Joint Dementia Strategy 2010 – 2015

"*The challenges of dementia are significant but can be met*"
Department of Health 2009

Draft Version 0.09

Contents

1. EXECUTIVE SUMMARY

The Local Context – Dementia in Harrow – Key Points

- 13.6% of Harrow's residents are over the age of 65. Harrow has the highest proportion of elderly residents in the North West London sector.
- There is significant geographical variation in the proportion of elderly residents within Harrow.
- The estimated number of people with late-onset dementia in Harrow is 2,287.
- Only 32% of the estimated total dementia cases in Harrow are recorded on the GP register.
- The prevalence of dementia in over 65 year olds in Harrow was estimated as 7.7% in 2007, giving Harrow the highest prevalence of dementia of the 8 London boroughs in the North West London sector and a higher prevalence than the London average.
- The prevalence of dementia in Harrow increases with age, from around 1 in 14 people over the age of 65 to 1 in 6 people over the age of 80 and nearly 1 in 3 people over the age of 90.
- Over 160 people were diagnosed with early-onset dementia by the Young Onset Dementia Team in Harrow from 1999-2009.
- Alcohol related dementia is a significant cause of early-onset dementia in Harrow.
- Harrow has a significant South Asian elderly population. Previous research suggests that there may be a stigma associated with dementia in this ethnic group and a reluctance to use available services.
- Recent work by MIND in Harrow makes recommendations about how mental health services can be tailored to meet the needs of Gujarati speaking people in Harrow.
- The number of people with dementia in Harrow is projected to rise over the next 15 years, as the size of the elderly population increases. The prevalence rate of dementia is not projected to rise significantly.

2. FOREWORD

Commissioners are required to use available resources to commission services to meet a population's needs, whilst ensuring value for money and balancing competing priorities.

When determining which priorities to focus on, commissioning decisions should be based on consideration of evidence and good practice guidance where available. However in social care, commissioners also need to be confident in using 'soft intelligence' and local knowledge to inform decisions. This could include feedback and evaluation from people who use services and their carers, informal and formal; community networks, management information gathered for performance returns and feedback from operational staff on what works well in practice.

Harrow's Joint Dementia Strategy has combined all elements of expertise , as guided by both our operating plan and commissioning strategic plan including the local needs assessment in order to produce a document that addresses the challenges ahead within the area of dementia whilst ensuring that local services meet local needs .as stated by the Department of Health in 2009: "The challenges of dementia are significant but can be met" Harrow is confident that with the valuable contributions and support of general practioners , Central North West London NHS Foundation Trust, The Third Sector, carers and people with dementia, the significant challenges that dementia brings will be addressed. This strategy outlines Harrow's five year plan to achieve this.

John Webster Chief Operating Officer Harrow NHS

Signature  August 2010

Paul Najsarek Corporate Director of Adult Services and Housing

Signature August 2010

3. WHAT IS DEMENTIA?

Dementia is a clinical syndrome characterized by a widespread loss of mental function, with the following features:

- memory loss
- language impairment
- disorientation (not knowing the time or place)
- change in personality (becoming more irritable, anxious or withdrawn; loss of skills and impaired judgment)
- self neglect
- behavior which is out of character

In the later stages patients have difficulty feeding, dressing and washing themselves and are highly dependent on carers. There is no cure for dementia and it ultimately results in death.

3.1 Early and Late onset dementia

Traditionally there has been a distinction between late-onset dementia, which firsts manifests itself in people over the age of 65, and early-onset dementia which affects younger age groups. Late-onset dementia is far more common than early-onset dementia, because dementia is primarily a disease associated with ageing. However the underlying disease for all age ranges is the same.

3.2 Underlying causes of dementia

Dementia is caused by diseases or injuries which affect the function of the brain. There are a number of such diseases which cause dementia. The most common cause of dementia is Alzheimer's disease, followed by vascular dementia. Table 1 shows the estimated proportions of people with different underlying causes of late-onset dementia in the UK.

Alzheimer's disease and vascular dementia are also the most common causes of early-onset dementia in the UK – Table 2. Of note, alcohol related dementia and frontotemporal dementia are significant causes of early-onset dementia.

What is Dementia? – Key Points

- Dementia is a term used to describe a collection of disorders which include memory loss and behavioral change
- Dementia results an inability to carry out the activities of daily living without assistance.
- Dementia is almost always progressive.
- Dementia is caused by a number of different diseases. The symptoms experienced by a person with dementia and the way in which these symptoms progress vary according to the underlying cause.
- Old age is the most important risk factor for dementia. Important modifiable risk factors for dementia include smoking, hypertension, diabetes and excessive alcohol intake.
- Early memory loss identified as mild cognitive impairment is also recognized as a possible precursor

Table 1: Causes of late-onset dementia

Underlying cause	**Proportion of UK dementia cases**
Alzheimer's disease	62%
Vascular dementia	17%
Mixed Alzheimer's and vascular dementia	10%
Dementia with Lewy bodies	4%
Frontotemporal dementia	2%
Parkinson's dementia	5%
Other	3%

Source: Knapp M, Prince M, Albanese E et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

Table 2: Significant causes of early-onset dementia

Underlying cause	**Proportion of UK dementia cases**
Alzheimer's disease	35%
Vascular dementia	18%
Frontotemporal dementia	15%
Alcohol related dementia	14%

Source: Harvey et al 2003. The prevalence and causes of dementia in people under the age of 65 years J Neurol Neurosurg Psychiatry 2003;74:1206-1209

It is important to make a distinction between the different underlying causes of dementia because they vary in the range of symptoms suffered and the rate of progression of symptoms. The key features of the most common underlying causes of dementia are summarised here.

Alzheimer's disease:

- The most common cause of dementia.
- Caused by a degenerative process, which leads to the death of brain cells
- Characterised by a gradual progression of symptoms.
- The first symptoms to appear are usually a loss of memory.
- As symptoms progress, the person will have increasing difficulty carrying out daily functions.

Vascular dementia

- Caused by disease to circulation of blood to the brain.
- Unlike Alzheimer's, progression of symptoms may be sudden (after a stroke) or step-wise rather than gradual.

Dementia with Lewy bodies:

- Associated with protein deposits that develop inside nerve cells in the brain and affect the function of the brain
- Type of dementia may have symptoms similar to those of Parkinson's disease, such as tremors and slowness of movement.
- The disease is progressive, although a person's level of function may fluctuate on an hourly basis.

Frontotemporal dementia

- Is rare, and can be caused by a number of degenerative diseases affecting the brain including Pick's disease.
- In the early stages of disease, memory is often intact, but personality and behaviour change are apparent.
- Incontinence may be a relatively early feature of the disease.

3.3 Risk factors for dementia

The risk factors for dementia are summarised in table 3 below. The most important non-modifiable risk factor for dementia is age. A number of modifiable risk factors for dementia exist. These include the risk factors for vascular diseases, such as diabetes, hypertension, smoking and high cholesterol, which all increase the likelihood of both vascular dementia and Alzheimer's disease. Excessive alcohol consumption is also an important modifiable risk factor.

Table 3: Risk factors for dementia

Risk factor	Comments
Non-modifiable risk factors	
Age	Increasing age is the most important risk factor for dementia.
Sex	Alzheimer's disease is slightly more common in women, particularly in those over 80 years of age
Genetic factors	Mutations in 3 individual genes cause familial Alzheimer's disease. Down's syndrome is associated with an increase risk of Alzheimer's (this is rare)
Family history	Family history of a first degree relative with Alzheimer's disease may increase the risk of Alzheimer's, however caution should be used when interpreting this information and association can only determined on an individual basis given the number of other associated variables.
Modifiable risk factors	
Hypertension	Associated with an increased risk of both vascular dementia and Alzheimer's disease.
High cholesterol	Associated with an increased risk of both vascular dementia and Alzheimer's disease.
Diabetes	Associated with an increased risk of both vascular dementia and Alzheimer's disease.
Smoking	Associated with an increased risk of both vascular dementia and Alzheimer's disease.
Excessive alcohol consumption.	Excessive alcohol intake is associated with Korsakoff's syndrome, and other of dementias.
Educational level	Additional years of education appear to offer some protection against Alzheimer's disease.

Source: Kester and Scheltens. Dementia: The Bare Essentials Pract Neurol 2009;**9:**241-251

What is special about dementia in people with learning disabilities?

Dementia does not affect people with learning disabilities differently to how it affects other people. However, the early stages are more likely to be missed or misinterpreted - particularly if several professionals are involved in the person's care. The person may find it hard to express how they feel if their abilities have deteriorated, and problems with communication may make it more difficult for others to assess change.

It is vital that people who understand the person's usual methods of communication are involved when a diagnosis is being explored - particularly where the person involved does not use words to communicate.

4. THE NATIONAL CONTEXT

4.1. Prevalence of dementia in the UK

Dementia UK: the full report 2007 provides the best available estimates for the national prevalence of dementia. The report estimated the total number of people with dementia in the UK as nearly 700,000 people. Of these around 660,000 (98%) have late-onset dementia and 15,000 (2%) have early onset dementia

The prevalence of dementia in the UK Population increases with age (see table 4). From age 65 to 95 the prevalence of dementia roughly doubles for every five year age group.

Table 4: UK prevalence of dementia by age group

Age range	Prevalence of dementia (%)
55-64	1%*
65-69	1.3
70-74	2.9
75-79	5.9
80-84	12.2
85-89	20.3
90-94	28.6
95+	32.5

Source: Knapp M, Prince M, Albanese E et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society. * Figure provided by Harrow Young Onset Team

4.2 The National Dementia Strategy

Dementia is currently estimated to cost £17 billion to the UK economy. Over the next 30 years, as the UK population ages, the number of people with dementia is expected to double and cost to the UK economy is expected to treble.

As a result, the first National Dementia Strategy was published in February 2009 with the aim of transforming the quality of dementia care. It set initiatives designed to make the lives of people living with dementia, their carers and families better and more fulfilled. Its aim is to increase awareness of dementia, ensure early diagnosis and intervention and radically improve the quality of care that people with the condition receive. Proposals include the identification of leaders for dementia care in every general hospital and care home and for mental health teams to assess people living with dementia.

The 17 key objectives of the National Dementia Strategy are as follows:

1. Improving public and professional awareness and understanding of dementia.
2. Good-quality early diagnosis and intervention for all.
3. Good-quality information for those with diagnosed dementia and their carers.
4. Enabling easy access to care, support and advice following diagnosis.
5. Development of structured peer support and learning networks.
6. Improved community personal support services.
7. Implementing the Carers' Strategy.
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.
12. Improved end of life care for people with dementia.
13. An informed and effective workforce for people with dementia.
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.
16. A clear picture of research evidence and needs.
17. Effective national and regional support for implementation of the Strategy.

The National Picture – Key Points

- Around 700,000 people in the UK have dementia
- Dementia costs the UK around £17 billion a year.
- A national dementia strategy has been developed, which outlines objectives for high-quality care to meet the needs of people with dementia.

5. THE LOCAL CONTEXT – DEMENTIA IN HARROW

5.1 Harrow's elderly population

In 2007 Harrow was home to some 215,000 people in total. Of these 29,300 (13.6%) were over the age of 65.[1] Old age is the most important risk factor for dementia and Harrow has the highest percentage of elderly residents of the 8 boroughs in the North West London sector. In addition Harrow has a higher percentage of elderly residents than the London average (see table 5).

Table 5: Percentage of population over the age of 65 – North West London Boroughs.

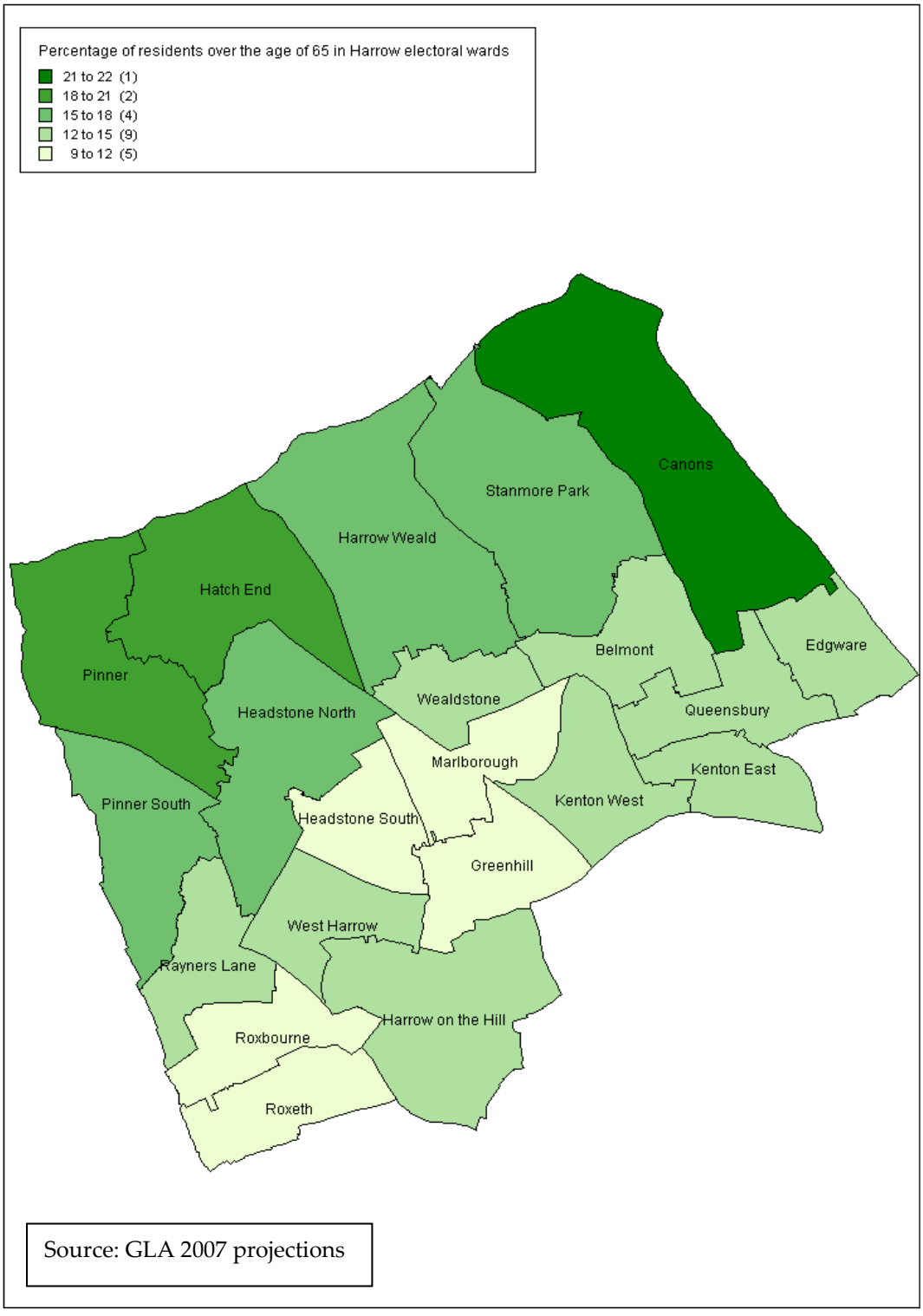
London Borough	Percentage of total population over 65
HARROW	13.6
Hillingdon	13.4
Brent	12.0
Kensington and Chelsea	11.8
Ealing	11.4
Westminster	11.0
Hounslow	10.9
Hammersmith and Fulham	9.5
LONDON average	11.5

Source: GLA 2007 projections

There is a wide variety in the proportion of elderly residents across Harrow electoral wards (figure 1). Canons has the highest proportion of people over the age of 65, with over 1 in 5 people being over the age of 65. Roxbourne has the lowest proportion of people over the age of 65, with only 1 in 10 people over 65. The north of the borough has a higher percentage of elderly residents than the south and central areas of the borough.

1 Source GLA 2007 projections

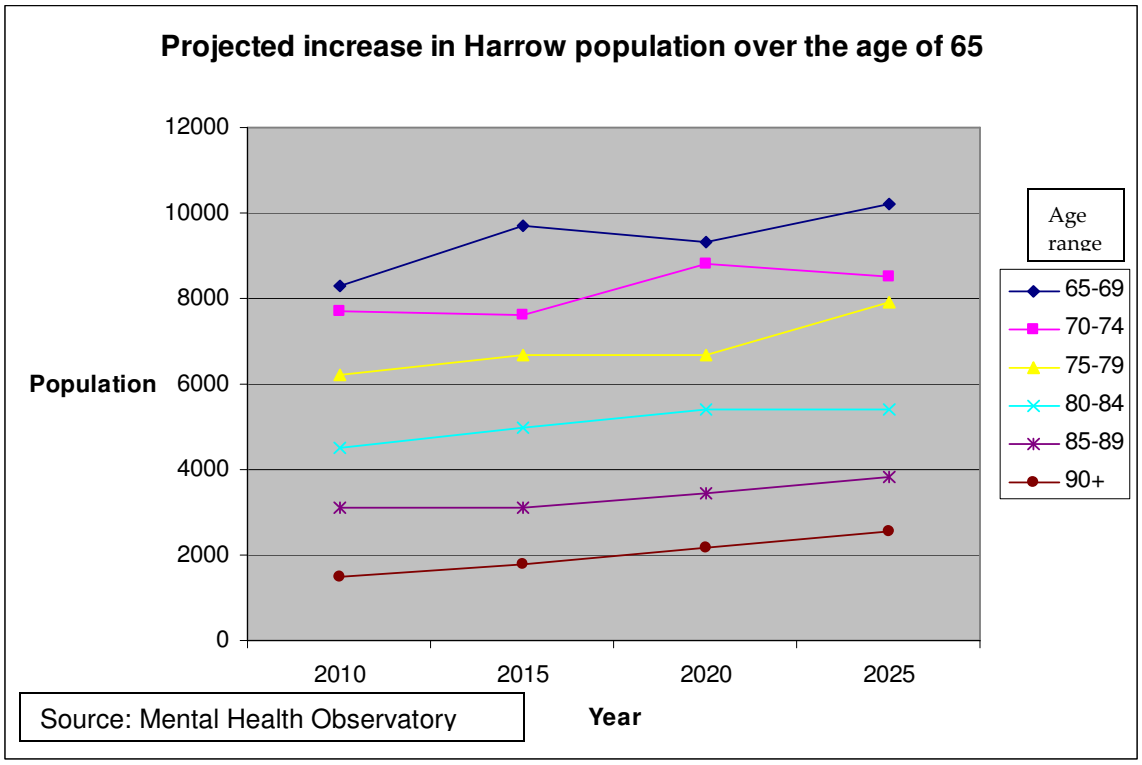
Figure 1. Percentage of elderly residents across Harrow's electoral wards.



5.2. Harrow's elderly population is projected to rise over the next 15 years

The population of over 65s is projected to rise by around a quarter to 38,400 in 2025. Rises will be seen in the numbers of people in all age groups over the age of 65 between 2010 and 2025 (see figure 2). As the number of elderly people rises in Harrow, so will the numbers of people with dementia.

Figure 2: Projected Harrow population over the age of 65 by age group, 2010-2025



5.3. Current prevalence of late-onset dementia in Harrow

The Mental Health Observatory has provided modeling of estimated numbers of people with late-onset dementia by age, gender and PCT across the UK. According to this modeling there are currently an estimated 2287 people with dementia over the age of 65 in Harrow.

The prevalence rate of dementia in people over the age of 65 is estimated as 7.7%. This equates to around 1 in 14 people in this age group. **This was the highest prevalence rate of the 8 boroughs in the North West London sector and was higher than the London average of 7.3% (see table 5)**.

Table 6 – estimated prevalence of dementia in people aged 65+ by London borough

London Borough	Percentage of total population over 65
HARROW	7.7
Hillingdon	7.4
Westminster	7.4
Kensington and Chelsea	7.4
Hammersmith and Fulham	7.4
Ealing	7.2
Hounslow	7.1
Brent	6.9
LONDON average	7.3

Source: Healthcare for London: Dementia Needs Assessment 2009

5.3.1 Recording of dementia on the GP register

In February 2010, there were 725 patients in Harrow, recorded as having dementia in their GP records[2]. This accounts for only 32% of the estimated 2287 patients currently living with dementia in Harrow. This means that there are over 1500 people with dementia in Harrow, who are not recognised as having dementia in their GP record.

5.4. The prevalence of dementia increases in the oldest age groups

About 1 in 14 people over the age of 65 have dementia and this figure rises to around 1 in 6 people over the age of 80 and to nearly 1 in 3 people over the age of 90. As a result of the increasing prevalence of dementia in the very oldest age groups, the majority of people in Harrow with dementia are over the age of 80.

Table 7: Estimated prevalence of late-onset dementia in Harrow by age group

Age group	Estimated prevalence of dementia in Harrow
Over 65 years of age	1 in 14 people
Over 80 years of age	1 in 6 people
Over 90 years of age	nearly 1 in 3 people

Source: Mental Health Observatory

5.5. The prevalence of late-onset dementia is greater in females than in males

The prevalence of dementia in females over the age of 65 in Harrow is estimated as 8.2% compared to 6.1% for males. This equates to a total of 1458 females with late onset dementia in Harrow compared to only 829 males. The higher prevalence rate in females can largely be explained by the fact that women have

[2] Source: QOF data from from Harrow GPs - extracted Feb 2010

a longer life expectancy and so are more likely to live into their 80s and 90s, when dementia is most prevalent. However, even allowing for age, Alzheimer's disease is thought to be slightly more common in females than in males[3].

5.6. Prevalence of early-onset dementia

In early-onset dementia, symptoms start below the age of 65. Data on the prevalence of dementia in people under the age of 65 is not as abundant as data on late-onset dementia. Healthcare for London's Dementia Needs Assessment estimates that there were 49 people with early onset dementia in Harrow in 2007[4]. This estimate is modelled on national prevalence rates for early onset dementia.

However, data on service use from the Early-Onset Dementia Team, based at Atkin's House in Harrow, suggests that the actual prevalence of early-onset dementia in Harrow could be higher than suggested by such modelling.

Between 1999 and 2009 there were 808 referrals to the Early Onset Dementia Team, of which 167 (20.7%) were found to have dementia and 347 (45%) were found to have mild cognitive impairment[5].

Of the 167 people identified with early-onset dementia in Harrow from 1999 to 2009, 25 (15%) were diagnosed with an alcohol related cause for their dementia, including 8 people diagnosed with Korsakoff's syndrome.

The needs of all people with dementia are complex. However, it is noted that people with early-onset dementia have needs that can be different from older people with dementia as they are more likely to be employed or have young children for whom they are main carers.

5.7. Underlying causes of dementia in Harrow

There is no data that is specific to Harrow for the underlying cause of dementia. It is likely that the proportions of people with the various underlying causes of dementia are similar to those seen nationally. This data is presented in section 2.2 (please note that there is some data available from the Harrow Young onset Team that has been included in this report)

5.8. Dementia and Ethnicity in Harrow

[3] Health Council of the Netherlands. Dementia. The Hague: Health Council of the Netherlands, 2002
[4] Healthcare for London: Dementia Needs Assessment 2009
[5] Data provided by Young Onset Dementia Team, Harrow.

Harrow is an ethnically diverse borough. 30% of Harrow's total population is from a South Asian background and there are also small but significant Black African and Black Caribbean communities. This ethnic diversity is reflected in Harrow's elderly population, where Indians and other South Asians make up around 20% of over 65 year olds (figure 5). In 2001, an estimated 377 people from black and minority ethnic groups in Harrow were thought to have late onset dementia. By 2021 this is projected to rise to 972 people, an increase of over 150%[6].

Perceptions of dementia and dementia care have been shown to vary in different ethnic groups. Studies in South Asian communities in Britain have highlighted a sense of stigma and a lack of knowledge about dementia and available services, as well as a feeling of disillusionment with doctors and exclusion from services[7]. In addition, South Asian carers may feel it is a failure of family structure to ask for help from health professionals[8].

Gujarati is the most widely spoken language amongst the South Asian population in Harrow. Research conducted by MIND, inconjusnction with CNWL, into the views, experiences and attitudes of Gujarati speaking Asian elders towards mental health services, highlighted a lack of awareness within the Gujarati-speaking community about the causes of memory loss[9]. The report also identified a sense of stigma towards mental health issues within the Gujarati-speaking community.

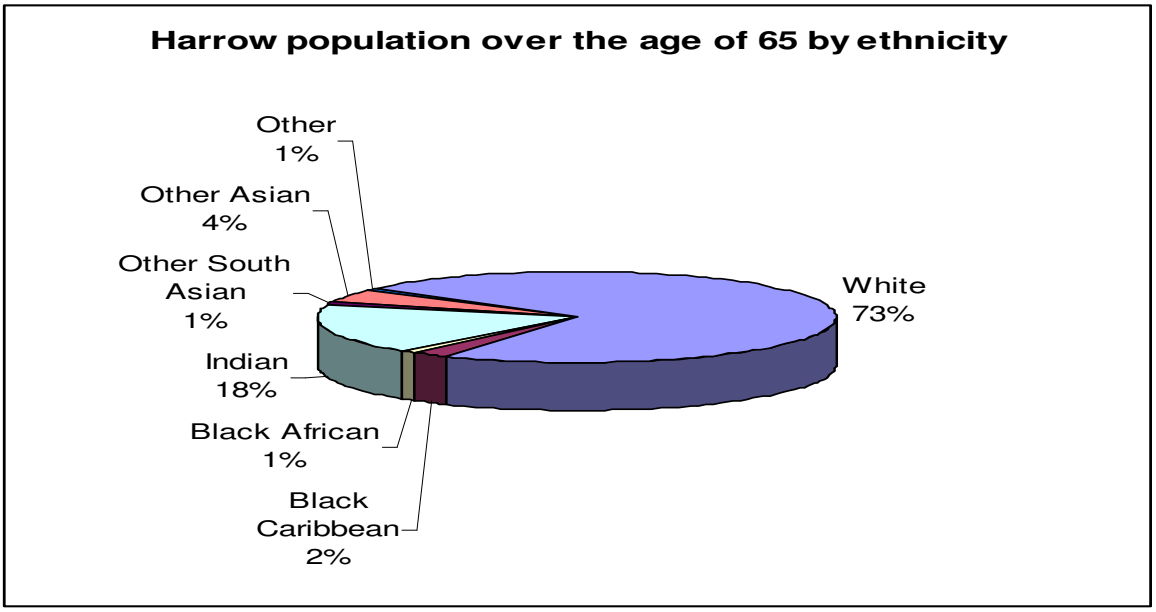
The report made the following recommendations to improve mental health services, including dementia services, for the Gujarati speaking community in Harrow.

1. All Harrow mental health services should recognise and offer Gujarati specific service options.
2. Mental health services should pro-actively recruit Gujarati-speaking workers.
3. Promotion of capacity building in the local communities: work should be undertaken to improve information available to Gujarati speaking people and to create positive links between the cultural needs of the Gujarati-speaking Asian elders and service providers.

[6] Source: Prevalence rates from Dementia UK applied to population data from 2001 census and 2021 GLA projections.
[7] La Fontaine et al. Understanding dementia amongst people in minority ethnic and cultural groups. J Adv Nurs. 2007 Dec;60(6):605-14.
[8] Lawrence et al. Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. Br J Psychiatry. 2008 Sep;193(3):240-6.
[9] MIND in Harrow. Report of the community led research project focusing on Gujarati-speaking Asian elders' experiences, views and attitudes of mental health and mental health services in Harrow. May 2008.

4. Provide training opportunities to Gujarati speaking service users and carers who have identified that they would value much more information, knowledge and awareness of mental health issues.
5. Gujarati speaking elderly communities and service users should be involved in monitoring and reviewing mental health services, and in the development of new ways of reaching those in need.

Figure 3: Ethnic makeup of Harrow population over the age of 65



Source: GLA Ethnic Population Projections 2009.

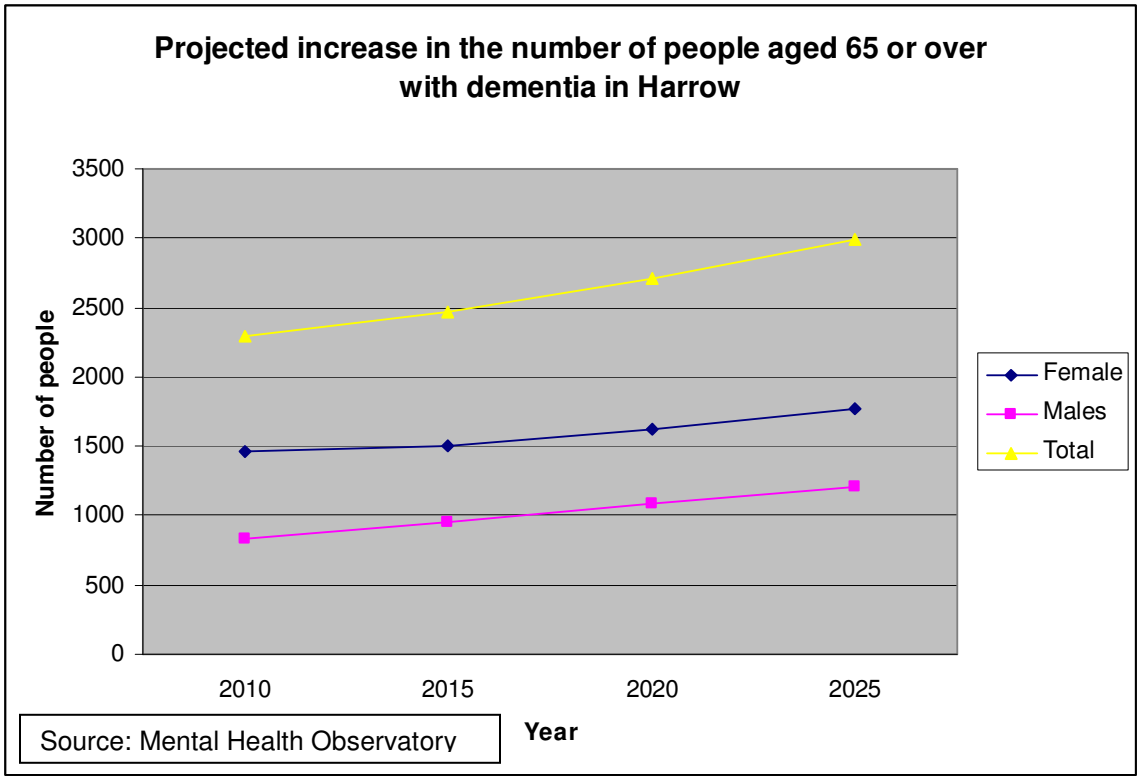
5.9. The number of people with dementia in Harro r the next 15 years.

The number of people in Harrow with late-onset dementia in Harrow is projected to rise by 30% over the next 15 years to 2985 in 2025 (see figure 3). This equates to an average year on year increase in the number of people with dementia of 1.7%. This increase can be attributed to the increase in Harrow's elderly population over the same time period, as described above. The prevalence rate of dementia in over 65s is projected to rise only slightly to 7.8%.

There is also supporting evidence that the current Harrow population may be at higher risk than other sector as there is a significant number of the population with factor that contribute to dementia. Harrow has the highest North West sector rate for coronary heart disease, stroke and transient ischemic attacks, hypertension, heart failure, asthma, diabetes, chronic kidney disease, obesity and significantly there is a possible increase of coronary heart disease projected - 6.6% by 2015 within the Asian population.[10]

[10] Harrow Primary Care Trust, Strategic Plan, 2009/10 to 2013/14

Figure 4: Projected increase in the number of people with late-onset dementia in Harrow from 2010-2025



6. BENCHMARKING AGAINST 17 NATIONAL OBJECTIVES

The Dementia Strategy Group in February 2010 benchmarked current services in Harrow against the 17 Objectives outlined in the National Dementia Strategy and awarded the following traffic lights:

National Objective	Service	RAG Rating
1 Improving public and professional awareness	Alzheimer's Society, population raising awareness (Professional).Awareness of dementia in general hospitals through discussions with GP.MIND Asian elder's research Project, focus groups DOH general awareness raising campaign post March. Not enough training awareness around this	AMBER
2 Good-quality early diagnosis and intervention	GPs not apt at recognizing early dementia. QOF data not very good. Needs to be reviewed more frequently. Not enough support after diagnosis	RED
3 Good-quality information	Access to info through internet but not getting through to the right people 50% there, need to review communication methods	AMBER
4. Enabling easy access to care, support and advice following diagnosis	Dementia Advisor engaged	AMBER
5 Development of structured peer support and learning networks.	Carers support group's day centres exist but geographically limited and run by unfunded voluntary organizations	AMBER
6 Improved community personal support services.	Crossroads offers respite care but limited by council requirements .No specialist homecare services	AMBER
7 Implementing the Carers' Strategy.	Carers strategy does not include dementia .Carers assessment but not enough .support with chasing resources for the self funders	AMBER
8 Improved quality of care for people with dementia in	Too much demand and not enough resources	RED

general hospitals.		
9 Improved intermediate care for people with dementia.	Green View Intermediate Care Unit opened in November 2008	GREEN
10 Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers	A lot of provision of telecare for those entitled following assessment .There is no extra care housing	AMBER
11. Living well with dementia in care homes.	No specialist in reach service and quality of care homes vary	RED
12 Improved end of life care for people with dementia	Dementia to be included in End of Life Strategy	AMBER
13 An informed and effective workforce for people with dementia.	Not for health related staff	RED
14 A Joint Commissioning strategy for Dementia	This strategy	GREEN
15 Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.	National	Non Applicable
16 A clear picture of research evidence and needs.	National	Non Applicable
17 Effective national and regional support for implementation of the Strategy.	National	Non Applicable

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7. SERVICE MAPPING

Service	Commissioner	Provider
Continuing Care Placements	Harrow NHS	Various private providers
Supporting People Service	Harrow Council	Notting Hill Housing Group
Milmans Day Centre	Harrow Council	Older Peoples Services
Greenview Unit Intermediate Care	Harrow NHS & Harrow Council	CNWL ,Care UK,Ealing and Harrow Community Services
Admiral Nurses	Harrow Council	CNWL
Ellington Ward	NHS Harrow	CNWL
Byron Day Centre	Harrow Council	Harrow Council
CMHT Mental Health Services	NHS Harrow	CNWL
Dementia Advisor/ Dementia support services	Harrow Council	Alzheimer's Society
Jewish Care housing support	Privately Funded	Jewish Care
Young Onset Team	Section 75 agreement	CNWL
Templeton Centre & Dementia Cafe	Various	Alzheimer's Society

8. VIEWS OF KEY STAKEHOLDERS

The necessity of providing integrated dementia services to suit local communities will be a challenge. In Harrow we are determined to respond to that challenge and to achieve this end we have worked together with three main groups to develop our local approach to the national guidance and key objectives:

Carers and people living with dementia
On 11th March 2010, a stakeholder event was organised by Harrow NHS on dementia services Those attending included carers and people living with dementia and members of the public wishing to know more about prevention. As a result the views and ideas of people living with dementia contributed to the strategy. Over 70 delegates attended– 25 professionals / 20 Users / 25 Carers.

Providers in statutory, voluntary, private and social care fields

A steering group of clinical and voluntary sector providers (The Dementia Strategy Group) has provided important information on what is available in Harrow and how this might be improved.

Independent Experts advice provided by the Dementia Services Development Centre in Stirling, a recognised international expert resource on the management of dementia, and Commissioning Support for London.

8.1 Feedback from stakeholder event – Primary care

Overall most delegates thought that Harrow provides good services .however access to these services may sometimes be difficult. In particular for fewer than 65 age range .Furthermore service users and carers wanted a more locally based telephone support linked with other local services. And to be diverse in support for the ethnic minorities in terms of say language. It was generally thought that there are problems with diagnosis. Stakeholders felt the need for access to specialist services and dedicated services for dementia with these services being reviewed every 3 – 4 months. These need to link into advocacy and personalization. A triage was suggested for signposting and referral to secondary care in mental health for example where depression is present .Finally it was felt that Polyclinics with memory clinics, cognition stimulation and GPS tracking would be useful. Carer education post diagnosis would also help. One issue that many felt strongly about was lack of consistency and communication whether that is staff dealing with the patient and their family or carers or communication between polyclinics and GPs. Most people thought that more staff training in issues around Dementia and diagnosis was needed. Making these services more linked and centralized

8.2 Feedback from stakeholder event - Secondary Care

Information is available on the disease and medications, carer training, services available (financial, legal, benefits, DVLA etc) and team and role. The infrastructure (mainly IT) does not support access to it though and sharing. It also needs to be user friendly. Some GP's are not sure of what is available and therefore, signposting can be poor. More awareness on Dementia needs to be produced to avoid stigma. There needs to be a process to the diagnosis also to help people adjust. More follow up even if they are not on medication. Overall people think that hospital staff and in general health care and social care professionals have poor knowledge and awareness and poor training. Again, there needs to be more collaboration with Mental Health and services such as MIND. Where there are also physical complications the access and skill are limited. Care homes are variable and again home support is needed as before with contracted respite. Maybe a drop in style café with skilled staff could be useful with extended hours. Personalised care is needed not just for the individual but to make sure their

families can access visits etc. Also more stimulation and activities needed and specialist staff. There is more focus on physical care than emotional. This is the same in hospitals it was felt.

Overall the feeling is that services and resources are limited perhaps due to budgets. Even when they are available they are not always accessible. It is a bit like a lottery depending on which GP or healthcare professional one gets access to. Referral needs to be clearer and more structured. The congruency is poor. Therefore, again training and awareness is key. There is a division between secondary and primary care it is felt by some. Pathways of care and support need to be promoted more.

8.3 Feedback from stakeholder event - End of life care

It was thought that there is a lack of information, expertise and infrastructure when it comes to hospices and specialist services.
There is a lack of communication and involvement with the carers during this period and support for them after bereavement when illness such as depression can develop. It is sometimes unclear when intermediate care finishes and end of life care begins. They feel there is also a lack of training in hospital and that hospices do have links with mental health but they are poor and unfunded. They want the choice to be supported properly at home in their own environment at this time. They really need respite to be regular and agreed and things like holiday accommodation with carers arranged. There needs to be nurses and domiciliary care. Health
services working efficiently in conjunction with Social care would make it easier to support people living with dementia and their carers.
Simple things could make a big difference such as specialist education in acute wards. Finally cultural sensitivity for carer and patients needs to be considered as well as catering for younger people living with dementia. They want to know why the gold standard framework[11] in care homes is not used universally

8.4 Feedback from stakeholder event – Access to services.

Access to dementia services is fragmented. Although there are lots of different providers available, GPs, patients and carers do not have a great insight into how one can access these services. There is a great disparity amongst level of provision in Harrow, and it is felt that the patients who have carers who are more proactive in seeking help, tend to be better off than those who do not have such advocates.
A central referral system for dementia patients may help coordinate care more freely and appropriately. Primary and secondary care services need to be able to communicate more effectively also.

[11] http://www.goldstandardsframework.nhs.uk/GSFOtherSettings/SpecialistPalliativeCare

8.5 Feedback in relation to people with learning disabilities

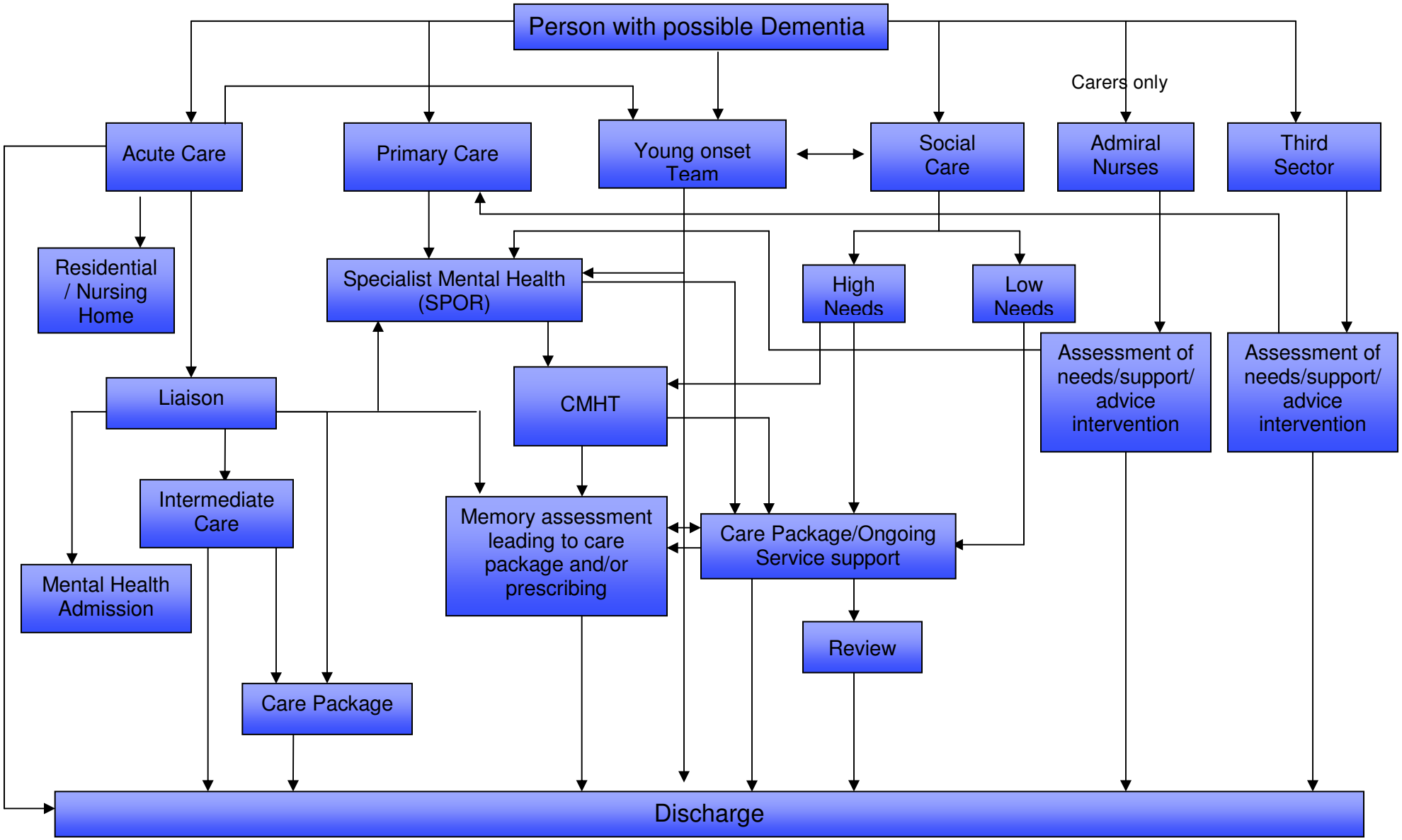
Prevalence of dementia is 4 times that of the general population with the risk of the onset of dementia amongst individuals with Downs's syndrome even higher. It is recognized that given the difficulties that some individuals with Learning disabilities face especially in relation to communication, the diagnosis In early stages of dementia are likely to be missed or at times misinterpreted leading to poor quality of care and inappropriate support.

8.6 Issued raised by the Young Onset Team following the event

There is a need for:

- on-going age-appropriate facilities such as respite and rehabilitation
- Specialised, trained care-agency to support families
- Cheaper transport costs in order to avail of day-care
- Need for family fostering for respite
- Need for dementia counsellors from those who have direct experience
- Appropriate self-contained flats within residential home as well nursing homes
- Database of age-appropriate facilities should be accessible to all teams
- Streamlined service and appropriate respite facilities for dementia
- In-house respite attached to the memory clinic is an ideal situation so that clients are not admitted and placed in acute, inappropriate wards in the NHS.

9. CURRENT MODEL

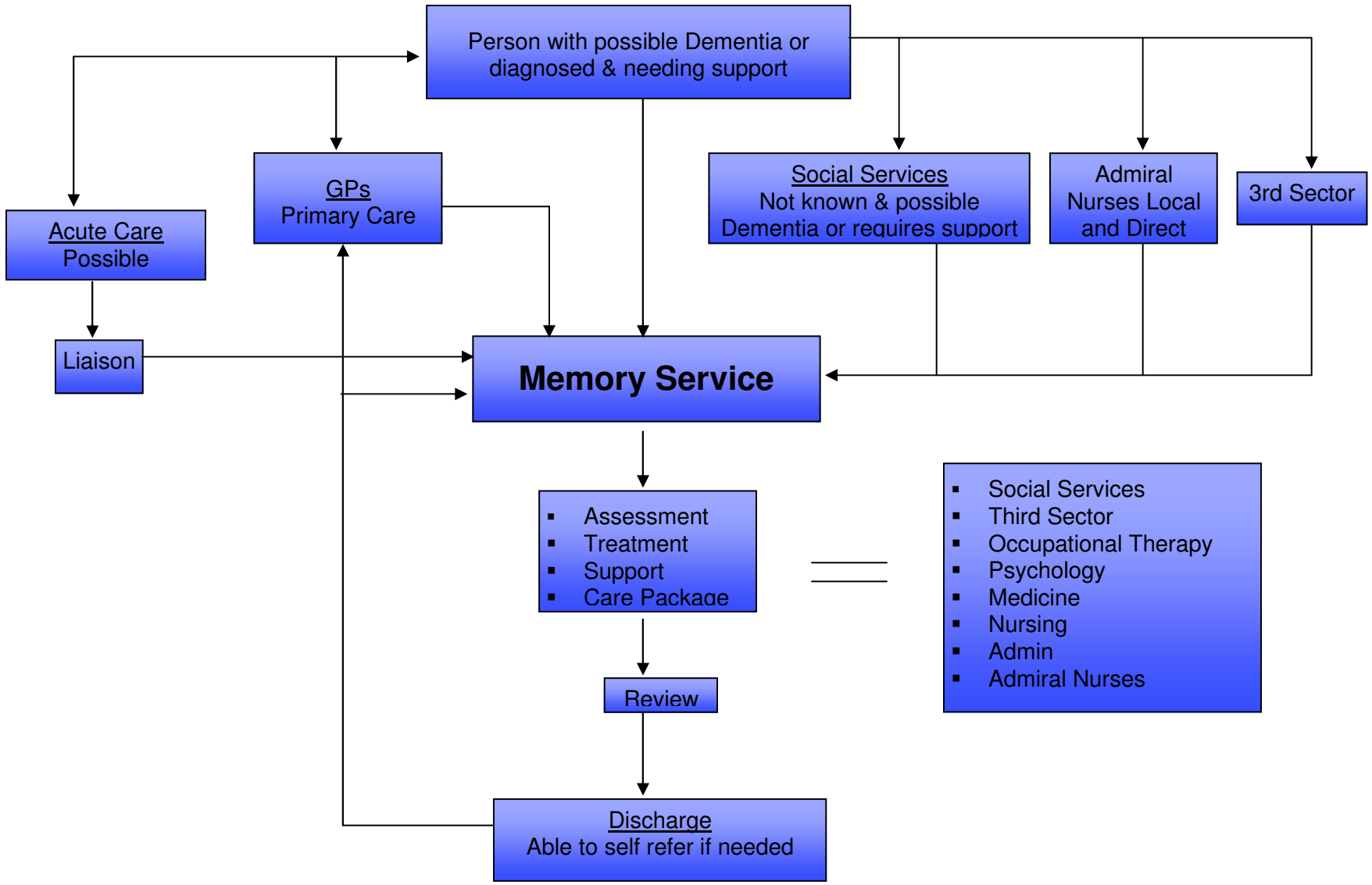


As seen by our stakeholders' feedback it is felt that our current model of service delivery for people living with dementia is not sufficiently joined up or designed to be proactive enough to identify people early and thus prevent people reaching crisis point. Consequently national evidence, *Dementia UK2007* suggests that too many resources are tied up in expensive acute care. People living with dementia may be repeatedly admitted to hospital because they are not otherwise in touch with services and their dementia means they are neither aware of their disability nor able to ask for assistance. Many admissions happen when people living with dementia are unwell, but not acutely ill enough to need the specialist care provided in acute hospitals, they are admitted simply because it is difficult to diagnose and manage their care. From acute settings people living with dementia are more likely to be admitted to long term care and not given the opportunity to return home with support. Our aim is to substantially improve this over the next few years.

Turning the vision into reality by bringing together the information gathered in this strategy, we can see where we have good services, and where there are gaps or room for improvement. We have considered different ways to deliver the necessary change, and have chosen to identify a set of outcomes and to deliver these through a selected number of the objectives from the *Living Well with Dementia: A National Dementia Strategy.* We believe that by focusing our plan around these outcomes and objectives, we will have the basis to deliver swift and effective change.

Harrow will construct a single integrated care pathway for dementia so that people are assessed, diagnosed and maintained at home for as long as possible in accordance with the wishes of both the service user and carer and also have access to specialist mental health services when needed.

10. PROPOSED PATHWAY



11. ACTION PLAN 2010 2015

Dementia Strategy Action Plan

June 2010 to 2015 - DRAFT

Project	2010/11	2011/12	2012/13	2013/14	2014/15
Event for Dementia Awareness Week in Harrow ,July					
Monitor referral rates per GP cluster (CNWL)					
Develop Memory Advice, Assessment & Treatment Centre					
Review information available on dementia services					
Employment of Dementia Advisor					
Support all people to access individualised budgets					
Ensure access to Carers Emergency Plan system					
Acute hospital to identify dementia leads					
Continue with contracting process and review					
Every provider must identify local lead for dementia					
NWL NHS Trust should include dementia awareness in their induction					
Training and education sessions for all clinicians within all care sectors					
Identify team able to deliver web based learning package					
Review Dementia Advisor role					
Ongoing commissioning of and provision of Tele Care					
Review /Audit of service at end of each year to monitor progress					
Ensure care packages are made available to meet needs of people with dementia					
Raise awareness of carers rights via local Carers Strategy					
Range of treatments to be made available including cognitive stimulation therapy					
To improve access to advocacy service for people with dementia					
Improved End of Life Care to be addressed in EOLC Strategy					
The Dementia Strategy will form part of NHS Harrow and Harrow Council integrated Commissioning Strategy					

12. MONITORING

The implementation of the action plan will be monitored jointly by NHS Harrow and Harrow Council and will take responsibility to progress the day to day actions necessary to deliver the strategy.

13. APPENDICES

Appendix 1
National Policy Documents

The National Dementia Strategy: Living Well with Dementia (2009) the Strategy outlines three key steps to improve the quality of life for people living with dementia and their carers. First, to ensure better knowledge around dementia and remove stigma associated with it. Second, to ensure proper diagnosis of dementia, this takes place as early as possible. Third, to develop a range of services for people living with dementia and their carers, this fully meets their changing needs over time

Dementia UK report (2007)
One of the main recommendations of this important Alzheimer's Society report was making dementia an explicit national health and social care priority and the need to improve the quality of services provided for people living with dementia and their carers.

.Dementia services guide (2009) Healthcare for London

This guide aims to advise London commissioners and clinicians with local authority partners how to follow the integrated care pathway for dementia developed by Healthcare for London in order to:

- help all London commissioners plan services in partnership along with local authority colleagues in social care
- provide a quality check against which they can benchmark services
- provide performance outcomes to help them review services.

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Appendix 2 Sources

1. Parliamentary Office of Science and Technology
   Post note January 2010 249

2. Dementia UK Report 2007

14. GLOSSARY

BMER	Black Minority Ethnic Refugee
LGBT	Lesbian Gay Bisexual Transgender
MMS	Memory Management Service
PBC	Practise Based Commissioning
LA	Local Authority
CNWL	Central North West London NHS Foundation Trust
NWLH	North West London Hospital NHS Trust
HART	Health Assessment and Rehabilitation Team
JSNA	Joint Strategic Needs Assessment
POPPI	Projecting Older Peoples Information System
NPH	Northwick Park Hospital
MCI	Mild Cognitive Impairment *(condition of cognitive impairments beyond that expected for their age and education, but that does not interfere significantly with their daily activities. At the boundary between normal ageing and dementia)*