion.<br>Reducing the health inequalities associated with childhood poverty is a key strategic priority for Hammersmith and Fulham in the Public Health Strategy.<br>Priority 1- Supporting families to engage with services<br>• Development of Family Information Service (FIS) is underway<br>• Public Health are contributing over £1m during the coming three year period to support the continued provision of targeted activity in children centres ensuring that vulnerable families are able to access a range of health promoting and preventative services.<br>Priority 2 - Promoting parental employment<br>• The Public Health Investment Fund is funding an initiative that will target employers within the borough area to promote the London Healthy Workplace Charter and engage with businesses to support them to achieve recommended standards. It is intended that one area of focus will be family friendly terms and conditions.<br>Priority 3 - Access to quality/affordable childcare, for all families<br>• The council is working to increase availability of the national entitlement to free childcare for up to 15 hours a week for all 3-4 year olds, and for those 2 year olds from eligible families (parents on low incomes).<br>• The national entitlement of 30 hours of childcare a week once a child reaches their 3rd birthday will begin in September for working parents.<br>• The Family Information Service are planning for the take-up of tax free childcare which will be launched in Autumn 2015, targeted |

at working families with children under the age of 12 or with children with disabilities under the age of 17.

- In July the Play Service circulated a newsletter to all parents and service users to advise on how they will be able to access the tax-free childcare scheme that is being launched in September. We will be working in partnership with the FIS to ensure consistency in communications.
- The Play Service is currently developing a Summer Holiday Childcare and Play programme that will provide flexible childcare for working parents or parents seeking employment to use the service either for shorter or extended days.

Priority 4 – Supporting the role of the school community

- The Play Service is working with Head Teachers to ensure greater access to the targeted places scheme for children in need.
- The Early Help Strategy has been agreed across all three boroughs and is informing the development and recommissioning of the new school health service
- The On Track programme is using predictive modelling to identify children (older primary and early teens) who are at risk of poor outcomes and on the cusp of care, and putting in school and family based interventions
- As part of the School Food Plan, funding was allocated to Magic Breakfast to pilot and evaluate a number of models of school breakfast club provision. Public Health worked with Magic Breakfast to identify and contact eligible schools. 12 schools with high Free School Meal eligibility across the three boroughs have taken the opportunity to take part in this 2 year pilot, including four primary schools, six secondary schools and one Pupil Referral Unit. It will significantly expand the number of free breakfasts available to pupils.

Priority 5 – Appropriate healthcare, at the right time

- The CCGs launched a programme called Connected Care for Children promoting and facilitating paediatricians to share knowledge with GPs.
- Action is underway to improve the maternal and child health outcomes of the most disadvantaged groups. Maternity champions for Old Oak have been recruited and are currently being trained. This initiative has a particular emphasis on improving access to services and enhancing the support available to BME and other families who find it difficult to access mainstream provision.

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| | Implementation of the maternity champions initiative is being supported by community midwives, who are also now operating out of children's centres in areas of the highest deprivation across all three borough. This enables earlier and more timely access to maternity services and the provision of a more integrated maternity care pathway.<br>• The Community Champions in Hammersmith and Fulham delivered health events including oral health reaching over 700 people.<br>• Keep Smiling oral health improvement programme for 3-7 year olds has been delivered in 5 schools in Hammersmith and Fulham. The Community Champions have The Community Champions have delivered 12 public health campaigns including oral health reaching 2016 residents. The provided training around oral health including sign posting residents to the dentist, and Health Visitors give Brushing for Life packs at 8/9 months and 2 ½ years and encourage the positive messages around oral health and attending a dentist.<br><br>Priority 6 – All families have access to housing of a reasonable standard<br><br>• An award from the Public Health Investment Fund is being used to add capacity to the residential environmental health team to specifically target those residents whose health and wellbeing is vulnerable to poor housing conditions, undertaking home visits to identify and address any housing issues that might compromised their health and wellbeing / put them at risk and developing and implementing an action plan to address these issues.. There is a specific focus in this work on households with young children.<br>• The recently published *Delivering the Change we need in Housing*, Hammersmith and Fulham's Housing Strategy makes a number of commitment which will improve housing conditions for families with low incomes, these include a reviewing of housing allocations criteria and working to improve standards in the private rented sector.<br>• In Hammersmith and Fulham the PHIF is supporting 'In Situ housing solutions', an initiative which alleviates the impact of living in overcrowded housing conditions while families await rehousing. |
| Future delivery | |
| Risks and issues | N/A |
| Actions for Health and Wellbeing Board | N/A |

| **5. Physical Activity JSNA** | |
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| Summary | The estimated direct cost of physical inactivity to the NHS across the UK is £1.06 billion. This is based upon five conditions specifically inked to inactivity – coronary heart disease, strokes, diabetes, colorectal cancer and breast cancer – and this is likely to be a conservative estimate, as it does not include a range of other health conditions likely to be accountable to physical inactivity.<br>The data analysis indicates that although the percentage of people meeting the DH recommended levels of physical activity are higher in the three compared to England and London, there is evidence of inequalities in physical activity levels. In particular, BME groups, women, people with long term conditions and those living in the most deprived areas have low participation rates.<br>Nearly 250 premature deaths and 3000 new cases of diabetes per year could be prevented if all the population of the three boroughs met the recommended levels of physical activity. This would have represented a saving of over £5m for healthcare costs in 2010/11. |
| Purpose of JSNA | Designed to inform the promotion of physical activity into policies and strategies and to guide local implementation of the government programme ‘Let’s Get Moving – the Physical Activity Care Pathway’. |
| Recommendations | 1. In order to identify how existing community assets can be best utilised to improve participation in physical activity, an **asset mapping** approach/exercise should be undertaken in each of the boroughs to address specific or targeted needs . The community should be engaged in this exercise.<br>2. **Communications and messaging**. In order to promote physical activity participation effectively there is a need for consistent messaging pertaining to: |

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| | a) The definition of physical activity<br>b) Key messages regarding Department of Health recommended levels of physical activity for all age groups<br>c) The promotion of physical activity as part of everyday life including active play and transport i.e. 'everyday activity'<br>Local authorities, the NHS, and the Third Sector should take a lead in promoting participation in physical activity across the three boroughs. Physical activity messages should be embedded in all local statutory and voluntary sector strategies and policies that relate to health and wellbeing.<br>To ensure consistency of messaging and to improve participation levels, GPs and other front-line health and social care workers should be offered training on giving advice on physical activity: what it is, the benefits of physical activity, recommended levels, and the promotion of physical activity as part of everyday life.<br>There is strong evidence that school based strategies, particularly with a family or extracurricular component, are effective in improving physical activity uptake among children and young people. In order to best inform strategy development, target and evaluate interventions, and monitor trends over time, a process should be established to capture data in levels of physical activity and physical education in schools.<br>Local analysis indicates that certain communities and population groups have low participation rates of physical activity, and do not meet the Department of Health recommendations. Specific communities and groups should be targeted around the promotion of physical activity, and access to opportunities for physical activity.<br>National guidance endorses the delivery of brief interventions for physical activity in primary care as both clinically and cost effective in the long term. The implementation of the Lets Get Moving Physical Activity Care Pathway should be facilitated across the three boroughs, with the appropriate monitoring and evaluation. |
| Lead responsibility | Mary Russell, Public Health Commissioner |
| Progress to date | The Shared services physical activity action plan has been developed addressing the recommendations from the JSNA the implementation of which is overseen by the Shared Services Physical Activity Steering Group, and is also linked in with the work of each of the three local Community Sport and Physical Activity Networks (CSPANs). |

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| | Physical activity promotion training has become an integral part of the specification for the re-commissioned Childhood Obesity Prevention Service.<br>The ‘f-activity’ sheet with **key messages on physical activity** has been developed and there is ongoing work on a communications strategy in order to ensure consistent messaging and language pertaining to the promotion of physical activity as part of everyday life.<br>**Physical activity promotion training** has become an integral part of the specification for the re-commissioned Childhood Obesity Prevention Service.<br>Active Champions training to support the roll out of the Lets Get Moving (adapted from the Health Improvement Team’s Making Every Contact Count Training) has been developed and the first cohort of Active Champions Trained.<br>The Annual Public Health Report (Shared Services) 2014/15 has a focus on physical activity. |
| Future delivery | Progress will continue through the delivery of the Physical Activity Action Plan. |
| Risks and issues | Some departments or organisations may not yet see the relevance of physical activity promotion to their work. This can be mitigated through consistency in promoting the wide ranging benefits of physical activity, as per the action plan and communications plan. |
| Actions for Health and Wellbeing Board | Support the identification of a physical activity champion, or champions, for example and elected member or other member of the HWB to ensure physical activity is embedded in all strategies and policies that relate to health and wellbeing. |

# Agenda Item 7

| | London Borough of Hammersmith & Fulham<br>HEALTH & WELLBEING BOARD<br>9 September 2015 |
|---|---|
| **Better Care Fund Quarter 1 Submission** | |
| **Report of the Chair of Hammersmith and Fulham Clinical Commissioning Group** | |
| **Open Report** | |
| **Classification - For noting**<br>(delete as appropriate)<br>**Key Decision: No** | |
| **Wards Affected:** All | |
| **Accountable Executive Director:** Janet Cree, Managing Director, Hammersmith and Fulham Clinical Commissioning Group | |
| **Report Author:** Janet Cree, Managing Director, Hammersmith and Fulham Clinical Commissioning Group | **Contact Details:**<br>Tel: 020 3350 4368<br>E-mail:<br>janet.cree@nw.london.nhs.uk |

## 1. EXECUTIVE SUMMARY

1.1. The quarter one submission of the Better Care Fund deliverables against plan was submitted on 28 August. This is attached. The submission focusses on budget arrangements, the national conditions, payments for performance, income and expenditure to and from the Better Care Fund and performance on local metrics.

## 2. RECOMMENDATIONS

*2.1.* The Health and Wellbeing Board is asked to note the detail in the submission

## 3. REASONS FOR DECISION

*3.1.* N/A

## 4. INTRODUCTION AND BACKGROUND

4.1 The BCF is a single pooled budget for health and social care services to work closer in local areas, based on a plan agreed between the NHS and local authorities. The Better Care Fund came into effect this year. Quarterly returns on agreed parameters are required to be made in respect of the Better Care Fund.

## 5. PROPOSAL AND ISSUES

*5.1.* N/A

## 6. OPTIONS AND ANALYSIS OF OPTIONS

*6.1.* N/A

## 7. CONSULTATION

*7.1.* N/A

## 8. EQUALITY IMPLICATIONS

*8.1.* N/A

## 9. LEGAL IMPLICATIONS

9.1. N/A

## 10. FINANCIAL AND RESOURCES IMPLICATIONS

*10.1.* There are no financial implications over and above those already approved within the Better Care Fund programme.

## 11. RISK MANAGEMENT

11.1. N/A

## *12.* PROCUREMENT AND IT STRATEGY IMPLICATIONS

12.1. N/A

## LOCAL GOVERNMENT ACT 2000
## LIST OF BACKGROUND PAPERS USED IN PREPARING THIS REPORT

| No. | Description of Background Papers | Name/Ext of holder of file/copy | Department/ Location |
|---|---|---|---|
| 1. | None | | |

# Quarterly Reporting Template - Guidance

## Notes for Completion

The data collection template requires the Health & Wellbeing Board to track through the high level metrics and deliverables from the Health & Wellbeing Board Better Care Fund plan.

The completed return will require sign off by the Health & Wellbeing Board.

A completed return must be submitted to the Better Care Support Team inbox (england.bettercaresupport@nhs.net) by midday on 28th August 2015

This Excel data collection template for Q1 2015-16 focuses on budget arrangements, the national conditions, payment for performance, income and expenditure to and from the fund, and performance on local metrics. It also presents an opportunity for Health and Wellbeing to register interest in support. Details on future data collection requirements and mechanisms will be announced ahead of the Q2 2015/16 data collection.

To accompany the quarterly data collection Health & Wellbeing Boards are required to provide a written narrative into the final tab to contextualise the information provided in this report and build on comments included elsewhere in the submission. This should include an explanation of any material variances against planned performance trajectories as part of a wider overview of progress with the delivery of plans for better care.

## Content

The data collection template consists of 9 sheets:

**Validations** - This contains a matrix of responses to questions within the data collection template.
**1) Cover Sheet** - this includes basic details and tracks question completion.
**2) Budget arrangements**- this tracks whether Section 75 agreements are in place for pooling funds.
**3) National Conditions** - checklist against the national conditions as set out in the Spending Review.
**4) Non-Elective and Payment for Performance** - this tracks performance against NEL ambitions and associated P4P payments.
**5) Income and Expenditure -** this tracks income into, and expenditure from, pooled budgets over the course of the year.
**6) Local metrics -** this tracks performance against the locally set metric and locally defined patient experience metric in BCF plans.
**7) Understanding support needs -** this asks what the key barrier to integration is locally and what support might be required.
**8) Narrative** - this allows space for the description of overall progress on plan delivery and performance against key indicators.

## Validations

This sheet contains all the validations for each question in the relevant sections.
All validations have been coloured so that if a value does not pass the validation criteria the cell will be Red and contain the word "No" and if they pass validation they will be coloured Green and contain the word "Yes".

## 1) Cover Sheet

On the cover sheet please enter the following information:
The Health and Well Being Board
Who has completed the report, email and contact number in case any queries arise
Please detail who has signed off the report on behalf of the Health and Well Being Board.

Question completion tracks the number of questions that have been completed, when all the questions in each section of the template have been completed the cell will turn green. Only when all 8 cells are green should the template be sent to england.bettercaresupport@nhs.net

## 2) Budget Arrangements

This plays back to you your response to the question regarding Section 75 agreements from the 2014-15 Q4 submission and requires 2 questions to be answered. Please answer as at the time of completion. If you answered 'Yes' previously you can selection 'Not Applicable' this time.
**If your previous submission stated that the funds had not been pooled via a Section 75 agreement, can you now confirm that they have?**
**If the answer to the above is 'No' please indicate when this will happen**

## 3) National Conditions

This section requires the Health & Wellbeing Board to confirm whether the six national conditions detailed in the Better Care Fund Planning Guidance are still on track to be

It sets out the six conditions and requires the Health & Wellbeing Board to confirm 'Yes', 'No' and 'No - In Progress' that these are on track. If 'No' or 'No - In Progress' is selected please provide a target date when you expect the condition to be met. Please detail in the comments box what the issues are and the actions that are being taken to meet the condition.
'No - In Progress' should be used when a condition has not been fully met but work is underway to achieve it by 31 March 2016.
Full details of the conditions are detailed at the bottom of the page.

## 4) Non-Elective and Payment for Performance

This section tracks performance against NEL ambitions and associated P4P payments. The latest figures for planned activity and costs are provided along with a calculation of the payment for performance payment that should have been made for Q4. Three figures are required and one question needs to be answered:

**Input actual Q1 2015-16 Non-Elective performance (i.e. number of NELs for that period) - Cell L12**
**Input actual value of P4P payment agreed locally - Cell D23**
**If the actual payment locally agreed is different from the quarterly payment taken from above please explain in the comments box**
**Input actual value of unreleased funds agreed locally**

This section also requires indication of the area of spend that unreleased funds have been spent on for Q4 and Q1 using a drop-down list. If no funds were left unreleased then 'Not Applicable' should be selected.

## 5) Income and Expenditure

This tracks income into, and expenditure from, pooled budgets over the course of the year. This requires provision of the following information:

**Planned and forecast income into the pooled fund for each quarter of the 2015-16 financial year**
**Confirmation of actual income into the pooled fund in Q1**
**Planned and forecast expenditure from the pooled fund for each quarter of the 2015-16 financial year**
**Confirmation of actual expenditure into the pooled fund in Q1**

Figures should reflect the position by the end of each quarter. It is expected that planned income and planned expenditure figures for Q4 2015-16 should equal the total pooled budget for the Health and Wellbeing Board.

There is also an opportunity to provide a commentary on progress which should include reference to any deviation from plan.

## 6) Local metrics

This tab tracks performance against the locally set metric and locally defined patient experience metric submitted in approved BCF plans. In both cases the metric is set out as defined in the approved plan for the HWB and **the following information is required for each metric:**

**Confirmation that this is the same metric that you wish to continue tracking locally**
**Confirmation of planned performance for each quarter of 2015-16** (against the metric being tracked locally - whether the same as within your plan or not)
**Confirmation of actual performance for Q1 2015-16** (against the metric being tracked locally - whether the same as within your plan or not)
**Commentary on progress against the metric and details of any changes to the metric including reference to reasons for changing**

## 7) Understanding Support Needs

This asks what the key barrier to integration is locally and what support might be required in delivering the six key aspects of integration set out previously. This section builds upon the information collected through the BCF Readiness Survey in March 2015. HWBs are asked to:

**Confirm which aspect of integration they consider the biggest barrier or challenge to delivering their BCF plan**
**Confirm against each of the six themes whether they would welcome any support and if so what form they would prefer support to take**

There is also an opportunity to provide comments and detail any other support needs you may have which the Better Care Support Team may be able to help with.

## 8) Narrative

In this section HWBs are asked to provide a brief narrative on overall progress in delivering their Better Care Fund plans at the current point in time with reference to the information provided within this return.

# Better Care Fund Template Q1 2015/16

## Data collection Question Completion Validations

**Cover**

| Health and Well Being Board | completed by: | e-mail: | contact number: | Who has signed off the report on behalf of the Health and Well Being Board: |
|---|---|---|---|---|
| Yes | Yes | Yes | Yes | Yes |

**Budget Arrangements**

| S.75 pooled budget in the Q4 data collection? and all dates needed |
|---|
| Yes |

**National Conditions**

| | 1) Are the plans still jointly agreed? | 2) Are Social Care Services (not spending) being protected? | 3) Are the 7 day services to support patients being discharged and prevent unnecessary admission at weekends in place and delivering? | i) Is the NHS Number being used as the primary identifier for health and care services? | ii) Are you pursuing open APIs (i.e. systems that speak to each other)? | iii) Are the appropriate Information Governance controls in place for information sharing in line with Caldicott 2? | 5) Is a joint approach to assessments and care planning taking place and where funding is being used for integrated packages of care, is there an accountable professional? | 6) Is an agreement on the consequential impact of changes in the acute sector in place? |
|---|---|---|---|---|---|---|---|---|
| Please Select (Yes, No or No - In Progress) | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| If the answer is "No" or "No - In Progress" estimated date if not already in place (DD/MM/YYYY) | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Comment | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

**Non-Elective and P4P**

| Actual Q1 15/16 | Actual payment locally agreed | Comments | Any unreleased funds were used for: Q4 14/15 | Any unreleased funds were used for: Q1 15/16 |
|---|---|---|---|---|
| Yes | Yes | Yes | Yes | Yes |

**I&E (2 parts)**

| | | Q1 2015/16 | Q2 2015/16 | Q3 2015/16 | Q4 2015/16 | Please comment if there is a difference between the total yearly plan and the pooled fund |
|---|---|---|---|---|---|---|
| Income to | Plan | Yes | Yes | Yes | Yes | Yes |
| | Plan | | | | | |
| | Forecast | Yes | Yes | Yes | Yes | |
| | Forecast | | | | | |
| | Actual | Yes | | | | |
| | Actual | | | | | |
| Expenditure From | Plan | Yes | Yes | Yes | Yes | Yes |
| Expenditure From | Plan | | | | | |
| | Forecast | Yes | Yes | Yes | Yes | |
| | Forecast | | | | | |
| | Actual | Yes | | | | |
| | Actual | | | | | |
| | Commentary | Yes | | | | |

**Local Metrics**

| Same local performance metric in plan? | If the answer is No details |
|---|---|
| Yes | Yes |

| | Plan<br>Q4 14/15 | Plan<br>Q1 15/16 | Plan<br>Q2 15/16 | Plan<br>Q3 15/16 | Actual<br>Q4 14/15 | Actual<br>Q1 15/16 |
|---|---|---|---|---|---|---|
| Local performance metric plan and actual | Yes | Yes | Yes | Yes | Yes | Yes |
| Commentary | Yes | | | | | |

| Same local performance metric in plan? | If the answer is No details |
|---|---|
| Yes | Yes |

| | Plan<br>Q4 14/15 | Plan<br>Q1 15/16 | Plan<br>Q2 15/16 | Plan<br>Q3 15/16 | Actual<br>Q4 14/15 | Actual<br>Q1 15/16 |
|---|---|---|---|---|---|---|
| Local patient experience plan and actual | Yes | Yes | Yes | Yes | Yes | Yes |
| Commentary | Yes | | | | | |

**Understanding Support Needs**

| | |
|---|---|
| Area of integration greatest challenge | Yes |

| | Interested in support? | Preferred support medium |
|---|---|---|
| 1. Leading and Managing successful better care implementation | Yes | Yes |
| 2. Delivering excellent on the ground care centred around the individual | Yes | Yes |
| 3. Developing underpinning integrated datasets and information systems | Yes | Yes |
| 4. Aligning systems and sharing benefits and risks | Yes | Yes |
| 5. Measuring success | Yes | Yes |
| 6. Developing organisations to enable effective collaborative health and social care working relationships | Yes | Yes |

**Narrative**

| Brief Narrative |
|---|
| Yes |

**Cover and Basic Details**

**Q1 2015/16**

| | |
|---|---|
| **Health and Well Being Board** | **Hammersmith and Fulham** |
| **completed by:** | James Eaton |
| **E-Mail:** | jameseaton@nhs.net |
| **Contact Number:** | 02033504283 |
| **Who has signed off the report on behalf of the Health and Well Being Board:** | tbc |

**Question Completion - when all questions have been answered and the validation boxes below have turned green you should send the template to england.bettercaresupport@nhs.net saving the file as 'Name HWB' for example 'County Durham HWB'**

| | **No. of questions answered** |
|---|---|
| **1. Cover** | 5 |
| **2. Budget Arrangements** | 1 |
| **3. National Conditions** | 24 |
| **4. Non-Elective and P4P** | 5 |
| **5. I&E** | 21 |
| **6. Local metrics** | 18 |
| **7. Understanding Support Needs** | 13 |
| **8. Narrative** | 1 |

# Budget Arrangements

**Selected Health and Well Being Board:**

**Hammersmith and Fulham**

**Data Submission Period:**

**Q1 2015/16**

**Budget arrangements**

| | |
|---|---|
| Have the funds been pooled via a s.75 pooled budget? | No |
| If it has not been previously stated that the funds had been pooled can you now confirm that they have? | No |
| If the answer to the above is 'No' please indicate when this will happen (DD/MM/YYYY) | 30/09/15 |

**Footnotes:**

Source: For the S.75 pooled budget question which is pre-populated, the data is from the Q4 data collection previously filled in by the HWB.

# National Conditions

**Selected Health and Well Being Board:**

**Hammersmith and Fulham**

**Data Submission Period:**

**Q1 2015/16**

**National Conditions**

The Spending Round established six national conditions for access to the Fund.
Please confirm by selecting 'Yes', 'No' or 'No - In Progress' against the relevant condition as to whether these are on track as per your final BCF plan.
Further details on the conditions are specified below.
If 'No' or 'No - In Progress' is selected for any of the conditions please include a date **and** a comment in the box to the right

| Condition | Please Select (Yes, No or No - In Progress) | If the answer is "No" or "No - In Progress" please enter estimated date when condition will be met if not already in place (DD/MM/YYYY) | Comment |
|---|---|---|---|
| 1) Are the plans still jointly agreed? | Yes | | |
| 2) Are Social Care Services (not spending) being protected? | Yes | | |
| 3) Are the 7 day services to support patients being discharged and prevent unnecessary admission at weekends in place and delivering? | No - In Progress | 31/03/16 | Health has 7 day services in place in the form of a Rapid Response Nursing Service which accepts referrals from GPs and an In-Reach Team which diverts admissions from A&E. These services are in early stages of development across 3 CCGs. An annual target for reduction in NEL admissions has been set per CCG. A Lead Health Provider has been |
| 4) In respect of data sharing - confirm that: | | | |
| i) Is the NHS Number being used as the primary identifier for health and care services? | No - In Progress | 30/09/15 | A programme of work is underway to align IT systems across health and social care to enable use of NHS number as the primary identifier. A further update from programme team is due at end of Q2. |
| ii) Are you pursuing open APIs (i.e. systems that speak to each other)? | Yes | | |
| iii) Are the appropriate Information Governance controls in place for information sharing in line with Caldicott 2? | Yes | | |
| 5) Is a joint approach to assessments and care planning taking place and where funding is being used for integrated packages of care, is there an accountable professional? | No - In Progress | 31/03/16 | Health and Social care providers are working towards joint assessment forms and alignment of care plans. They are currently delivering shared care, with Hammersmith & Fulham being the most advanced in terms of fully integrated care within the three boroughs. Lead Providers have been tasked with delivery of a truly integrated service by 31.3.2016 and a programme plan is in place to achieve this and create equity of care across the three boroughs. |
| 6) Is an agreement on the consequential impact of changes in the acute sector in place? | Yes | | |

**National conditions - Guidance**

The Spending Round established six national conditions for access to the Fund:

**1) Plans to be jointly agreed**

The Better Care Fund Plan, covering a minimum of the pooled fund specified in the Spending Round, and potentially extending to the totality of the health and care spend in the Health and Wellbeing Board area, should be signed off by the Health and Wellbeing Board itself, and by the constituent Councils and Clinical Commissioning Groups. In agreeing the plan, CCGs and councils should engage with all providers likely to be affected by the use of the fund in order to achieve the best outcomes for local people. They should develop a shared view of the future shape of services. This should include an assessment of future capacity and workforce requirements across the system. The implications for local providers should be set out clearly for Health and Wellbeing Boards so that their agreement for the deployment of the fund includes recognition of the service change consequences.

**2) Protection for social care services (not spending)**

Local areas must include an explanation of how local adult social care services will be protected within their plans. The definition of protecting services is to be agreed locally. It should be consistent with 2012 Department of Health guidance to NHS England on the funding transfer from the NHS to social care in 2013/14:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213223/Funding-transfer-from-the-NHS-to-social-care-in-2013-14.pdf

**3) As part of agreed local plans, 7-day services in health and social care to support patients being discharged and prevent unnecessary admissions at weekends**

Local areas are asked to confirm how their plans will provide 7-day services to support patients being discharged and prevent unnecessary admissions at weekends. If they are not able to provide such plans, they must explain why. There will not be a nationally defined level of 7-day services to be provided. This will be for local determination and agreement. There is clear evidence that many patients are not discharged from hospital at weekends when they are clinically fit to be discharged because the supporting services are not available to facilitate it. The recent national review of urgent and emergency care sponsored by Sir Bruce Keogh for NHS England provided guidance on establishing effective 7-day services within existing resources.

**4) Better data sharing between health and social care, based on the NHS number**

The safe, secure sharing of data in the best interests of people who use care and support is essential to the provision of safe, seamless care. The use of the NHS number as a primary identifier is an important element of this, as is progress towards systems and processes that allow the safe and timely sharing of information. It is also vital that the right cultures, behaviours and leadership are demonstrated locally, fostering a culture of secure, lawful and appropriate sharing of data to support better care.

Local areas should:

- confirm that they are using the NHS Number as the primary identifier for health and care services, and if they are not, when they plan to;
- confirm that they are pursuing open APIs (i.e. systems that speak to each other); and
- ensure they have the appropriate Information Governance controls in place for information sharing in line with Caldicott 2, and if not, when they plan for it to be in place.

NHS England has already produced guidance that relates to both of these areas. (It is recognised that progress on this issue will require the resolution of some Information Governance issues by DH).

**5) Ensure a joint approach to assessments and care planning and ensure that, where funding is used for integrated packages of care, there will be an accountable professional**

Local areas should identify which proportion of their population will be receiving case management and a lead accountable professional, and which proportions will be receiving self-management help - following the principles of person-centred care planning. Dementia services will be a particularly important priority for better integrated health and social care services, supported by accountable professionals. The Government has set out an ambition in the Mandate that GPs should be accountable for co-ordinating patient-centred care for older people and those with complex needs.

**6) Agreement on the consequential impact of changes in the acute sector**

Local areas should identify, provider-by-provider, what the impact will be in their local area, including if the impact goes beyond the acute sector. Assurance will also be sought on public and patient and service user engagement in this planning, as well as plans for political buy-in. Ministers have indicated that, in line with the Mandate requirements on achieving parity of esteem for mental health, plans must not have a negative impact on the level and quality of mental health services.

# Better Care Fund Revised Non-Elective and Payment for Performance Calculations

| | |
|---|---|
| **Selected Health and Well Being Board:** | Hammersmith and Fulham |

| | Baseline | | | | Plan | | | | Actual | | | | | | | Planned Absolute Reduction (cumulative) [negative values indicate the plan is larger than the baseline] | | | | Maximum Quarterly Payment | | | | Performance against baseline | | | | Suggested Quarterly Payment | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Q4 13/14 | Q1 14/15 | Q2 14/15 | Q3 14/15 | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 | % change [negative values indicate the plan is larger than the baseline] | Absolute reduction in non elective performance | Total Performance Fund Available | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 | Total Performance fund | Total Performance and ringfenced funds | Q4 Payment locally agreed |
| **D. REVALIDATED:** HWB version of plans to be used for future monitoring. | 3,965 | 3,977 | 4,020 | 4,019 | 3,934 | 4,098 | 4,138 | 4,103 | 4,205 | 3,691 | | | -1.8% | -292 | £0 | 31 | -90 | -208 | -292 | £0 | £0 | £0 | £0 | -240 | 286 | | | £0 | £0 | | | £0 | £3,800,000 | £0 |

| | | | |
|---|---|---|---|
| Which data source are you using in section D? (MAR, SUS, Other) | SUS | If other please specify | |

| | |
|---|---|
| Cost per non-elective activity | £1,745 |

| | Total Payment Made | | | |
|---|---|---|---|---|
| | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 |
| Quarterly payment taken from above | £0 | £0 | | |
| Actual payment locally agreed | £0 | £0 | | |

| | |
|---|---|
| If the actual payment locally agreed is different from the quarterly payment taken from above please explain in the comments box (max 750 characters) | |

| | Total Payment Made | | | |
|---|---|---|---|---|
| | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 |
| Suggest amount of unreleased funds | £0 | £0 | | |
| Actual amount of locally agreed unreleased funds | £0 | £0 | | |

| | Q4 14/15 | Q1 15/16 | Q2 15/16 | Q3 15/16 |
|---|---|---|---|---|
| Confirmation of what if any unreleased funds were used for (please use drop down to select): | not applicable | not applicable | | |

**Footnotes:**

Source: For the Baselines, Plans, data sources, locally agreed payment and cost per non-elective activity which are pre-populated, the data is from the Better Care Fund Revised Non-Elective Targets - Q4 Playback and Final Re-Validation of Baseline and Plans Collection previously filled in by the HWB. This includes all data received from HWBs as at 10am on 19th August 2015.

# Plan, forecast, and actual figures for total income into, and total expenditure from, the fund for each quarter to year end (in both cases the year-end figures should equal the total pooled fund)

**Selected Health and Well Being Board:** Hammersmith and Fulham

**Income**

| | | Q1 2015/16 | Q2 2015/16 | Q3 2015/16 | Q4 2015/16 | Total Yearly Plan | Pooled Fund |
|---|---|---|---|---|---|---|---|
| Please provide , plan , forecast, and actual of total income into the fund for each quarter to year end (the year figures should equal the total pooled fund) | Plan | £16,833,972 | £16,833,972 | £16,833,972 | £16,833,972 | £67,335,886 | £80,155,000 |
| | Forecast | £16,833,972 | £16,833,972 | £16,833,972 | £16,833,972 | | |
| | Actual* | £16,833,972 | | | | | |

| | |
|---|---|
| Please comment if there is a difference between the total yearly plan and the pooled fund | The original submission includes S256 and existing NHS community services which are no longer part of the BCF currently being finalised |

**Expenditure**

| | | Q1 2015/16 | Q2 2015/16 | Q3 2015/16 | Q4 2015/16 | Total Yearly Plan | Pooled Fund |
|---|---|---|---|---|---|---|---|
| Please provide , plan , forecast, and actual of total expenditure from the fund for each quarter to year end (the year figures should equal the total pooled fund) | Plan | £16,833,972 | £16,833,972 | £16,833,972 | £16,833,972 | £67,335,886 | £80,155,000 |
| | Forecast | £16,833,972 | £16,833,972 | £16,833,972 | £16,833,972 | | |
| | Actual* | £16,833,972 | | | | | |

| | |
|---|---|
| Please comment if there is a difference between the total yearly plan and the pooled fund | The original submission includes S256 and existing NHS community services which are no longer part of the BCF currently being finalised |

| | |
|---|---|
| Commentary on progress against financial plan: | On Plan |

Footnote:

Actual figures should be based on the best available information held by Health and Wellbeing Boards.
Source: For the pooled fund which is pre-populated, the data is from a Q4 collection previously filled in by the HWB.

# Support requests

| | |
|---|---|
| **Selected Health and Well Being Board:** | Hammersmith and Fulham |

| | |
|---|---|
| Which area of integration do you see as the greatest challenge or barrier to the successful implementation of your Better Care plan (please select from dropdown)? | 5.Measuring success |

Please use the below form to indicate whether you would welcome support with any particular area of integration, and what format that support might take.

| Theme | Interested in support? | Preferred support medium | Comments - Please detail any other support needs you feel you have that you feel the Better Care Support Team may be able to help with. |
|---|---|---|---|
| 1. Leading and Managing successful better care implementation | No | [redacted] | |
| 2. Delivering excellent on the ground care centred around the individual | No | [redacted] | |
| 3. Developing underpinning integrated datasets and information systems | No | [redacted] | |
| 4. Aligning systems and sharing benefits and risks | No | [redacted] | |
| 5. Measuring success | No | [redacted] | |
| 6. Developing organisations to enable effective collaborative health and social care working relationships | No | [redacted] | |

# Support requests

|  |  |
|---|---|
| **Selected Health and Well Being Board:** | Hammersmith and Fulham |

|  |  |
|---|---|
| Which area of integration do you see as the greatest challenge or barrier to the successful implementation of your Better Care plan (please select from dropdown)? | 5.Measuring success |

Please use the below form to indicate whether you would welcome support with any particular area of integration, and what format that support might take.

| Theme | Interested in support? | Preferred support medium | Comments - Please detail any other support needs you feel you have that you feel the Better Care Support Team may be able to help with. |
|---|---|---|---|
| 1. Leading and Managing successful better care implementation | No |  |  |
| 2. Delivering excellent on the ground care centred around the individual | No |  |  |
| 3. Developing underpinning integrated datasets and information systems | No |  |  |
| 4. Aligning systems and sharing benefits and risks | No |  |  |
| 5. Measuring success | No |  |  |
| 6. Developing organisations to enable effective collaborative health and social care working relationships | No |  |  |

# Narrative

Selected Health and Well Being Board:

Hammersmith and Fulham

Data Submission Period:

Q1 2015/16

| Narrative | Remaining Characters | 31,316 |
|---|---|---|

**Please provide a brief narrative on overall progress in delivering your Better Care Fund plan at the current point in time with reference to the information provided within this return where appropriate.**

BCF/CIS Partnership working is progressing well from both provider and commissioner perspectives as evidenced by the Clinical Redesign Group and Partnership Board.  Service redesign and implementation work streams are working towards roll out of new structures in October.   Rapid response volumes increasing but more slowly than anticipated and further work will be undertaken with GPs across the three boroughs to increase engagement with the service.  In-Reach is working well and targets have been exceeded.  An approach to CIS Evaluation (due M9) has been  jointly developed across health, adult social care and public health.

It is becoming apparent that innovative approaches to integrated working (particularly in CIS transition) may take longer than expected to resolve. Implementation delays may impact on realisation of benefits targets in 15/16 meaning savings from joint commissioning and pooled budgets will be less than originally estimated.  ASC and health are agreeing measures to address the savings gap.

7 Day discharge pilot is being undertaken in eight wards, achieving positive results.  Options for further development identified for review with stakeholders across the system, and for agreement on next steps.  This will link with the integrated hospital discharge design service currently being formalised with adult social care, Imperial Healthcare and Chelsea & Westminster and CWHHE strategy team discharge plan.

**Joint Strategic Needs Assessment (JSNA) Steering Group**

27th July 2015

Rm 5.4, 15 Marylebone Road

## Minutes

| **In attendance** | |
|---|---|
| Daniela Valdés (DV) (chair) | Head of Planning and Governance, CLCCG |
| Stuart Lines (SL) | Deputy Director of Public Health |
| Meenara Islam (MI) | Principal Policy Officer, Westminster City Council |
| Jessica Nyman (JN) | JSNA Manager, Public Health |
| Steve Bywater (SB) | Interim Policy Manager, Children's Services |
| Mark Jarvis (MJ) | Company Secretary, Hammersmith & Fulham CCG |
| Shelley Gittens (SG) | Public Health Performance Manager |
| Angela Spence (ASp) | Kensington and Chelsea Social Council |
| Angela McCall (AM) (minutes) | Business Support Officer, Public Health |
| **Apologies**: Angeleca Silversides, Mike Rogers, Bridgitte Moess, Lisa Cavanagh, Colin Brodie | |

| Item | Action |
|---|---|
| **1. Welcome and introductions** | |
| **2. Minutes of last meeting and matters arising** | |
| SL met with Samar Pankanti (3 CCGs Public Health lead) last week and Samar is now invited to JSNA Steering Group meetings to strengthen the CCG links. | |
| Current attendance list to be reviewed to ensure that the meeting is pitched at the right level – DV. | DV to check quorum. |
| SL informed that the 3 Cabinet Members are concerned that the join up needs strengthening for the group and Health and Wellbeing Boards and CCGs. | AMc to let the H&WBB chairs have these minutes. |
| JN is going to the Hammersmith & Fulham CCG and West London CCG Governing Body Seminar and the Central London CCG Transformational Redesign Group to present on the JSNA and current work programme, and it | JN |

| | |
|---|---|
| is hoped to be a regular feature. | |
| **3. Overview of JSNA Project Plan**<br>- **Dementia JSNA sign-off**<br>This is about to be published after the next round of HWB meetings in September and will be presented by Lisa Cavanagh and Colin Brodie. This will be presented in parallel to the NWL Dementia Strategy for agreement of publication in September/early October. A local strategy for dementia is being created.<br>LBHF have decommissioned a memory clinic service and are recommissioning. MJ queried how this joined up with this JSNA.<br>This prompted discussion around how the JSNAs informed commissioning decisions.<br>MJ and DV advised that CCGs are pulling together their prospectus (commissioning intentions) for the following year. These will need to 'fit' with the work of this steering group.<br>- **Childhood Obesity JSNA**<br>This report is being redrafted, and a second draft will be circulated to wider stakeholders. It will go to the November H&WBB.<br>SL advised that H&F CCG Governing Body had expressed an interest in understanding referral pathways into the PH commissioned services better.<br>- **End of Life Care JSNA**<br>The data analysis has been shared with the End of Life Care Steering Group for comments. Interviews are currently taking place with stakeholders such as clinical leads and providers of End of Life Care services.<br>- **Housing: health and disability related housing needs**<br>This is finally underway after a prolonged scoping stage. The Task & Finish Group is being put together. Lead is Selina Douglas (ASC).<br>- **Evidence Hub**<br>SL is looking into back fill for TJ's position so he can focus on building the Evidence Hub. A prototype will be delivered on the JSNA portal including a supplement to the Childhood Obesity JSNA, and the JSNA Highlight Reports for each borough.<br>- **Westminster Needs Modelling project**<br>This project aims to develop a range of projections of need of the population in Westminster over the medium and long term. The projections will be informed by data relating to the demographic profile and disease profile of | PH childhood obesity programme manager to be advised |

| | |
|---|---|
| Westminster, including changes caused by long-term housing, regeneration and infrastructure plans. The final product is due to be presented to the Health and Wellbeing Board in March 2016.<br>This is being led by SL, AR and MI.<br><br>**Risks and issues**<br>• Capacity of public health intelligence team<br>• Governance of processes across the 3 boroughs | |
| **4. Engagement and alignment with Health and Wellbeing Boards/CCGs**<br>Discussion around the communication of knowledge and the findings of JSNAs that have been produced, and whether they are actually reaching the right people and informing commissioning decisions.<br><br>MJ commented that CCG priorities are shaped by the 5 Year Forward View, which could be included in prioritising and informing future JSNAs.<br><br>This group has been given delegated authority to make decisions on behalf of the H&WBB. As the JSNA Steering Group is a sub-committee of the Health and Wellbeing Board, they should be regularly reviewed at the HWB. Additionally, minutes need to reflect and escalate issues up to the HWBs. SL advised that minutes will now routinely be sent to HWBB chairs.<br><br>CCGs to present at the next JSNA Steering Group meeting and discuss the commissioning process and what are the key stumbling blocks that are faced at the moment. This will enable greater understanding about the systems and processes that take place within the CCG, therefore council teams will have a better understanding.<br><br>It was agreed that the decision to rotate the chair between CCG and council helps to share ownership, so DV will continue for the time being. | DV / MJ to organise<br><br>JN to add to the next agenda. |
| **5. JSNA Impact and Review (2013/14 programme – for information)**<br><br>ASp raised the importance of monitoring the impact of JSNAs and commissioning / strategy decisions and them being reported on a regular basis.<br><br>SL advised that the HWBB Chairs were keen to understand this and that a summary was being prepared. However, the review of the whole commissioning cycle is outside the capacity of the Public Health team so other options would need to be considered. On this note, MJ remarked it was unclear how the TB JSNA had been taken forward in terms of commissioning services.<br><br>Lesson learnt process to be reviewed for one of the areas within the impact paper. | JN - Invite a past project lead to discuss lessons learned at next meeting<br><br>JN to put MJ in contact with JSNA writer |

| | |
|---|---|
| **6. AOB Date of next meeting** | |
| Public Health and CCGs Memorandum of Understanding – Samar and Matthew Bazeley are discussing this with SL. | Copy of minutes to Samar |
| Angelica Silversides sent her apologies though registered her interest in contributing to the housing project. | |
| Public health / Local Authority colleagues are invited to hot desk at the CCG offices when coming for meetings, SL advised that the MoU discussions will help with this arrangement, colleagues are invited to contact DV for this to be arranged on a regular basis. | DV to arrange for seating for the PH team to work at Marylebone Road on the date of the next meeting or an ad hoc basis. |
| **Date of next meeting will be Wednesday 30th September at 2pm at 15 Marylebone Road.** | DV to continue chairmanship |