Newham London

Newham Joint Dementia Strategy 2015-2018

Living well with dementia in Newham

NHS
Newham Clinical Commissioning Group

CONTENTS

APPENDICES

Our Vision is

for people with dementia - and their families and carers - to be helped to live well with dementia, at all stages of the illness and with the support they need.

1. Introduction

1.1 This strategy has been developed in response to the National Dementia Strategy (2009), the Prime Minister's Challenge on Dementia (2015) and relevant changes in the law and local priorities. The strategy sets out how Newham Council, Newham Clinical Commissioning Group (NCCG) and their partners intend to support and enable the development of services that explicitly improve outcomes for people with dementia and their carers whilst also maximising efficiency and generating whole system savings. In line with the Care Act (2014), health and social care services will work towards integration in order to deliver high-quality outcomes for people with dementia and their family/carers, who have been consulted and whose feedback and recommendations have been used to inform the strategy.

1.2 We are responsible for the planning and commissioning of health and social care services on behalf of the local population. We are also responsible for ensuring that public monies are spent effectively and for achieving the best possible outcomes for people in Newham with dementia and their families/carers. This includes the delivery of high-quality, specialist and universal services in order to ensure that, whenever needed, people with dementia receive the best possible care and support in primary, community and secondary health, social care and housing services.

1.3 Our focus is on improving services for people in Newham with dementia, from early diagnosis and the prevention of unnecessary hospital and care home admissions, to facilitating early discharge from hospital and appropriate community support. This will include setting targets for reduction of activity in acute settings and identifying how best to use savings from acute care.

1.4 Increased investment in the identification of people with dementia has meant that greater numbers of people are being diagnosed with dementia, often at an early stage. This is creating greater demand for services that support people to live well with dementia. There is evidence that investing in this care and support can help prevent crises, avoid unnecessary hospital admissions and reduce the need for residential care.

1.5 An extensive mapping exercise has been carried out to identify what is currently being provided for people with dementia and their families/carers in Newham. This strategy will examine: current investment in dementia services; what is being achieved from this investment; how local services fit with the National Dementia Strategy and the Prime Minister's Dementia Challenge; and what we need to do locally to ensure that we achieve the best possible outcomes for people with dementia and their families/carers.

1.6 There are a number of themes that run through this strategy, including:

Dignity and Respect

Value for Money

Personalisation

PERSON-CENTRED PLANNING

Higher Quality of Care

Prevention

Independence, Choice and Control

Outcomes

1.7 This strategy is a key part of our vision in Newham to improve the outcomes for people with dementia. We have explained in this Introduction how and why the strategy has been developed. We now go on to explain: what dementia is; our long-term objectives (what we want to achieve); demographics (what we know about the population); funding, services and support (resources), consultation (what concerns people); service gaps; and what we plan to do (commissioning intentions).

2.What is dementia?

2.1 Dementia is the term used to describe a collection of symptoms caused by chemical and structural changes in the brain. Dementia is a progressive condition, which means that the symptoms will gradually get worse. The progression will vary from person to person – often, people have some of the same general symptoms but each will experience dementia in a different way.

2.2 Many people with dementia retain positive personality traits and personal attributes but as their condition progresses, they can experience some or all of the following: memory loss, language impairment, disorientation and wandering, changes in personality, decline in communication skills, difficulties with activities of daily living, self-neglect, psychiatric symptoms (e.g. apathy, depression or psychosis) and out-of-character behaviour (e.g. aggression, sleep disturbance or disinhibited sexual behaviour - although the latter is not typically the presenting feature of dementia).

2.3 Dementia is associated with complex needs and especially in the later stages, with high levels of dependency and morbidity. These care needs often challenge the skills and capacity of carers and services. As the condition progresses, people with dementia can present carers and staff with complex problems including aggressive behaviour, restlessness and wandering, eating and drinking problems, incontinence, delusions and hallucinations and mobility difficulties that can lead to falls and fractures. The impact of dementia on an individual may be compounded by personal circumstances, such as changes in financial status, living situation or bereavement.

2.4 Many people living with dementia are able to make decisions about their treatment and care. Professionals endeavour to respect their choices when working with them and their families. However, if people with dementia are struggling to make decisions, it may be necessary to assess their mental capacity. If they are found to lack capacity in relation to specific care decisions, a 'Best Interest' decision will be made. This will involve family members, professionals and others involved in the individual's care and will take into account their past and present wishes, values and beliefs.

2.5 Dementia can occur at any age but most commonly occurs in older people. One sixth of people over 80 years of age have a form of dementia[1]. Research is ongoing into the exact origin of these diseases. It is widely thought that the onset of dementia is caused by a combination of factors including age, lifestyle, medical history and genetic inheritance.

2.6 Types of dementia

Alzheimer's disease
The most common type of dementia. It changes the chemistry and structure of the brain, causing brain cells to die. It is used sometimes as a shorthand to cover all forms of dementia.

Vascular dementia
Caused by stroke or small vessel diseases that affect the supply of oxygen to the brain. Vascular dementia affects people in different ways, causing communication problems, stroke-like symptoms and acute confusion.

Dementia with Lewy bodies
Caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brain's normal functioning, affecting the person's memory, concentration and language skills.

Alcohol-related dementia
Caused by long-term excessive alcohol consumption which results in neurological damage and memory loss.

Fronto-temporal dementia
A rare form of dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65 years of age. In the early stages, the memory may remain intact, while the person's behaviours and personality change.

Early-onset/Young-onset/Working-age dementia
Terms used to describe the development of dementia in people aged under 65 years.

2.7 The spectrum of conditions referred to as Mild Cognitive Impairment (MCI) and Vascular Cognitive Impairment (VCI) are related but not equivalent to dementia. MCI is a descriptive term rather than a specific medical condition or disease. It describes memory loss apparent to the individual and those around them. The memory loss is supported by formal memory tests but other features of dementia are absent. VCI has been used as an umbrella term to include people affected with any degree of cognitive impairment resulting from cerebro-vascular disease, ranging from MCI to vascular dementia.

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[1] http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=100

3. Our vision and long-term objectives - what we want to achieve

3.1 Our vision is for all people in Newham with dementia, their families and carers to be helped to live well with dementia, at all stages of their illness and with the support they need. All people living with dementia in Newham should be able to say:

- **I was diagnosed early**
- **I am treated with dignity and respect**
- **I feel support as a carer**
- **I got the right information at the right time**
- **I can enjoy my life**
- **I am confident my end of life wishes will be respected**
- **I have choice and in control of my care**
- **I am supported to do the things and activities that I like**
- **I have GP support**
- **I get good support and breaks as a carer**
- **The care and support I receive is joined up**

Adopted from 'A call to Action: The National Dementia Declaration'[2].

3.2 Our long-term objectives are to achieve the following:

i Anyone with worries about their memory will be offered an assessment by their GP.

ii Following that assessment and if someone has memory problems impacting on their daily life, they will be referred to Newham's specialist diagnostic memory service.

iii Within three months of the referral: they and their GP will be notified of the diagnosis; a care co-ordinator will be identified; and the issue of advance care planning will be raised, in a sensitive manner, with them and where appropriate, with their families/carers.

iv Depending on the diagnosis, a year later, there will be follow up and further assessment by Newham Memory Services. At this and subsequent reviews, the issue of advance care planning will continue to be raised in a sensitive manner.

v Their care co-ordinator will be available to liaise with the 'accountable' GP and with dementia services to support them in living well with dementia.

vi As the disease progresses, the care co-ordinator may need to connect with more specialised dementia care and palliative care teams, with a view to ensuring that:

> "People approaching end of life receive consistent care that is co-ordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences."

Quality Statement 8, NICE Quality Standard for end of life care for adults.[3]

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[2] A call to Action: The National Dementia Declaration – www.dementiaaction.org.uk/nationaldementiadeclaration

[3] NICE Quality standard for end of life care for adults, August 2013: http://www.nice.org.uk/guidance/QS13

4. Demographics - what we know about Newham's population

4.1 According to the 2011 Census, Newham's population is 308,000 - an increase from 244,000 in the 2001 Census. The increase reflects major regeneration and increased migration into Newham over the past 10 years. The Newham population is expected to increase to nearly 350,000 by 2021, the second biggest population increase in London[4]. Because the population is increasing, we would expect there to be a proportional increase in the number of people with dementia. In 2012/13, the population registered on Newham GP lists (includes people living in neighbouring boroughs) was 375,864.

4.2 Newham has an unusually young age profile in comparison to the age profile for England, with a larger than average proportion of people aged under 10 years and 20 to 39 years and a correspondingly smaller than average proportion aged 40 years and above. People aged 65 years and over make up a relatively small proportion of the Newham population: in 2011, 6.7% of Newham's population were estimated to be aged 65 years and above, compared to 16.5% nationally[5]. Newham also has the most ethnically diverse community in England and Wales - 72% of the population are from African, African-Caribbean, Asian and minority ethnic groups[6] - with over 100 languages spoken. According to the Census 2011, the population over 65 years of age is 20,400 (11,300 women, 9,100 men)

4.3 The borough is uniformly poor with no significantly affluent areas. Overall, 27% of households have an annual income of less than £15,000, whilst only 6% of households have an annual income of over £60,000, compared to the London average of 15% and 15% respectively[7]. In addition, 30% of Newham's wards are among the 10% most deprived in the country, with Newham the second most deprived borough in London[8]. For more information on prevalence and the trends in demand for health and social care in Newham please refer to Newham's Market Position Statement[9].

4.4 Newham has poor health outcomes, including high mortality and poor mental health. Newham's premature mortality rates from circulatory diseases are the second highest in London and well above the national average[10]. Newham also has one of the highest levels of diabetes in the country, partly attributable to its ethnic mix (South Asian and African Caribbean people are more susceptible to developing the disease) and partly due to poor lifestyle choices. Newham also has exceptionally high levels of cardiovascular disease and stroke, whilst complex co-morbidities are common.

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[4] GLA Round Population Projections 2011

[5] The Office for National Statistics (2011): www.ons.gov.uk/ons/rel/npp/national-population-projections/2010-based-projections/stb-2010-based-npp-principal-and-key-variants.html

[6] ONS Census return and GLA Rounded population (2010)

[7] London Poverty Profile, Trust for London and New Policy Institute (2013)

[8] Newham Health and Wellbeing Strategy (2012)

[9] Newham Market Position Statement (2013)

[10] NCHOD

5. Dementia in Newham

5.1 The number of people diagnosed with dementia in Newham is estimated to be only a proportion of the total number. The term used to describe this is ‘prevalence’, defined as the expected or predicted number of people with dementia. The prevalence rate is the expected or predicted prevalence as a percentage of the population, at any one point in time.

5.2 Table 1 shows the current picture in Newham. In August 2014, the number of people in Newham with dementia (dementia prevalence rate) was 1,521, including 540 people with undiagnosed dementia. By 2031, the rate is forecast to rise by around 50% to 2,250.

5.3 The numbers recorded by GPs are gleaned through the national Quality and Outcomes Framework (QOF), which was introduced as part of the new General Medical Services (GMS) contract in April 2004. The objective of the QOF is to improve the quality of care that patients are given through an annual reward and incentive programme that details GP practice achievement results and rewards practices for the quality of care they provide to their patients. Participation by practices in the QOF is voluntary, though participation rates are very high. Table 2 provides an overview of Newham GP list size, dementia diagnosis and prevalence in 2014.

5.4 There are three QOF indicators covering dementia care:

- QOF Indicator DEM001: GPs establish and maintain a register of patients diagnosed with dementia.
- QOF Indicator DEM002: The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months.
- QOF Indicator DEM003: The percentage of patients with a new diagnosis of dementia recorded in the preceding 1 April to 31 March with a record of key medical functions recorded between six months before or after entering on to the register.

Table 1: Number of people in Newham with dementia

Domain	2011	2012	2013	2014
Number of people on QOF dementia register (number with a diagnosis) †	865	875	919	998
Estimated number of people with diagnosed and undiagnosed dementia (i.e. prevalence)	1,410	1,406	1,534	1,541

† Dementia Diagnosis rates: Number of people diagnosed with dementia is taken from data on NHS QOF indicator number DEM001.

Table 2: Dementia diagnosis and prevalence in Newham (2014)

Newham GP List Size (176,978 women, 196,008 men)	372,986
Patients in Nursing Homes	448
QOF Dementia Register	998
National Dementia Prevalence	1,532
Adjusted Dementia Prevalence	1,541
Adjusted Community Prevalence	1,283
Adjusted Nursing Home Prevalence	258
Estimated Number of People with Undiagnosed Dementia	543
Dementia Diagnosis Rate 2014/15 (Feb)	65.77%
Dementia Diagnosis Rate 2013/14	**62.7%**
Ambition Diagnosis Rate 2014/15	**66%**
Ambition Diagnosis Rate 2015/16	**68%**

Figures obtained using the NHS England National Dementia Prevalence Calculator[11]

5.5 Prior to 2013, Newham QOF data was recognised to be under-reporting in comparison with the Public Health estimate and the number of patients known to Newham NHS Memory Services. The Clinical Effectiveness Group (jointly run by Queen Mary University and Barts Health Trust) carried out an exercise in 2013/14, aimed at improving the quality of the QOF coding. This has resulted in improvement in the accuracy of data and shows an increase in diagnosed prevalence.

5.6 Although the increasing referral rate may be seen as a 'scooping up' of pre-existing cases of dementia/cognitive impairment, the fact that the rate of referral has yet to slow suggests that there is an under-estimation of both prevalence and incidence of dementia or a related impairment in Newham. Professionals in the borough think this is a reflection of Newham's poor vascular health and high level of stroke, which in turn causes vascular cognitive complications.

5.7 A national Dementia Enhanced Service (DES), covering primary care, has been implemented since 2013/14. The DES aims to promote early identification of dementia in high-risk groups. 59 GP practices (98%) in Newham have signed up for the DES. An updated DES has been introduced in 2014/15.

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[11] Dementia Prevalence Calculator v3 4th Edition, January 2014: http://dementiapartnerships.com/diagnosis/

5.8 Early onset dementia

5.8.1 The high proportion of people under 65 years in Newham's population means that, inevitably, there are a number of adults under 65 years with early onset dementia. Table 3 below shows actual and forecast figures for Newham[12].

Table 3: Early onset dementia in Newham

Age (years)	2010	2015	2020	2025
Men 30-64	25	26	28	29
Women 30-64	18	19	20	20
Total	**43**	**45**	**48**	**49**

5.8.2 Newham's primary care professionals will in future work closely with dementia diagnostic services to ensure that access to diagnosis and treatment is appropriate for all ages. In addition, Newham will be developing the market for residential services for people under 65 years with more advanced dementia.

5.9 Learning disabilities and dementia

5.9.1 According to the Centre for Disability Research, sustained and accelerating growth is predicted for the numbers of adults with profound and multiple learning disabilities (PMLD) in England between 2009 and 2026, with an average annual percent increase of 1.8%. The rate of increase grows markedly toward the latter end of the forecast period, due to increases in birth rates in the general population.

5.9.2 People with learning disabilities are at higher risk than the general population of developing dementia before the age of 65 and people with Down's syndrome are particularly affected. About 20% of people with a learning disability have Down's syndrome. This group of people often have complex needs, as dementia impacts upon their pre-existing psychological and physical health conditions.

5.9.3 Figure 1, below, summarises the age-related prevalence rates of dementia in people with Down's Syndrome, people with learning disabilities without Down's syndrome, and the general population. The figures are not exact but it is suggested that the trend represented in the figure is increasingly accepted. In particular, it is now well established that people with Down's syndrome appear to have a unique risk of developing dementia – usually Alzheimer's – at an early age. Amongst people with learning disabilities without Down's syndrome, the rates for developing dementia before the age of 65 are brought forward to a small degree compared to the general population – but not to the same extent as for people with Down's Syndrome – and the full range of causes of dementia is observed.

5.9.4 The numbers below show the Newham population forecasts based on learning disability as the primary need. Only a small proportion of the predicted population will be eligible for social care services but this indicates the growing need and demand:

2012	2014	2016	2018	2020
5,310	5,437	5,545	5,630	5,697

Source: PANSI (Projecting Adult Needs and Service Information), Institute of Public Care, Oxford Brookes University.

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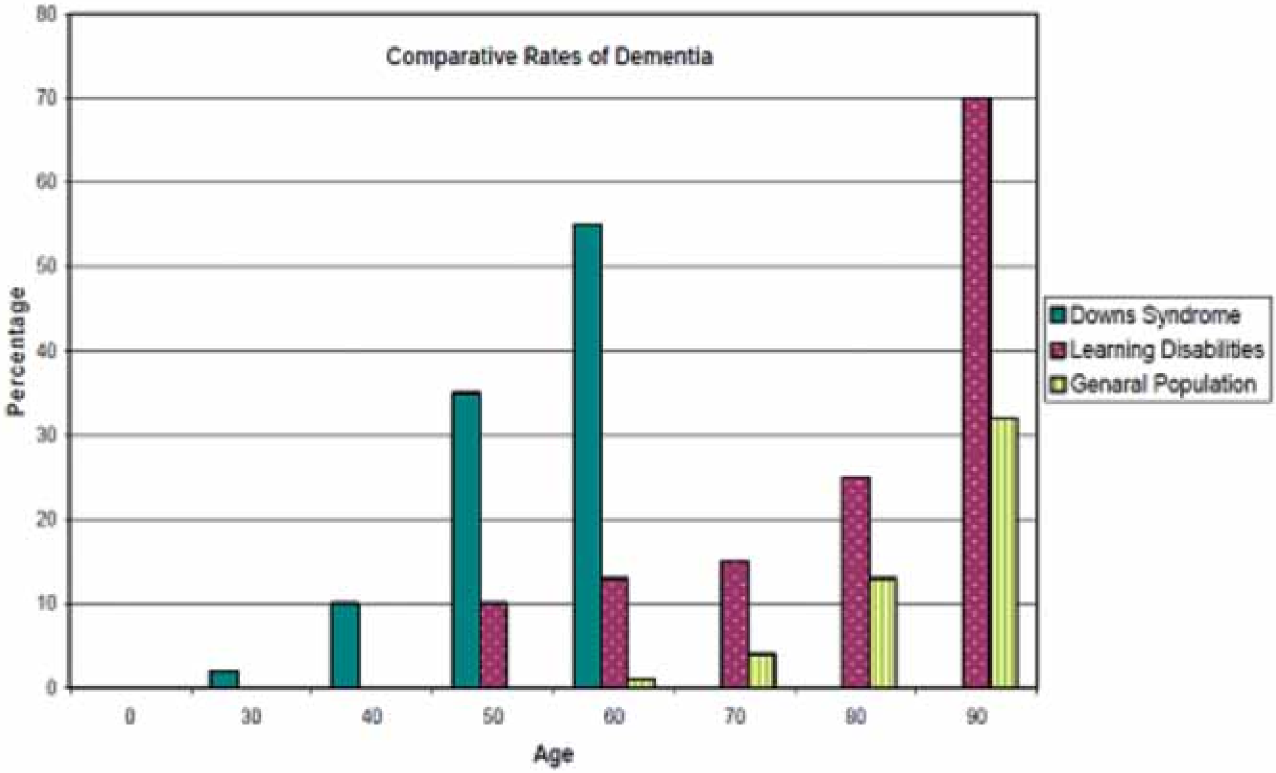
[12] This table is based on the Alzheimer's Society report, Dementia UK - the full report. This is a 2007 report into the prevalence and cost of dementia, prepared for the Alzheimer's Society by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London.

Figure 1: Comparative rates of dementia for Down's syndrome, learning disabilities and the general population



Source: Cooper S.A. (1997) and BPS and RCP 2009

5.9.5 According to Newham Adult Social Care data in March 2013, 775 people with learning disabilities and over 180 people with autistic spectrum disorders were known to services. According to 2013 Newham QOF data, 995 people with learning disabilities aged 18 years and above were registered with Newham GPs (includes people not eligible to receive social care services and those living in neighbouring boroughs but registered with Newham GPs).

5.9.6 There are 83 adults with Down's Syndrome known to Newham Health Team for People with Learning Disabilities, of whom:

- five have a confirmed diagnosis of dementia
- two have possible early signs
- 22 others are screened every two to five years, depending on their age
- 54 under the age of 40 years have not yet been screened.

The team knows of one person with learning disabilities without Down's Syndrome who has a confirmed diagnosis of dementia and five others who have possible early signs.

5.9.7 The projected number of young people transferring from Children's Services to Adult Social Care in 2014/15 is 22. Most of these young people will have complex disabilities, including learning disabilities, autism, challenging behaviour and health issues.

5.10 Alcohol-related dementia

5.10.1 It is estimated that up to 10% of dementias are related to alcohol misuse.[13] Services to support people with alcohol-related dementia frequently fall between standard dementia care services and alcohol harm-reduction services.

5.10.2 Standard dementia care services are unlikely to meet the needs of an individual who misuses alcohol, particularly if the individual is still in an acute phase of drinking, whilst standard alcohol harm-reduction services are designed to meet the needs of those who wish to stop misusing alcohol.

5.10.3 A small number of people with long-term alcohol issues and dementia are likely to be dependent on social and health care services and requiring residential or nursing/medical care in a supported environment. Their needs are taken into account in this strategy

5.11 Families and carers

5.11.1 Caring for someone with dementia is a demanding job and families/carers need support. In Newham, families/carers follow people with dementia along a common pathway. Families/carers have access to support from pre-diagnosis to diagnosis and post-diagnosis services such as one-to-one psychotherapy, carers support groups and Cognitive Stimulation Groups provided by Psychotherapy for Older Adults. The Newham Carers Strategy outlines the specific support services available across the borough to families/carers.

5.12 Preventing dementia

5.12.1 Dementia in later life affects individuals, families and society as a whole, causing reduced quality of life, ill-health and premature mortality. It has a direct effect on community resources, because people are less able to do their usual daily activities and often need support and long-term care. This effect is set to increase in the future as the population ages.

5.12.2 The beginnings of ill health can occur in mid-life. Reported changes include the start of a decline in various cognitive functions (such as memory, reasoning and verbal fluency) by age 45 years (Newman et al. 2011; Singh-Manoux et al. 2011). Some limitations in mobility have been identified in 18% of men and 19% of women aged 50–64 years in England.

5.12.3 Indications are that mid-life approaches to preventing or delaying dementia, disability and frailty can be effective. The aim is to increase the number of older people who can lead independent, healthy and active lives by:

- reducing the prevalence of behaviours that increase the risk of dementia, disability and frailty
- reducing the incidence of dementia, disability and frailty and delaying their development in people who experience them
- reducing the incidence of a range of other chronic non-communicable conditions in later life that can contribute to disability and frailty (such as cardiovascular diseases, diabetes, chronic obstructive pulmonary disease, and some cancers).

5.12.4 This can be done by promoting change in various behaviours aimed at: encouraging people to stop smoking; helping them to become more physically active; helping them to reduce their alcohol consumption; and helping them to improve their diet and, where necessary, lose weight and maintain a healthy weight.

5.12.5 Sensory impairment, including hearing loss and visual impairment, is estimated to be responsible for 7–10% of all years lived with disability among those aged 70 years or over in the UK. The odds of people with hearing loss or visual impairment developing dementia or

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[13] Living well with dementia: the National Dementia Strategy – Joint commissioning framework for dementia

Alzheimer's disease are more than double those of people with good hearing and vision (CMO annual report: Surveillance volume 2012, On the state of the public's health, March 2014).

5.12.6 Between 2003 and 2008, the greatest reduction in the number of adults in the general population displaying four behavioural risk factors (smoking, lack of physical activity, consuming alcohol, and poor diet) was seen in higher socioeconomic and more highly educated groups. People from unskilled households were three times more likely to adopt behavioural risk factors that put them at greater risk than people in professional groups[14].

5.12.7 Life expectancy continues to increase in the UK, but this increase is not necessarily extra years spent in good health and free of disability. By 2035, it is estimated that 23% of the population will be aged 65 or over[15].

5.12.8 The incidence of dementia increases with age. Increases in life expectancy and in the proportion of older people in the UK population suggest that dementia incidence would also rise. However, data suggests that the incidence of dementia in 2011 was lower than had been predicted from the 1991 data. This finding is consistent with findings from other high income countries. The lower incidence is attributed to a reduction in risk factors, for example smoking, and societal changes such as better education (Matthews et al., 2013).

5.12.9 However, in 2012 around 800,000 people in the UK were living with some form of dementia. More than 17,000 of these people were under 65 years of age. Around 11,500 people were from black and minority ethnic groups. Family and friends were acting as primary carers for about 670,000 people. In 2012 the annual cost of dementia to the NHS, local authorities and families was estimated to be £23 billion[16].

5.12.10 Having two or more chronic conditions (multi-morbidity) is common among people aged 65 and older. However, there are more people under 65 than over 65 with multi-morbidity (Barnett et al. 2012; Agborsangaya et al. 2012). Multi-morbidity is associated with low socioeconomic status and it can begin 10–15 years earlier in people living in the most deprived areas than in those living in the most affluent ones (Barnett et al. 2012). Multi-morbidity is also associated with low educational attainment (Nagel et al. 2008). Therefore, risk reduction may need to occur earlier in life in some disadvantaged groups.

5.13 Diagnosing dementia

5.13.1 The Government's goal is that the diagnosis, treatment and care of people with dementia in England should be among the best in Europe.

5.13.2 NHS England agreed a national ambition for diagnosis rates that, by 2015, two-thirds of the estimated number of people with dementia in England should have a diagnosis, with appropriate post-diagnosis support. Better dementia diagnosis will improve the lives of people with the condition and give them, their carers and professionals the confidence that they are getting the care and treatment they

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[14] Clustering of unhealthy behaviours over time. Implications for policy and practice. The King's Fund (2012)

[15] Health expectancies at birth and age 65 in the United Kingdom. 2008–10 Office for National Statistics, (2012)

[16] Alzheimer's Society's Dementia 2012 report

need. NHS England is working with CCGs to support local proposals for making the best treatment available across the country.

5.13.3 A dementia diagnosis resource pack has been produced to support NHS commissioners and general practices to design and implement dementia diagnosis improvement plans. This is based on 10 key steps to improving diagnosis and diagnosis pathways and is accompanied by a range of resources, tools, and examples of innovation and positive practice. The resource pack is available at the Dementia Partnerships knowledge portal[17].

5.13.4 According to a national survey by the Alzheimer's Society[18] into the numbers of people with dementia in 2011 and 2012 in local health areas, Newham has one of the highest rates of detection: thirteenth in the UK and third in England & Wales.

5.14 Prescription of anti-psychotic and anti-dementia drugs

5.14.1 The publication in 2009 of the Banerjee report[19] highlighted increasing concern about the over-prescription of anti-psychotic medication in the NHS. The report's key recommendations were that each PCT should 'commission from specialist older people's mental health services' and 'support primary care in its work in care homes and in the community'. Commissioners in Newham are working closely with GPs and residential and nursing homes to reduce the level of anti-psychotics and to promote the effective use of non-pharmaceutical solutions. Newham CCG currently commissions the Older People's Community Mental Health Team, a specialist service that has taken the lead on reducing the use of anti-psychotic medication.

5.14.2 Primary care prescribing of anti-psychotic medication in Newham has been audited using the NHS London antipsychotics audit tool. In August 2014, of the 981 people in Newham on the QOF dementia register (i.e. with a diagnosis), 16 were patients open to secondary mental health with a diagnosis of dementia and prescribed anti psychotic drugs.

5.14.3 The cost per patient of anti-dementia medication (previously £2.50 per day) has plummeted in the last year since the introduction of generic options that have replaced specialist medications. Newham Memory Services (NMS) have a shared-care protocol with GPs, whereby NMS prescribe for the first six to 12 weeks, after which prescribing is continued by GPs.

5.14.4 People aged over 65 years face a one in 14 chance of developing dementia, and those aged over 80 years face a one in six chance. Only 30% of people in the UK with Alzheimer's disease who are entitled to anti-dementia drugs actually receive them. Acetyl-cholinesterase inhibitors (AChEIs) provide symptomatic relief and may slow the progression of cognitive decline. Memantine is an option for managing moderate Alzheimer's disease in those who should not take AChEIs. All anti-dementia drugs need retitration if more than seven days of doses have been missed. The efficacy for each patient of anti-dementia drugs prescribed over the long-term needs to be regularly reviewed.

5.15 Hearing loss and dementia

5.15.1 Hearing loss is widespread and the single biggest cause is age-related damage. Some research has shown that people with hearing loss are more likely to develop dementia but the exact reasons for this are unclear. Both hearing loss and dementia can make communication more difficult and result in social isolation. If a person's hearing loss is managed well, this can help them cope better with their dementia.

5.15.2 We are learning more about the particular issues faced by deaf people with dementia but still there is no real concept of what 'living well

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[17] http://dementiapartnerships.com/diagnosis/resource-pack/

[18] Mapping the Dementia Gap 2012: Progress on improving diagnosis of dementia 2011-2012, Alzheimer's Society

[19] 'The Use of Antipsychotic Medication for People with Dementia: Time for action - A report for the Minister of State for Care Services' - Professor Sube Banerjee'

with dementia' means for deaf people nor what appropriate services might consist of. The early signs of dementia are often missed in deaf people because of problems with communication. There is very little information available in BSL about dementia and general knowledge about dementia in the deaf community is poor.

5.15.3 There is a strong link between hearing loss and dementia. According to one study, people with mild hearing loss are twice as likely to develop dementia and this increases to three times for those with moderate hearing loss (Lin et al, 2011). The reasons for this relationship are not clear but communication difficulties may be one reason, as both hearing loss and dementia can make communication more difficult.

5.15.4 Few support services for people with dementia and their carers are accessible for deaf people. It is essential to recognise and respond sensitively to hearing loss in people with dementia. If a person with dementia is unable to communicate problems they are having with their hearing, this is likely to cause distress. They may well become frustrated or aggressive, but unable to say why – these reactions may then be interpreted as resulting from the dementia.

5.15.5 Both hearing loss and dementia can cause social isolation and this is likely to be compounded when someone is experiencing both. For example, the person may be unwilling to attend social functions or participate in activities because their problems with hearing and memory make social situations much more uncomfortable.

5.16 Sight loss and dementia

5.16.1 Sight loss is very common among older people but can be missed because the symptoms may be misinterpreted as resulting from dementia. It is important to understand the signs and symptoms of sight loss and ensure that older people have regular eye examinations. There are many ways in which communication can be improved with people with sight loss and dementia, e.g. by ensuring that the correct and clean glasses are worn for activities undertaken. Environmental improvements, specialist equipment and technology can support people with sight loss and dementia to be more independent.

5.16.2 When a person has dementia and sight loss, many routine things – such as getting out and about, communicating and day-to-day living – become more difficult than if the person has only one of these conditions. Dementia combined with sight loss can lead to: profound disorientation and isolation; increased risk of falls; difficulties moving between light and dark spaces; difficulties learning to use new equipment; less independence; misperception and misidentification of people, articles and activities; anxiety and worry for carers and relatives.

5.16.3 A common problem for people with dementia is misinterpreting visually what they are seeing, e.g. a face in a patterned curtain or a shadow on the floor may be interpreted as a hole in the ground. Simple adjustments to lighting or décor may be able to stop this from occurring. People with sight loss can experience visual hallucinations, a common condition among people who have lost their sight, causing them to see things that aren't really there, e.g. Charles Bonnet Syndrome[20]. Sight loss can increase the risk of someone with dementia experiencing hallucinations. When supporting someone with sight loss and dementia, it is important to know whether, in the past, they experienced hallucinations related to sight loss.

5.16.4 People with certain types of dementia, e.g. dementia with Lewy bodies, Parkinson's Disease dementia and Alzheimer's Disease, may also experience hallucinations caused by the dementia but still have healthy eyes. Having a sight test can help to rule this out.

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[20] http://www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/charles-bonnet-syndrome

5.17 Dementia care pathway

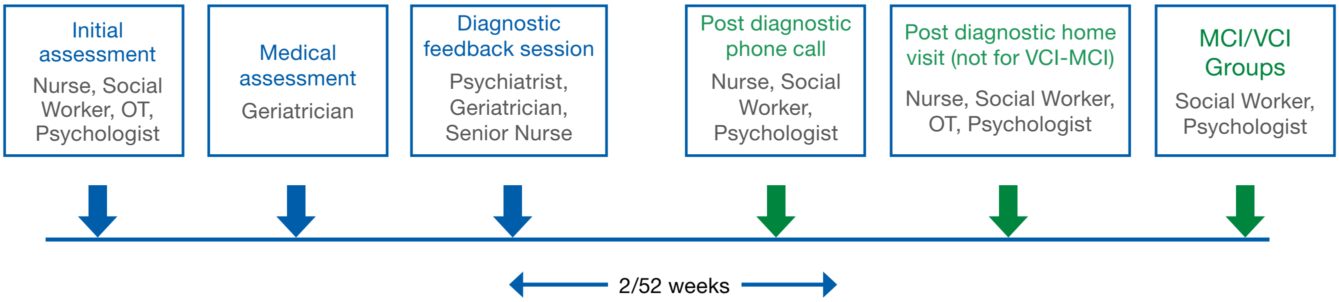
5.17.1 NICE, the National Institute for Health and Care Excellence, has produced guidance on a national dementia pathway, covering the following areas:

1. Dementia
2. Principles of care
3. Risk factors and prevention
4. Early identification
5. Diagnosis and assessment (+ sub-pathways)
6. Promoting choice
7. Providing support
8. Integrated and co-ordinated care and service provision
9. Promoting independence and maintaining function
10. Interventions (+ sub-pathways)
11. Living arrangements and care home placements
12. Inpatient care and care in an acute hospital
13. Palliative and end-of-life care
14. Staff training
15. Support for carers

5.17.2 A Newham-wide dementia care pathway is being developed, coupled with the establishment of Integrated Care. The dementia care pathway shown in Figure 2 below currently applies to Newham Memory Services.

Figure 2: Dementia care pathway within Newham Memory Services

The (abbreviated) Newham Dementia Care Pathway. Opportunities for helping people make decisions about LPAs



6. Funding and resources (dementia specific)

6.1 2014/15 funding

Nationally, NHS and social care dementia care costs are approximately equivalent. In Newham, we have been able to identify Adult Social Care costs of over £11 million. However, local NHS dementia care costs are much harder to quantify, beyond the Newham CCG budget of over £2 million for specific services. This is because so much of the health care is provided through generic services (e.g. community nursing). All we can confidently say is that dementia care currently costs Newham over £13.5 million per annum. The actual cost is likely to be at least £22 million.

		£'000	**£'000**
NHS England	Dementia Enhanced Service in Newham	189.14	**189.14**
CCG:	ELFT Newham Memory Services	813.46	
	ELFT community health services (inc DNs)	TBC	
	BHT – NUH A&E (High Risk & Very High Risk)	276.12	
	BHT - Other	TBC	
	Continuing Healthcare:		
	100% NHS funding	119.98	
	Joint funding	138.18	
	Funded Nursing Care	884.60	
	CCG total		**2,232.34+**
LBN:	Personal budgets	1,146.00	
	Home care	1,845.00	
	Samuel Boyce Centre (SBC)	778.00	
	Independent sector day centres	173.00	
	Supported and other accommodation	189.00	
	Care home placements	6,857.00	
	Newham Memory Services (Forget Me Not)	80.00	
	Memory Support Services (Alzheimer's Society)	43.00	
	Carers breaks	165.59	
	LBN total		**11,276.59**
Voluntary Sector:	Alzheimer's Society (Tudor Trust – ends 09/2015)	28.00	
	SubCo (Mercers Charitable Trust – ends 03/2015)	11.75	
	Voluntary Sector total		**39.75**
	TOTAL IDENTIFIABLE EXPENDITURE ON DEMENTIA		13,737.82+

6.2 Resources - services and support

6.2.1 Since its inception in 2002, Newham Memory Services have recorded a year-on-year increase in the number of referrals and diagnosis of dementia or cognitive impairment. Table 4 outlines the service staus for 2013/14.

Table 4: Newham Memory Services (NMS) Referrals

Referral status	2013/14	2014/15
Total number of referrals received	n/a	719 *
DAS referrals received	665	1029
DAS referrals accepted	652	891
DAS referrals refused	13	138
DAS discharges	1,442	896
DAS open referrals at 31 March	236	280
DCT referrals received (people with a diagnosis)	n/a	572
DCT referrals accepted	n/a	572
DCT referrals refused	n/a	0
DCT discharges	n/a	551
DCT open referrals at 31 March	116	145
Total number assessed	n/a	371 *
People waiting for a first appointment at 31 March	45-50	94 *
Referral to diagnosis waiting time	n/a	5.5 wks *
Treatment to diagnosis waiting time at 31 March	n/a	4.7 wks *
Assessed & into treatment	n/a	262 *

DAS: Diagnostic and Assessment Service (Memory Clinic)
DCT: Dementia Care Team

*January 2015 projection

- All people with a diagnosis of dementia had a follow-up appointment.
- Most people had a first appointment within the first four weeks of referral. No one waited longer than 11 weeks. For those who waited more than four weeks, there was a narrative to explain the wait, e.g. patient was out of the country; patient was referred while in hospital and awaiting a post-discharge review.

> "When a memory clinic begins, it gathers in many existing (i.e. prevalent) cases of dementia and is not simply assessing cases by incidence. However, a clinic that promotes itself for diagnosis of all possible dementias can narrow or almost eliminate the diagnosis gap – as in Newham, where over 2,000 cases have been diagnosed 2002-2009. This exceeds incidence. The 2009-10 Newham figure of 330 completed assessments also exceeds predicted incidence (at 270) but presumably there is still some 'scooping up' of previously undiagnosed"[21]

6.2.2 In 2013/14, 315 adults whose primary need was identified as dementia were Adult Social Care customers, including an average of 88 per week attending the Samuel Boyce Centre (dementia day service). Overall, 13 people were in the 18-64 years age bracket and 302 people were aged 65+ years. Service usage was as follows (some customers used more than one service):

Service	18-64 years	65+ years
Community-based	9	228
Residential care	2	73
Nursing care	3	47

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[21] Sean Haldane - 'Memory Assessment Services in East London', 2010.

Community based services were used as follows:

Service	18-64 years	65+ years
Home care	8	137
Day care	4	96
Meals	0	0
Short term residential (exc respite)	2	20
Direct payments	1	38
Professional support	0	0
Equipment & adaptations	3	135
Other	4	71

6.2.3 Older people's mental health services across Inner North East London were redesigned in 2012. Whilst reducing inpatient diagnostic services to one ward based at Mile End Hospital (Barts Health Trust), community services in Newham were increased to include:

- Older People's Mental Health Liaison Service in Barts Health Trust - Newham University Hospital (prompted by the NHS Confederation's 2010 document, 'Acute awareness - Improving hospital care for people with dementia').
- Improved diagnostic services to increase early identification of dementia.
- Dementia training programmes for health and social care staff.

This additional community resource is ensuring earlier recognition and referral for dementia across age and ethnic groups.

6.2.4 A national Dementia CQUIN (Commissioning for Quality and Innovation) for acute services is aimed at improving dementia care, including sustained improvement in finding people with dementia, assessing and investigating their symptoms and referring for support. The CQUIN is designed to: incentivise the identification of people with dementia and other causes of cognitive impairment alongside their other medical conditions; prompt appropriate referral and follow up after they leave hospital; and to ensure that hospitals deliver high quality care to people with dementia and support to their carers. In 2013/14, Newham University Hospital (part of Barts Health Trust) performed at 85.6%, with an estimated delivery value of £14,469k.

6.2.5 An additional national Dementia CQUIN has been introduced in 2014/15 for community dementia services, which applies to Newham Memory Services. This CQUIN is focused on 'Person-centred care' and aimed at supporting people with dementia to complete advance care plans.

7. Consultation – what people told us

7.1 Between March and July 2014 in five different venues, over 150 people with dementia, some accompanied by carers were consulted by asking the following questions:

- What should a good dementia service look like?
- What is more important for you?

7.2 Detailed feedback from the consultations is set out in Appendix A1 of this strategy. The common themes that emerged were:

1. **Awareness:** Need to raise awareness amongst professionals and volunteers.
2. **Diagnosis:** Early and speedy diagnosis essential – more needed.
3. **GPs:** Attitudes – not listening, not taking patients & families seriously, not allowing enough time. Appointments - difficulties with getting one even when urgent. Registration -

patients not accepted or removed “because they have so many problems and take a lot of GP time”.

4. **Information:** Needs to be more easily available and accessible, particularly for people living alone and for carers.
5. **Isolation:** Isolation and loneliness are real killers.
6. **Services:** LBN telephone system is confusing, especially for people with dementia - difficult for people with dementia to contact the right officer. Telephone assessments are inappropriate for people with dementia. More services needed - day centres can provide everything needed, including stimulation and social contact - reducing loneliness and depression. Care workers don’t understand dementia and its impact and they take advantage by arriving late and not staying the allocated time - people are frightened to report them.
7. **Support:** Support needed to continue doing the things that are important and to stay living at home as long as possible. Need more befriending services and friends/neighbours able to offer the right support. Support needed to have choice and control in the type of services available. Carers want to continue providing care but need support, including respite, that they can access immediately, when things get difficult.
8. **Training:** Professionals (including hospital staff) need education about the typical behaviours of dementia. Carers need training to continue providing effective support.
9. **Transport:** More Dial-a-Ride needed.

7.3 Newham Co-Production Forum commented on the commissioning intentions in Section 9, below. Their comments are included in Appendix 1.

8. Service improvements to be considered

Many of the following areas of service improvement have been identified through consultation with people with dementia and their families/carers:

1. Dementia awareness amongst professionals and volunteers.
2. Early and speedy diagnosis.
3. Pre- and post- diagnosis support.
4. Diagnosis and support that is sensitive to the needs of people with pre-existing support needs, e.g. learning disabilities, sensory loss.
5. GPs: more sympathetic attitude, flexible appointment systems, longer appointments.
6. More easily available and accessible information.
7. Benefits advice and advocacy for people with dementia and their families/carers who are hard to reach.
8. Community language interpreters / bilingual health advocates to enable families/carers to explain symptoms.
9. More straightforward methods of contacting the council.

10. Face to face social care assessments for people with dementia.
11. More day centre provision.
12. Local cultural activities for people with dementia from Asian communities.
13. More befriending services.
14. Easy access to support and respite for carers.
15. Closer monitoring of care workers.
16. Training/education of professionals (including GPs and hospital staff) and carers.
17. Specialist residential provision for people with Korsakoff's syndrome.
18. Appropriate support for people with early onset dementia.

9. Commissioning Intentions - what we plan to do

G General

G.1 The overall commissioning goal for the life of this strategy is for people with dementia – and their families and carers – to be helped to live well with dementia, at all stages of the illness and with the support they need.

G.2 GPs, primary care professionals, Newham Memory Services, Alzheimer's Society and Newham Council will work collaboratively with families, carers and care homes to identify people with dementia.

G.3 A comprehensive dementia care pathway in Newham will be developed, ensuring appropriateness for people with additional needs, eg learning disabilities, sensory loss.

G.4 Relatives/carers will be involved at all stages of the dementia care pathway, as appropriate.

G.5 Improved, integrated care services for people with dementia will help to prevent unnecessary hospital admissions and facilitate early discharge from hospital, through appropriate support at home.

G.6 Specialist and universal services and support will help to achieve the best possible outcomes for people with dementia and their families/carers.

G.7 People with dementia will receive high-quality care and support in primary, community and secondary health care, plus social care and housing services.

G.8 Pre- and post-diagnosis social care support for individuals and their families/carers will be in place.

G.9 People with dementia will have equal access to personal budgets and enablement services, with services taking account of fluctuating needs.

G.10 The needs of people in Newham with dementia will be addressed in future proposals for extra-care housing and housing-related support.

G.11 A set of outcomes and an action plan, aimed at improving the lives of people with learning disabilities and dementia and their families, will be co-produced and agreed by all key stakeholders.

G.12 Joint NHS/local authority working arrangements and integrated care services will be developed through the Integrated Care strategy, with GPs as the responsible physicians, supported by team with skills in dementia care.

G.13 Newham will become a community working to help people live well with dementia, in response to the Prime Minister's challenge on dementia.

G.14 The national Dementia Friends campaign will be promoted, with the aim of improving local people's understanding of dementia and its effects.

G.15 The use of appropriate telecare and other assistive technologies will be developed - together with a market for self-purchase - to enable people with dementia to continue living safely in the community for as long as possible.

G.16 Mid-life approaches to preventing, delaying and reducing the incidence of dementia will be developed, with the aim of increasing the number of older people who can lead independent, healthy and active lives (successful ageing) by reducing the prevalence of behaviours that increase the risk of dementia.

S Specific

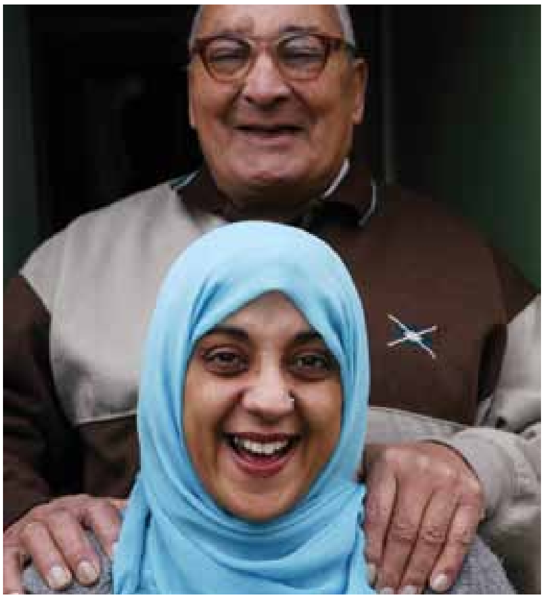
S.1 Preventing dementia

i Consider how the NHS Health Checks programme can be developed to promote opportunities in mid-life to reduce the risk of dementia, disability and frailty. Tailor the advice component of the NHS Health Check programme for different age groups and add dementia prevention advice to all health checks.

ii Use routine appointments and contacts (e.g. appointments with a GP or practice nurse or at leisure centres) to identify people at risk of dementia and give advice on how to reduce the risks.

iii Provide multi-component online interventions (web- and app-based) to help people change behaviours that put their health at risk.

iv Commission or provide initial training and continuing professional development programmes for local authority staff, all health and social care professionals and community volunteers on how to prevent dementia in later life.



S.2 Improved public awareness and understanding of dementia

i Encourage local organisations in all sectors to support staff members to become Dementia Friends and Champions.

ii Newham Council's Community Neighbourhood Link Workers to become Dementia Friends Champions.

iii Encourage people living and working in Newham to become Dementia Friends.

S.3 Improved professional awareness and understanding of dementia - an informed and effective workforce across all services

Joint dementia training strategy and development programme to be produced including:

i a range of qualification routes to key staff groups

ii joint Dementia Friends training

iii training on advance care planning for staff in all care sectors who may come into contact with people living with dementia.

Additional workforce development funding to be utilised, when available.

S.4 Good quality timely diagnosis and intervention for all

i 100% GP participation in the national Dementia Enhanced Service (DES), in order to meet the ambition of increasing the dementia diagnosis rate in Newham from 66% in 2014/15 to 68% in 2015/16.

ii GPs to ensure the DES screening tool is used appropriately with people with additional needs, e.g. learning disabilities and sensory loss.

iii GPs to consider how to improve access to and quality of care they provide for people with dementia and their families/carers.

iv GPs to use the national Alcohol Screening Tool[22].

v Newham Memory Services to have the ambition of assessing people with dementia within two weeks of GP referral.

vi CCG commissioners to work closely with alcohol/substance misuse commissioners to ensure that people who develop alcohol-related dementia are able to find a service that is close to home and meets their needs.

S.5 Easy access to good quality information, support and advice

i Develop clear specifications for all existing dementia services and monitor to ensure outcomes and value for money are achieved.

ii Expand post-diagnosis support for people with dementia and their families/carers, particularly where clinical intervention is not yet required.

iii Continue to support Memory Lane Cafés.

iv Ensure availability of BSL information and interpreters.

S.6 Community-based support

i Ensure that integrated care services meet the specific needs of people living with dementia, with clear pathways

ii Support people living with dementia to access personal budgets.

iii Ensure that all health and social care staff are confident in their ability to assess mental capacity and have a good understanding of the Best Interest decision-making process.

iv Newham Council to ensure that self directed support services are responsive to the specific needs of people living with dementia, including people with hearing and/or sight loss.

v Providers to be encouraged to develop support services accessible to people with dementia who also have hearing and/or sight loss.

vi Mobile opticians, audiologists and dentists to provide services for people with dementia.

S.7 Good quality care within general hospitals

Build on existing good practice by developing and monitoring the Older People's Liaison Service to prevent unnecessary admission, facilitate early discharge and ensure appropriate care for people living with dementia.

S.8 High quality services within care homes

i Providers will deliver to the Newham Council/NCCG service specification and implement best practice in dementia care.

ii Residential and nursing care home managers and staff will be appropriately trained and experienced in all aspects of excellence in dementia care.

iii Ensure safe and responsible prescribing of anti-psychotic and anti-dementia drugs for nursing and care home residents.

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[22] http://www.alcohollearningcentre.org.uk/Topics/Browse/BriefAdvice/?parent=4444&child=4898

iv Extend the work of the Dementia Care Team in care homes to include residential care homes, as appropriate.

S.9 Good End of Life Care

i GPs to recognise the palliative care needs of people with dementia.

ii The issue of advance care planning to be raised by professionals in a sensitive manner with people with dementia and where appropriate, with their families/carers, at all stages of assessment, care planning and reviews.

iii GPs, acute trust consultants, Newham Memory Services and care homes to ensure that the end of life care wishes of people with dementia and their families/carers are met, with specific reference to preferred place of death, presence of families/friends and freedom from pain.

iv The five Priorities for Care of the Dying to be implemented sensitively for people with dementia and their families/carers.

S.10 Monitoring progress

i Dementia Strategy Action Plan and updated Equality Impact Assessment to be presented to Newham Health and Wellbeing Board in March 2015 for agreement.

ii Robust data collection and management to be developing, ensuring consistent use of data categories across health and social care.

iii Newham Health and Wellbeing Board to receive an annual progress report and strategy update.

Appendix A1: Consultation feedback

Memory Lane Café, City Road Outreach Centre, 21/03/2014 (19 attendees plus five volunteers)

Memory Lane Café, Well Community Centre, 27/03/2014 (43 attendees plus eight volunteers)

Samuel Boyce Centre, 01/04/2014
(17 attendees plus three staff)

Older People's Reference Group, 12/06/2014 (45 people plus three staff)

SubCo Trust, 19/06/2014
(30 people plus four staff)

Questions asked:

- What should a good dementia service look like?
- What is more important for you?

Memory Lane Café, City Road	Memory Lane Café, Well Community Centre	Samuel Boyce Centre
1. We need someone to talk to, to explain and give information in different formats about causes of dementia, symptoms (CD to listen to, DVD to watch etc.) 2. Information for volunteers to help them understand about dementia so that they are well equipped to support people living with dementia 3. there is still a lot of stigma and lack of understanding attached to dementia 4. Early diagnosis is essential (knowledge about symptoms is important) 5. We need to be supported to continue to do the things that are important to us 6. We want to be supported to have choice and control in the type of services available 7. Professionals need education about typical behaviours of dementia 8. We want to be able to stay living at home as long as possible	1. There are some good services and support available in Newham but we have to struggle to find what is available and sometimes difficult to access 2. Transport is poor, people can wait for up to three hours 3. Dial-a-Ride is good transport, we need more of this available 4. Need to improve on information and how we give it to people 5. Our experience with GPs is still poor, some GPs are not taking seriously our worries about our condition and access is still patchy and poor 6. Professionals need to communicate more with carers 7. Happy with Mayor as streets are much cleaner and services better 8. Taxi card scheme 9. Better funding from the council to provide more services for people living with dementia	1. Difficulties to register with a GP, one person was told to wait three months to register, someone else was told he was out of catchment 2. Early diagnosis is essential (knowledge about symptoms is important) 3. It takes a long time to get an appointment to see your GP - sometimes a month 4. We need to be supported to continue to do the things that are important to us 5. Most GP practices are shut every Thursday afternoon 6. Same day GP appointments booking must be done between 8am and 9am. But whenever you call, the telephone is engaged and when you get through you are told there are no more appointments and then you start the following day with same experience 7. Care workers not having any understanding about dementia and its impact to people 8. Care workers taking advantage not to come to deliver care at right time; always late and not staying all the allocated time

Memory Lane Café, City Road	Memory Lane Café, Well Community Centre	Samuel Boyce Centre
9. Services do not appear to be co-ordinated 10. Having the right support of friends 11. The diagnostic process sometimes takes a long time. This increases people's anxiety and uncertainty and it means that they are not able to access services early enough 12. Training for carers to continue supporting people living with dementia 13. Better health care and attention 14. Better funding from the council to provide more services for people living with dementia 15. Readily available appointments 16. Community centre that can provide everything we need nd accessible to all those living with dementia	10. Stopping hot meals was a bad plan 11. Having good neighbours is a blessing 12. Carers want to continue providing care but want support to be available that they can access immediately when things get difficult for them 13. Early diagnosis is essential (knowledge about symptoms is important) 14. Having friends would be a great help 15. We need to be supported to continue to do the things that are important to us 16. Support is available but still poor and not co-ordinated 17. Need more activities to keep people active and not being stuck indoors 18. Respite care in not readily available and still not enough 19. Regardless of dementia, isolation is a real killer 20. Keep the Well Centre open - it stops us from going to GPs 21. Improve information sharing 22. Newham Mag has small print and is hard to read	9. People frightened to report if care workers don't attend or not stay all allocated time 10. The diagnostic process sometimes takes a long time. This increases people's anxiety and uncertainty and it means that they are not able to access services early enough 11. Isolation and loneliness are real killers - keeping the centre open is very important 12. Training for carers to continue supporting people living with dementia 13. Information sharing and how information is given to people is an issue 14. Those people who live alone may not get the right information 15. No consistency in point of contact as council officers change - makes it more difficult for people living with dementia to contact to speak to right officer 16. Tried to speak to an officer in council over six months with no success 17. Attending the Samuel Boyce Centre is great: friends, company, food, staff are good. Please keep centre open. It gets us out of the house and keeps us away from GPs 18. Coming to the centre gives respite to carers. If I did not come to the centre, my daughter/son or family would not be able to go to work 19. Newham Council telephone system is not customer friendly and especially for those living with dementia (so many options to choose from/follow)

Older People's Reference Group	SubCo Trust
1. Professionals especially hospital teams need education about typical behaviours of dementia 2. The right family support and training for carers to continue supporting people living with dementia 3. Raising awareness amongst professionals about dementia 4. Early diagnosis and intervention is essential (knowledge about symptoms is important) 5. We need to be supported to continue to do the things that are important to us 6. We want to be supported to have a choice and control in the type of services available 7. Better health care and attention 8. We want to be able to stay living at home as long as possible 9. More services, activities/stimulation and homes, day or Community centres that can provide everything we need and accessible to all those living with dementia 10. We need someone to talk to, to explain and give information in different formats about causes of dementia, symptoms (CD to listen to, DVD to watch etc.) 11. Information for volunteers to help them understand about dementia so that they are well equipped to support people living with dementia 12. There is still a lot of stigma and lack of understanding attached to dementia 13. Services do not appear to be coordinated 14. Having more dementia friends and the right support of friends 15. The diagnostic process sometimes takes a long time. This increases people's anxiety and uncertainty and it means that they are not able to access services early enough	1. It is so lonely at home, need to increase number of days to attend Subco 2. Early diagnosis and intervention is essential (knowledge about symptoms is important) 3. GPs must listen to their patients and families take them seriously and stop ignoring them 4. GPs' refusal to discuss dementia issues with patients and families is an issue 5. Sometimes it is so difficult to make appointment to see your own GP. GPs need to give regular appointments to see their patients 6. We need to be supported to continue to do the things that are important to us 7. We want to be supported to have a choice and control in the type of services available 8. Better health care and attention 9. Loneliness kills 10. We want to be able to stay living at home as long as possible 11. GPs writes letter to remove patient from register 12. GPs refuse to keep patients on register because they have so many problems and take a lot of GP time 13. SubCo centre is heaven for dementia people to meet together, socialise and it reduces loneliness and depression etc 14. We need someone to talk to, to explain and give information in different formats about causes of dementia, symptoms (CD to listen to, DVD to watch etc) 15. Need support for dementia carers and make services easily available (advice, advocacy etc.) and information about how to get other support and help 16. Need to recognise dementia under FACS so that people diagnosed with dementia can access services directly

Older People’s Reference Group	SubCo Trust
	17. SubCo runs once a fortnight. This is not enough as the rest of the time we are left lonely and tend to be more depressed, confused and helpless. This puts families and carers under more pressure, leading to poor relationships, poor health and wellbeing, loss of jobs to family members and can lead to abuse 18. Some members in the group remained tearful about spending a lot of time alone at home 19. We need orientation support to enable us remain longer independently at home 20. Telephone assessments with people affected by dementia are inadequate and must not be practised 21. Language barriers may present a problem in communication 22. GPs attitude is an issues, GPs spend less than 10 minutes and refuse to spend more time with dementia patients 23. Charging policy is making dementia people refuse help as they are scared of costs 24. More befriending services

Newham Co-production Forum proposals for additional Commissioning Intentions

1. Community language interpreters to enable families/carers to explain symptoms.

2. Local cultural activities for people with dementia from Asian communities.

3. Benefits advice and advocacy for people with dementia and their families/carers who are hard to reach.

Appendix A2: National and local policy

1. National policy

The Government is very committed to ensuring there is a greater focus on accelerating the pace of improvement in dementia care through local delivery of quality outcomes and local accountability for achieving these outcomes.

Living Well with Dementia, the National Dementia Strategy published by the Department of Health (DH) in February 2009[23], prioritises improved awareness, early diagnosis and intervention and improving the quality of care, especially through better education and training. The strategy's vision is that services and society should transform their approach and attitudes to enable people with dementia, their families and carers to live well with dementia. The strategy sets out 17 objectives for commissioners and providers of dementia care. The first 12 are aimed at supporting a defined pathway for commissioning services and are grouped under three main headings: Raising awareness and understanding dementia; Early diagnosis and support; and Living well with dementia. Objectives 13 to 17 are cross-cutting to enable change to be implemented. They cover: Performance monitoring and evaluation; Commissioning; Workforce development; and Research. In addition, the National Strategy makes a commitment to ensure both regional and national support is available to support the implementation of the strategy.

The DH also published a *Joint Commissioning Framework* in 2009 to support implementation of the National Dementia Strategy. The Framework outlines how commissioners can ensure that the objectives of the National Strategy can be implemented at a local level and highlights the importance of the development of local joint strategies such as this one.

The Use of Antipsychotic Medication for People with Dementia: Time for action was published in November 2009[24] and outlined the widespread over-prescription of anti-psychotic medication for people with dementia, particularly in care homes. This report led to a further objective in the National Dementia Strategy to reduce the use of anti-psychotic medication.

In January 2010, the *National Audit Office* published *Improving Dementia Services in England - An Interim Report,* outlining the challenges to the implementation of the National Dementia Strategy and the huge economic impact of dementia care. It recommended that implementing the strategy should be given the same urgency as that accorded to other national health priorities.

Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, published by the DH in September 2010, sets out the Coalition Government's plans to implement the Dementia Strategy. It highlights four priority objectives:

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

The Prime Minister's Challenge on Dementia, issued in March 2012, recognises the low rates of formal diagnosis of dementia and aims to improve the quality of care and help reduce future pressures on health and social care by focusing on three key areas:

1. Driving improvements in health and care.
2. Creating dementia friendly communities that understand how to help.
3. Better research.

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[23] Living Well with Dementia: A National Dementia Strategy, DH, 3 February 2009

[24] A report for the minister of state for care services by Prof. Sube Banerjee (Nov 2009): The use of antipsychotic medication for people with dementia: Time for action. http://psychrights.org/research/digest/nlps/Banerjee.

Dementia Friendly communities

The aim of Dementia friendly communities is to cooperate to support people with dementia to live independently for as long as possible, with choice and control over their lives. Organisations from all sectors can get involved in networks across the country.

National Dementia Pathway

The National Institute for Health and Care Excellence (NICE) has produced guidance on a national dementia pathway and quality standards for the delivery of dementia care services, including the NICE Dementia Pathway, shown below.

NICE National Dementia Pathway

Unplanned Admissions Enhanced Service[25]

In April 2014, NHS England introduced the Unplanned Admissions Enhanced Service (ES), which is designed to help reduce avoidable unplanned admissions by improving services for vulnerable patients and those with complex physical or mental health needs, who are at high risk of hospital admission or re-admission. This clearly includes people with dementia. The ES was to be complemented by whole system commissioning approaches, aimed at reducing avoidable unplanned admissions. The ES was in place for one year, subject to review.

Participating GP practices were to review emergency admissions and A&E attendances of patients on the case management register in order to understand why these admissions or attendances occurred and whether they could be avoided. Practices also reviewed patients newly identified as at risk and other vulnerable patients (such as those living in residential or nursing homes) to identify what would have avoided the admission or A&E attendance, with a view to taking appropriate action to prevent future episodes. This action could include: changes that the practice could make to their management of these patients; other community support services that needed to be put in place for these patients; and changes to admission and discharge processes that would be fed back by the practice to commissioners.

2. Local policy

Newham's Joint *Dementia Strategy* links to Newham's *Health and Wellbeing Strategy*, which is concerned with improving health and social care outcomes and reducing health inequalities for all people, including people with dementia, their families and carers. The *Dementia Strategy* also links to the *Autism Strategy, Carers Strategy* and the over-arching *Mental Health Strategy*. Strategies and plans developed in future, including a *Learning Disabilities Strategy*, will in turn link with the *Dementia Strategy*.

Newham's *Joint Strategic Needs Assessment* provides a basis for understanding the demographic context of this strategy and underlines the challenges of commissioning Dementia services in Newham. The objectives in the national strategy provide the basis of our needs analysis in Newham and enable us to identify the areas where we need to improve service.

Newham CCG has identified dementia as a key part of the strategic direction of the organisation and is reflected in the priority given to this document.

Newham Council is equally committed to ensuring high quality social care support for people with dementia and their families/carers. The overall aim and vision for adult social care includes:

- Increased choice and control for individuals.
- Individuals have increased independence.
- People are included and connected in the community.
- Services offer quality and value for money.
- Services meet the needs of the people they are supporting.
- People with social care needs are safe.

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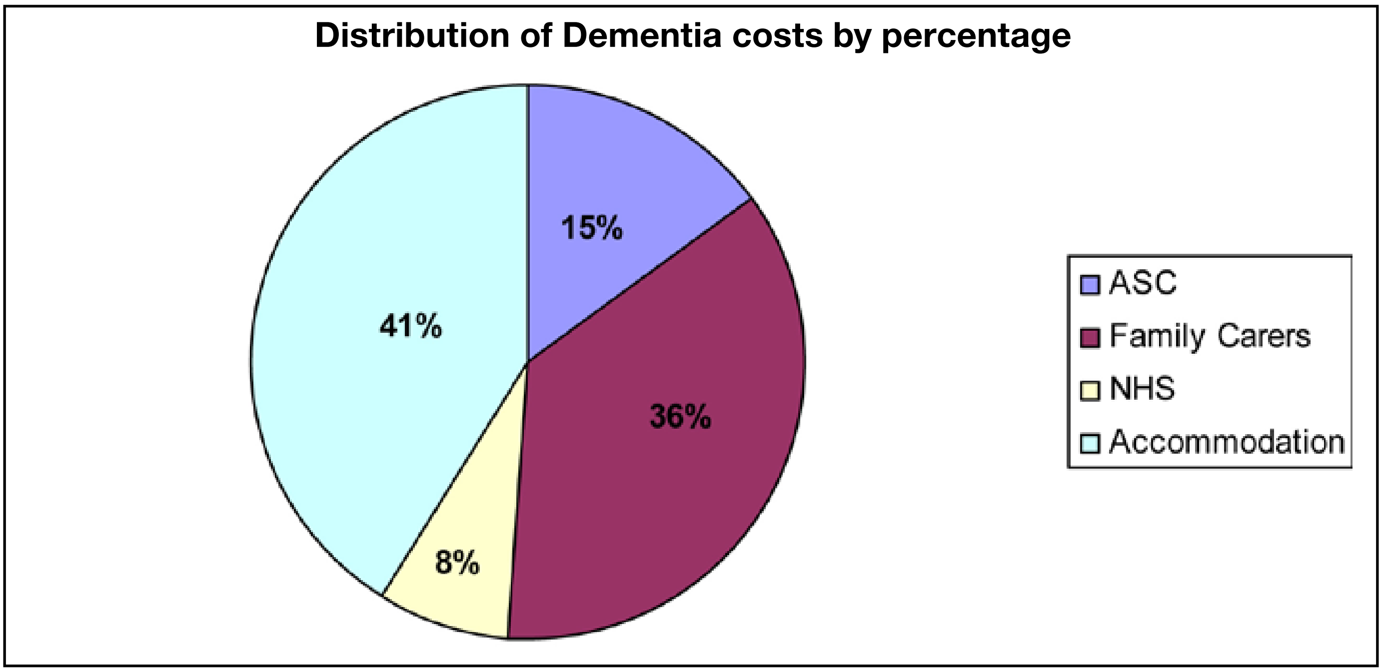
[25] Avoiding unplanned admissions guidance 2014-15, NHS Employers, 10 April 2014: http://www.nhsemployers.org/case-studies-and-resources/2014/04/avoiding-unplanned-admissions-guidance-2014-2015

Appendix A3: Dementia nationally

Dementia is one of the biggest challenges facing health and social care commissioners and policy-makers now and in the coming decades. The Alzheimer's Society report *Dementia 2014: Opportunity for change*[26] provides a comprehensive summary of key areas affecting people with dementia in England, Wales and Northern Ireland. The report identifies an increase in the number of people living with dementia in the UK from 835,000 in 2014 to 850,000 by 2015, of whom 700,000 are in England, with 72,000 in London. The UK figure is predicted to rise to over one million by 2025 and over two million by 2051. In 2013, 65% of people with dementia were women and 35% were men. The number of people who are living in UK care homes with dementia is 311,730, of whom 180,500 are living in residential care and 131,230 in nursing homes. An estimated 25,000 people from black, Asian and minority ethnic groups have the condition.

The total cost of dementia in the UK is estimated to have reached £26.3 billion. The NHS picks up £4.3 billion of the costs and social care £10.3bn, of which £4.5bn is attributed to local authority social services for state funded care. The remaining £5.8 billion is paid out annually by people with dementia and their families for help with everyday tasks provided by professional care workers, like washing and dressing. 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.

Estimated distribution of dementia costs in England



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[26] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2313

[27] Dementia UK, Alzheimer's Society, 2007

[28] Mirando-Costillo, C et al (2010). People with dementia living alone: what are their needs and what kind of support are they receiving? International Psychogeriatics 22(4): 607–17.

The total annual cost per person with dementia in different settings is estimated as follows:

Living situation	Cost
People in the community with:	
Mild dementia	**£25,723**
Moderate dementia	**£42,841**
Severe dementia	**£55,197**
People in care homes with dementia	**£36,738**

Two-thirds of people with dementia live in the community[27]. Of these, one-third live alone in their own homes, the rest being mainly supported by family carers[28]. One-third of people with dementia live in care homes (Alzheimer's Society, 2007) and up to 70% of care home residents in the UK have dementia or significant memory problems. Seven out of 10 people with dementia are now living with another medical condition or disability.

Early-onset dementia

Estimates for early-onset dementia are also based on the Alzheimer's Society Dementia UK report. The table below shows the prevalence rates for early-onset dementia between the age of 30 and 64 years per 100,000 of the population[29]. Early-onset dementia is comparatively rare accounting for a lower percentage for all people with dementia in the UK. Alzheimer's Society estimates that there are 42,325 people with early-onset dementia in the UK, i.e. one in 688 of people aged under 65 years.

Number of people with early-onset dementia in the UK, by age and sex, 2013

Age (years)	30-34	35-39	40-44	45-49	50-54	55-59	60-64
Women	207	185	446	649	1,209	1,854	16,256
Men	191	124	180	735	1,348	3,330	15,611
Total	**398**	**310**	**626**	**1,383**	**2,557**	**5,184**	**31,867**

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[27] Dementia UK, Alzheimer's Society, 2007

[28] Mirando-Costillo, C et al (2010). People with dementia living alone: what are their needs and what kind of support are they receiving? International Psychogeriatrics 22(4): 607–17.

[29] 'Dementia UK', 2007 – Alzheimer's Society

Late-onset dementia

Dementia UK: Update (2014) reports that older age is the largest risk factor for dementia: 773,500 people with dementia (one in 14) are aged 65 years and over. Around 68% of people with dementia (one in six) are aged 80 years and over.

The table below shows the prevalence rates for late-onset dementia aged 65 and over per 100,000 of the population. The table shows higher prevalence of late-onset dementia for females aged over 75 years. Over all the population statistics tells us that the life expectancy of women is longer than that of men. This means there will be more women than men living with dementia. The Alzheimer's Society estimates that there are approximately two women for every man[30] living with dementia

Of people with dementia aged over 60 years, an estimated 55% have mild dementia, 32% have moderate dementia and 12% have severe dementia. Among people with late-onset dementia, 311,730 (38.7%) are living in residential or nursing care homes and 493,639 (61.3%) are living in the community.

Compared to the 2007 estimates, the current prevalence consensus found that there are slightly more people with dementia in the youngest (65 to 69) and oldest (90+) age bands and slightly fewer in the intermediate age groups.

Number of people with Late-onset Dementia in the UK, by age and sex, 2013

Age (years)	**65-69**	**70-74**	**75-79**	**80-84**	**85-89**	**90-94**	**95+**
Women	32,286	40,126	75,093	105,187	118,932	96,517	38,288
Men	25,467	37,250	50,580	67,040	51,818	28,236	6,681
Total	**57,753**	**77,376**	**125,674**	**172,226**	**170,750**	**124,754**	**44,969**

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[30] Alzheimer's Society (http://www.alzheimers.org.uk)

Appendix A4: Dementia Enhanced Service (DES)

Facilitating timely diagnosis and support for people with dementia

Aims

The aims of this enhanced service in 2014/15 are to encourage GP practices to:

a) identify patients at clinical risk of dementia

b) offer an assessment to detect for possible signs of dementia in those at risk

c) offer a referral for diagnosis where dementia is suspected and, in the case of a diagnosis, provide advance care planning in line with the patient's wishes

d) increase the health and wellbeing support offered to carers of patients diagnosed with dementia.

For patients with dementia, their carer(s) and families, the benefits of timely diagnosis and referral will enable them to plan their lives better, to provide timely treatment if appropriate, to enable timely access to other forms of support, and to enhance the quality of life.

Specification

The requirements for GP practices participating in this enhanced service are as follows:

a. The practice undertakes to make an opportunistic offer of assessment for dementia to 'at-risk' patients on the practice's registered list, where the attending practitioner considers it clinically appropriate to make such an offer. Where an offer of assessment has been agreed by a patient then the practice is to provide that assessment. For the purpose of this ES, an opportunistic offer means an offer made during a routine consultation with a patient identified as 'at risk' and where there is clinical evidence to support making such an offer. Once an offer has been made, there is no requirement to make a further offer during any future attendance, but it is expected that attending practitioners will use their clinical judgement for any concerns raised by the patient or their carer.

b. For the purposes of this enhanced service, 'at-risk' patients are:

  - patients aged 60 years or over with cardiovascular disease, stroke, peripheral vascular disease or diabetes
  - patients aged 40 years or over with Down's syndrome
  - other patients aged 50 years or over with learning disabilities
  - patients with long-term neurological conditions which have a known neurodegenerative element, for example Parkinson's disease.

These assessments will be in addition to other opportunistic investigations carried out by practices for whom the attending practitioner considers to have a need for such investigations (i.e. anyone presenting and raising a memory concern).

c. The assessment for dementia offered to at-risk patients shall be undertaken only following the establishment of patient consent to an enquiry about their memory.

d. The assessment for dementia offered to consenting at-risk patients shall be undertaken following initial questioning (through appropriate means) to establish whether there are any concerns about the attending patient's memory (GP, family member, the person themselves).

e. The assessment for dementia offered to consenting at-risk patients for whom there is concern about memory (as prompted from initial questioning) shall comprise administering a more specific test (where clinically appropriate[31]) to detect if the patient's cognitive and mental state is symptomatic of any signs of dementia, for example the General Practitioner assessment of Cognition (GPCOG) or other standardised instrument validated in primary care.

f. The assessment of the results, for the test to detect dementia, is to be carried out by healthcare professionals with knowledge of the patient's current medical history and social circumstances.

g. If, as a result of the assessment, the patient is suspected of having dementia the practice should:

   - offer a referral, where this is agreed with the patient or their carer, to specialist services such as a Memory Assessment Service or Memory Clinic for a further assessment and diagnosis of dementia
   - respond to any other identified needs arising from the assessment that relate to the patient's symptoms
   - provide any treatment that relates to the patient's symptoms of memory loss.

h. Patients diagnosed as having dementia will be offered an advance care planning discussion focusing on their physical, mental health and social needs and, where appropriate, including referral/signposting to local support services.

i. The advance care plan should, where possible and through encouragement from the attending practitioner, include a recording of the patient's wishes for the future. It should identify the carer(s) and give appropriate permissions to authorise the practice to speak directly to the nominated carer(s) and provide details of support services available to the patient and their family. For the purpose of this service, 'carer' will apply to a person - usually a family member, friend or acquaintance who takes responsibility for the patient's care needs - but will not include professional carers who have been employed for this purpose by the patient or their representative.

j. The care plan should be shared with the patient and their carer(s) and be reviewed on an appropriate basis.

k. The practice will seek to identify any carer (as defined above) of a person diagnosed with dementia and where that carer is registered with the practice, offer a health check to address any physical and mental health impacts, including signposting to other relevant services to support their health and well-being.

l. Where the carer of a patient on a practice's register who is diagnosed with dementia is registered with another practice, the patient's practice will inform the patient's carer that they can seek advice from their own practice.

m. The practice should record in the patient record relevant entries including the required Read2 or CTV3 Codes 5 to identify where an assessment for dementia was undertaken, where applicable, that a referral was made and patients diagnosed as well as whether or not an advance care planning discussion was given or declined. The practice should record in the carer record relevant entries including the required Read2 or CTV3 Codes.

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[31] It is recognised that in some cases (i.e. for people with severe learning disabilities) such a test may not always be appropriate. Further guidance on the assessment of dementia in people with learning disabilities has been produced by the Royal College of Psychiatrists and the British Psychological Society. Dementia and People with Learning Disabilities at http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf

Appendix A5: NHS England Dementia Prevalence Calculator (v3)

What the Dementia Prevalence Calculator does

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

- applies these figures to a general practice's registered patient population, by age and by gender
- in order to estimate local prevalence, the tool distinguishes between the patient population in the community, and those patients living in care homes
- it considers prevalence at different phases of the disease (mild, moderate, severe), and by age group
- it compares numbers on dementia registers with numbers of patients registered for co-morbid conditions, such as cardiovascular disease, in order to inform case finding
- it aggregates general practice data at the level of the Clinical Commissioning Group
- using prevalence data and the most recent Quality Outcomes Framework data (QOF DEM1), it allows the user to benchmark, and set trajectories for improvement in diagnosis rates
- based on local trajectories for improvement, CCGs may determine a quantified ambition for improvement in its average diagnosis rate, year-on-year.

What this means for GPs and CCGs

The calculator will enable general practices and commissioners to:

- take into account estimated prevalence among the general practice's patients in local care homes, and in the community
- review estimated local prevalence in relation to numbers of patients on the practice's dementia register, and estimate the practice's 'diagnosis gap'
- consider prevalence by age group, and by severity
- use the data as a means of benchmarking progress to improve diagnosis rates, particularly in relation to sub groups (for example, patients with early onset dementia; patients with co-morbid conditions)
- take action to improve local diagnosis rates using a range of mechanisms, including improving coding, case finding, indicative screening, and education to improve recognition, assessment, and diagnosis.

Definitions

The Dementia Prevalence Calculator (DPC) uses the following definitions:

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

For ‘model for dementia prevalence’ read ‘estimate of dementia prevalence’. Although the numbers of people diagnosed are going up steadily in Newham, the percentage of expected prevalence keeps going down because the estimate of prevalence is going up even faster.

www.newham.gov.uk