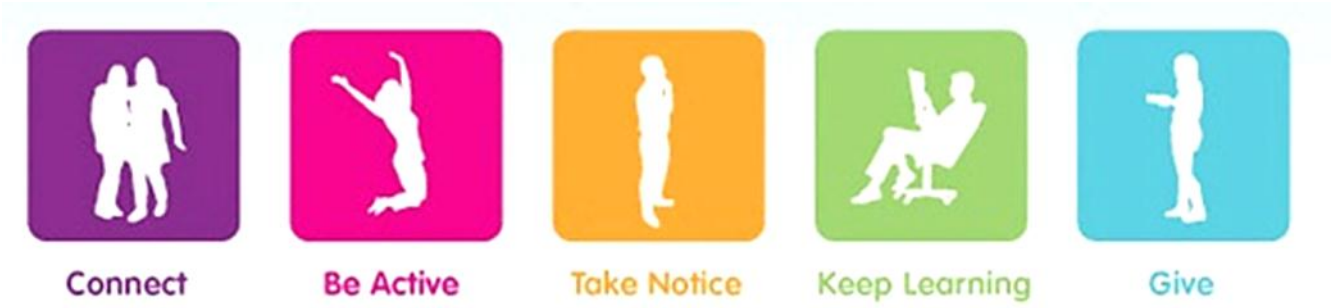
Liverpool City Council

Liverpool's Joint Strategic Needs Assessment

Dementia Health Needs Assessment

December 2013



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Executive Summary

The aims of this HNA are to:

- Describe the current and future health needs of those living with dementia in Liverpool
- Inform the development of a Dementia Strategy for Liverpool

There are about 800,000 people in the United Kingdom (UK) with dementia[1]. The current overall financial cost of dementia is £23 billion a year to the NHS, local authorities and families. This cost is expected to grow to £27 billion by 2018; approximately 55% of which is met by unpaid carers, 40% by social care and 5% by health care.

Most caregiving is provided informally by spouses, adult children, other family members and friends, which can have a psycho-social and economic impact as they may be forced to stop working, cut back on work, or take a less demanding job to care for a family member with dementia

Research[2] suggests that following general principles in relation to healthy ageing may be associated with the maintenance of cognitive health. These principles include:

- Preventing or controlling high blood pressure, cholesterol, diabetes, being overweight or obese
- Preventing or stopping smoking
- Being physically active
- Preventing or reducing social isolation

Increased consideration should also be given to certain high risk groups which include; those with learning disabilities, those with Down's Syndrome; people who have had a stroke or have a neurological condition such as Parkinson's disease.

There has been a raft of national policy and guidance in relation to dementia, which has provided a local context for the prioritisation for those living with dementia in Liverpool.

The changing demographic profile of the Liverpool population suggests that by 2021 there will be a significant fall in those of working age and a rise in the older population. This will have an impact of what is described as the 'old age dependency ratio'. This has implications

[1] *The Alzheimer's Society. Accessed on 1st November 2013 at: http://www.alzheimers.org.uk/infographic*

[2] *The Alzheimer's Association (2007) The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health. Accessed at: http://www.alz.org/national/documents/report_healthybraininitiative.pdf*

in terms of increasing prevalence of dementia, the ability of organisations to meet the growing needs of those living with dementia, compounded by the decline in the working age population that would ordinarily provide care and economically support the ageing population.

Between 2006/07 and 2012/13 there was a 33.5% increase in dementia prevalence in Liverpool. This compares to an increase in prevalence of 43.5% nationally over the same period. The number of patients with a diagnosis of dementia has increased by 745, up from 1962 registered patients in 2006/07 to 2707 registered patients in 2012/13, a 38% increase.

The number of people with dementia is predicted to rise in the city by 19.5% for males (from 1769 to 2114), by 5.8% for females (from 3113 to 3293) and by 10.7% overall (from 4883 to 5407) between 2013 and 2021 largely due to increases in the older population.

Dementia UK[3] estimates that 63.5% of people with late onset dementia live in private households (in the community) and 36.5% live in care homes. The proportion of those with dementia living in care homes rises steadily with age, from 26.6% among 65–74 year olds to 60.8% among ages 90 and over. Based on these estimates of dementia, in Liverpool it is estimated that 3,161 people with dementia live in the community and 1,651 require a care home.

Among people with late onset dementia (ages 65 and over), it is estimated that 55.4% (2,648) have mild dementia, 32.1% (1,570) have moderate dementia and 12.5% (598) have severe dementia. The proportion considered to have severe dementia increases with age, from 6.3% for those aged 65 to 69 years to 23.3% for those aged 95 years and over.

It is estimated that in 2013 residents in the city will lose 2324 healthy years due to dementia. As can be expected, the greatest burden falls among persons aged 60 and over who account for 92% of total Dementia DALYs. Among persons aged 60 and over in the city, healthy years lost due to dementia accounted for 8.99% of total DALYs for this age group.

Certain groups are at an increased risk of dementia, some of these include those with; cardiovascular disease; those with Down's syndrome; people with learning disabilities; those with long-term neurological conditions; those with alcohol dependency and those with mild cognitive impairment.

Reducing the risk of developing dementia can be supported through the adoption of a healthy lifestyle. Diet, healthy weight and physical activity play a significant role in reducing the risk of dementia. The Liverpool Lifestyle Survey estimated that 34% of those aged over

[3] *Dementia UK (2007) A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society.*

18 years are overweight and 21% are obese. The survey also found that whilst older people were less likely to drink alcohol than those in younger age groups, of those who do drink, do so more often.

Timely identification of those with dementia is advocated, with a recommendation to implement targeted screening programmes. Liverpool Clinical Commissioning Group developed a target to increase diagnosis rates for dementia in those aged over 65 by 7% by 2014/15, with a target prevalence rate of 57.7% (using the 2012 baseline of 50.6%). This suggests an increase of 511 newly diagnosed individuals. Current initiatives to improve prevalence rates include incentivising organisations through the use of commissioning for quality and innovation (CQUIN) incentives and directly enhanced service (DES) schemes in primary care.

In England, less than half of all cases of dementia are routinely recognised, and when a diagnosis is made, it is often at a relatively late stage of the disease. According to the NHS Dementia Calculator only 50.9% of dementia cases in Liverpool are diagnosed whilst numbers of cases are predicted to rise by 6% between 2011/12 and 2014/15 unless more is done to improve on current diagnostic rates.

NICE suggest the indicative benchmark rate for new referrals into a memory assessment service is 0.19%, or 190 per 100,000 population per year. Based on these estimates it is predicted that at least 936 registered patients in the city would have required referral to a memory assessment service in 2012/13 and 944 in 2013/14.

In 2012/13 there were 736 referrals to the Mossley Hill and Walton memory clinics which represent a referral rate of 0.15% or 148 per 100,000 population. This was an increase of 5.3% on the 2011/12 rate (Figure xx). NB: This estimate includes referrals from patients registered at Liverpool practices who were referred to Mossley Hill and Walton memory clinics but does not include patients referred to the Royal Liverpool University Hospital memory clinic with no onward referral to Mossley Hill, so the true referral rate is likely to be higher.

In 2012/13 the highest referral rate to Mossley Hill memory clinic for patients known to be registered with a Liverpool practice was from Childwall neighbourhood and the lowest rate was from Aintree neighbourhood. Statistically, Picton, Speke, Childwall, Garston/Allerton/Aigburth, Dovecot & Old Swan, have referral rates which were significantly higher than the Liverpool average (Figure XX). Aintree, Croxteth, Walton, Anfield, Norris Green and City Centre and Vauxhall neighbourhoods all have referral rates statistically significantly lower than the Liverpool average.

The three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine are now recommended as options for managing mild to moderate Alzheimer's disease. Memantine is recommended as an option for managing moderate Alzheimer's disease for

people who cannot take AChE inhibitors, and as an option for managing severe Alzheimer's disease; combination treatment with memantine and an acetylcholinesterase inhibitor is not recommended. Only specialists in the care of patients with dementia (that is, psychiatrists including those specialising in learning disability, neurologists, and physicians specialising in the care of older people) should initiate treatment. Carers' views on the patient's condition at baseline should be sought.

Prescribing rates at neighbourhood level also appear to run counter to previous dementia prevalence rates, whereby those neighbourhoods with highest dementia prevalence have lowest prescribing costs, and some of those with lowest dementia prevalence have higher than average costs. This also requires further investigation as may indicate that patients who may benefit from dementia drugs are not being prescribed. In the case of those with higher costs and lower prevalence it may indicate inappropriate or less cost-effective prescribing.

An audit of GP clinical systems in September 2013 showed that 390 patients with dementia had been prescribed anti-pyschotic drugs in the last 12 months (14%). The highest prescribing rates of antipsychotic drugs were found in North locality (17.3%), and the lowest in Matchworks (10.9%); whilst 14.7% of patients with dementia were prescribed anti-pyschotic drugs in Liverpool Central (Figure XX). It was not possible to calculate over what time period these drugs had been prescribed, it is recommended that further work is undertaken to determine this.

In Liverpool there are a range of organisations offering NPI: PSS offer a dementia befriending service: Alzheimer's Society provide "singing/dancing for the brain", peer support/carers groups: Local Solutions provide a Carers Centre as well as signposting and follow up services: Merseycare offer post diagnostic support groups: Age Concern provide a range of services and advice to elder individuals, including those living with dementia and their carers'. Work is currently underway to evaluate the effectiveness of these interventions locally.

Social support is critical to maintaining an individual with dementia in their community and supporting their carer(s). Health and social care staff should ensure that care of people with dementia and support for their carers is planned and provided within the framework of care management/coordination. Care managers and care co-ordinators should ensure the coordinated delivery of health and social care.

As of October 2013 there were 1,328 service users (SUs) listed with LCC as having dementia. The table and charts below show the age and sex profile of people with dementia in receipt of a care package in 2013 (this data excludes people with dementia who are privately funded and for whom data is not available). Among services users with dementia, 2 out of 3 are females and almost half are aged between 81-90 years (46.5%). It will be important to try to link this population with the GP registered population to ensure individuals are

receiving the support they require. The LCC figure of 1,328 SUS listed with dementia, and the GP registered list of 2,776 represents a difference of 1,448 residents. Some of this shortfall maybe as a result of those who are privately fund their care, but could to an extent be due to a lack of awareness by the public of the support available. It may also pose an opportunity to case find as may be two entirely separate populations.

The average length of stay in a residential or nursing home was 2 years from the date the resident was diagnosed with dementia. 44.2% of residents with dementia have a length of stay up to one year and a further 20% have a length of stay of between 1 and 2 years. 1.3% of residents with dementia have a length of stay longer than 10 years. These residents are likely to be younger, as the younger the person is diagnosed with dementia the slower the dementia progresses.

The End of life care strategy suggests 'although every individual may have a different idea about what would, for them, constitute a "good death", for many this would involve:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings
- being in the company of close family and/or friends'

Local work is currently underway to increase the numbers of care home residents with an ACP. In Liverpool ACPs have been completed for 595 residents since November 2009. Of these 250 have subsequently died – only 10 in hospital. In addition, the proportion of residents dying within 24 hours of hospitalisation has fallen by 52% to 13%. The main reason for implementation of an ACP was Advanced Dementia (50%). Relatives reported that having conversations about future prognosis and avoiding unnecessary distressing interventions is empowering, with care home staff feeling more confident about not sending frail residents into hospital when they are approaching the end of life.

In 2012/13 there were 2,889 admissions in the city with a primary or secondary diagnosis of dementia . The city has a directly age standardised admissions rate of 370 per 100,000 population, which is down 10.6% on the previous year. When the rates are broken down to GP neighbourhood there are 5 neighbourhoods with statistically significantly higher rates than the Liverpool rate, these were: Croxteth, Belle Vale, Everton and Great Homer Street, Riverside and Tuebrook/Stoneycoft. There were 5 neighbourhoods where admission rates are statistically significantly lower than the Liverpool rate, these were: Wavertree, Kensington and Abercromby, Gateacre and Woolton, Garston/Allerton/ Aigburth and Childwall. LCCG should look to investigate whether further resource is needed in those neighbourhoods with higher rates. Again some of these neighbourhoods were those with lower referral rates to memory clinics and the lowest prescribing rates of dementia drugs.

In 2012/13 almost a quarter of all dementia related admissions were due to symptoms, signs and abnormal clinical findings (ill-defined conditions such as nausea, headache, collapse where the primary cause is unknown at the point of admission). Other high ranking causes of admission included injury, poisoning and other external causes (falls included), as well as diseases of respiratory system.

Whilst deaths from dementia are relatively low when looking at underlying cause of death, the Alzheimer's Research Trust estimates that 1 in 3 people aged 65+ will have some form of dementia when they die. In Liverpool during the 5 year period 2008-12 there were 3331 deaths among residents aged 65 and over where dementia was stated as a cause of death on the death certificate (19% of all deaths in this age group). This means almost 1 in 5 people in the city aged 65 and over have a form of dementia when they die, although this is likely to be higher due to undiagnosed cases.

The Royal College of General Practitioners (RCGP) describe the impact that being a carer can have on an individual:

- Up to 40% of carers experience psychological distress or depression
- Carers have an increased rate of physical health problems. For example, providing high levels of care is associated with a 23% higher risk of stroke.
- Older carers who report 'strain' have a 63% higher likelihood of death in a year than non-carers or carers not reporting strain
- One in five gives up work to care, and
- More than half fall into debt as a result of caring

According to the 2011 Census, over 50,100 people in Liverpool stated they provided unpaid care. While the number of people in the city providing unpaid care is comparable to regional levels, figures indicate that Liverpool has the greatest level among the eight core cities, in addition to being above national levels.

In 2012-13, 290 unpaid carers of people with dementia in Liverpool completed a carer assessment with LCC. An audit of Liverpool GP clinical systems in September 2013 showed 386 patients with dementia had a registered carer recorded in the last 12 months (13.3%). Based upon the earlier Census figures, these figures are likely to under-estimate the true prevalence of carers for those with dementia in Liverpool.

In 2011/12 LCCG spent an estimated £25million on dementia services, the majority of which is spent on secondary care in a hospital setting. The table below illustrates the breakdown of spend by service type by LCCG. LCC spent an estimated £6.4m on dementia services (this is likely to be an under estimate of actual figure).

Currently Mersey Care NHS Trust delivers a 'care navigator' model from the Memory Clinic in Mossley Hill and one care navigator from Aintree University Hospital Trust. Each care navigator will have a caseload of approximately 200 people and deliver post diagnostic support groups. This model is accredited by The Royal College of Psychiatrists as excellent. Equitable access between those in the north and the South of the city needs to be addressed.

The WHO criteria for determining an 'age friendly city' includes housing which is affordable in areas that are safe and close to services and the rest of the community. It also lists:

- Affordable home maintenance and support services
- Well-constructed dwellings which provide safe and comfortable shelter from the weather
- Interior spaces and level surfaces allowing freedom of movement
- Home modification options are affordable
- Sufficient and affordable housing for frail and disabled older people, with appropriate services provided locally
- Designated older people's housing located close to services and the rest of the community

The Mayor of Liverpool has pledged to transform Liverpool into an "Age- Friendly City" as specified by the World Health Organisation. A report to Cabinet (31st August 2012) outlines a plan to create an integrated housing, health and social care system for older people in a phased development. Phase 1 is to provide fully integrated extra care housing. The Cabinet has approved additional investment to develop an additional 5 integrated extra care schemes. Phase 2 is to develop integrated pathways through a "virtual network" of health and social care in order to meet the needs of older people in the community. Phase 3 is capital investment in additional housing for the ageing population, including people with learning disability and dementias. The aim of this initiative is to work in partnership with key stakeholders, including LCCG to deliver this ambition.

As part of the work in becoming an "Age friendly City", there is an intention to develop a "virtual network" underpinned by increased focus on self-care and individuals taking more responsibility for planning their own health and well- being. In order to do this LCC and LCCG are working collaboratively to deliver the DALLAS (demonstrating assisted living lifestyles at scale) programme. The programme will invest in a range of initiatives to work with individuals, including older people with dementia to use technology in order to maintain their independence. The aim is to recruit 200 community champions who will raise the profile of the neighbourhood well- being assets, including assistive technology.

All health and social care staff involved in the care of people who may have dementia should have the necessary skills to provide the best quality of care. This should be achieved through effective training and continuous professional and vocational development in dementia.

The Prime Minister's Challenge on Dementia calls on the Royal Colleges to ensure all their members are capable and competent in dementia care. Health Education England (HEE) is the organisation responsible for overseeing education and training within the health and care system is working towards all NHS staff looking after patients with dementia undergoing foundation level dementia training, with HEE ensuring 100,000 staff have foundation level training by March 2014. This training will enable staff to spot the early symptoms of dementia, know how to interact with those with dementia and signpost staff to the most appropriate care.

1. Introduction

A health needs assessment (HNA) is a systematic method for reviewing the health issues facing a population. A HNA should lead to agreed priorities and resource allocation that will improve health and reduce inequalities.

The aims of this HNA are to:

- Describe the current and future health needs of those living with dementia in Liverpool
- Inform the development of a Dementia Strategy for Liverpool

The specific objectives of this HNA are to:

- Describe the epidemiology (patterns of disease in a population and factors which affect it) of both the older population generally and those living with dementia in Liverpool
- Describe current service provision and benchmark against what is considered best practice in caring for people and carers living with dementia
- Identify gaps in what we know about dementia in Liverpool
- Make recommendations for future policy and commissioning

2. Overview of Dementia

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes[4].

Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia progresses will depend upon the individual person and what type of dementia they have. Each person is unique and will experience dementia differently.

[4] *The Alzheimer's Society (2013).What is Dementia? Factsheet 400LP. Accessed at: http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1092*

What causes dementia?

There are several diseases and conditions that result in dementia. These include:

- Alzheimer's disease – this the most common cause of dementia. During the course of the disease the chemistry and structure of the brain change, leading to the death of brain cells. Problems of short-term memory are usually the first noticeable sign.
- Vascular dementia − If the oxygen supply to the brain fails due to vascular disease, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes.
- Dementia with Lewy Bodies (DLB) − this form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning and problem solving. Memory may be affected to a lesser degree. This form of dementia shares some characteristics with Parkinson's disease.
- Fronto-temporal dementia (including Pick's disease) − in fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs.
- There are many other rarer diseases that may lead to dementia, including progressive supranuclear palsy, alcohol-related brain damage (Korsakoff's syndrome), Binswanger's disease, HIV/AIDS, and Creutzfeldt–Jakob disease (CJD). Some people with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease may also develop dementia as a result of disease progression.

Mild cognitive impairment

Some individuals may have noticed problems with their memory, but a doctor may feel that the symptoms are not severe enough to warrant a diagnosis of Alzheimer's disease or another type of dementia, particularly if a person is still managing well. When this occurs, some doctors will use the term 'mild cognitive impairment' (MCI). Recent research has shown that individuals with MCI have an increased risk of developing dementia. The conversion rate from MCI to Alzheimer's is 10-20 per cent each year, so a diagnosis of MCI does not always mean that the person will go on to develop dementia[5].

[5] *The Alzheimer's Society. Accessed on 1st November 2013 at:* http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=106

Who gets dementia?

There are about 800,000 people in the United Kingdom (UK) with dementia[6]. Dementia mainly affects people over the age of 65 and the likelihood increases with age. However, it can affect younger people: there are over 17,000 people in the UK under the age of 65 who have dementia. Dementia can affect men and women. Scientists are investigating the genetic background to dementia. It does appear that in a few rare cases the diseases that cause dementia can be inherited. Some people with a particular genetic make-up have a higher risk than others of developing dementia.

What are the economic costs of dementia?

In 2009, the Alzheimer's Research Trust commissioned the Health Economics Research Centre at the University of Oxford to produce a report on the economic cost of dementia to the UK[7], and the country's investment in research to find new treatments, preventions and cures. They were asked to calculate the care costs of dementia to health services, social services, unpaid carers and others, and compare this to the other great medical challenges of our age: cancer, heart disease and stroke. The findings suggest that the average cost of caring for each individual with Dementia is £27,647 per year; that's more than the UK median salary. By contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year.

The current overall financial cost of dementia is £23 billion a year to the NHS, local authorities and families. This cost is expected to grow to £27 billion by 2018; approximately 55% of which is met by unpaid carers, 40% by social care and 5% by health care. Most caregiving is provided informally by spouses, adult children, other family members and friends, which can have an economic impact as they may be forced to stop working, cut back on work, or take a less demanding job to care for a family member with dementia.

Can Dementia be prevented?

NICE[8] is currently commissioning a number of reviews of the evidence and an economic analysis of; factors associated with dementia, disability and frailty; the effectiveness of

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[6] The Alzheimer's Society. Accessed on 1st November 2013at:
http://www.alzheimers.org.uk/infographic
[7] Alzheimer's Research Trust (2010) The economic burden of dementia and associated research funding in
the United Kingdom.
[8] NICE Accessed on 1st November 2013 at:
http://guidance.nice.org.uk/PHG/64

interventions in midlife to promote healthy behaviours; and the barriers and facilitators to their implementation. The reviews will cover three areas, specifically:

1) Lifestyle factors in midlife and their association with successful ageing and the primary prevention or delay of dementia, non-communicable chronic conditions, frailty and physical disability

2) A review of the effectiveness and cost-effectiveness of midlife interventions for increasing the uptake and maintenance of healthy lifestyle behaviours

3) A review of the issues that prevent or limit the uptake and maintenance of healthy behaviours by people in midlife

Research[9] suggests that following general principles in relation to healthy ageing may be associated with the maintenance of cognitive health. These principles include:

- Preventing or controlling high blood pressure, cholesterol, diabetes, being overweight or obese
- Preventing or stopping smoking
- Being physically active
- Preventing or reducing social isolation

Increased consideration should also be given to certain high risk groups which include; those with learning disabilities, those with Down's Syndrome; people who have had a stroke or have a neurological condition such as Parkinson's disease.

3. National Strategic Context

The National Dementia Strategy[10] set new standards for dementia care. The strategy outlines significant improvements to be made to dementia services across three key areas:

- Improved awareness
- Earlier diagnosis and intervention

[9] *The Alzheimer's Association (2007) The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health. Accessed at: http://www.alz.org/national/documents/report_healthybraininitiative.pdf*

[10] *Department of Health (2009) Living well with Dementia: A National Dementia Strategy. Accessed at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf*

- Improved quality of care

Following publication of the national strategy, The Joint Commissioning Framework[11] looked to integration of health and social care commissioning as one of the ways to deliver improved outcomes for people with dementia and their carers'. It provides a framework of best practice guidance on commissioning each of the service objectives set out in the strategy.

The Prime Minister's Dementia Challenge launched in March 2012[12] builds upon the strategy, but with a push to go further and faster in improving dementia care. The challenge focussed on increasing diagnosis rates and improving the skills and awareness needed to support people with dementia, as well as providing details of plans to improve dementia research.

A World Health Organisation (WHO) and Alzheimer's Disease International report[13] recommends that programmes need to focus on improving early diagnosis; raising public awareness about the disease; reducing stigma; and providing better care and support to caregivers.

The All Party Parliamentary Group (APPG) report[14] made a series of recommendations to improve diagnosis rates for those with dementia. Recommendations included:

- Investment in a sustained public dementia awareness campaign that would align with the Prime Minister's challenge on dementia.
- A recommendation to explicitly quantify the ambition around increasing diagnosis rates, which should be built into commissioning and outcome frameworks, with Public health directors making early dementia diagnosis a priority
- The establishment of a Dementia Action Alliance group to spearhead the creation of a clear and consistent message on the value of diagnosis, early in and throughout the course of the illness, for members to share and communicate

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[11] *Department of Health (2009) Living well with dementia – the National Dementia Strategy Joint commissioning framework for dementia. Accessed at: http://www.dhcarenetworks.org.uk/_library/Resources/Dementia/National_Dementia_Strategy_-_Joint_Commissioning_Framework.pdf*

[12] *Department of Health (2012) Prime Minister's challenge on dementia - delivering major improvements in dementia care and research by 2015. Accessed at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf*

[13] *WHO (2012) Dementia: a public health priority. Accessed at: http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf*

[14] *APPG (2012) Unlocking Diagnosis: The key to improving the lives of people with dementia. All-Party Parliamentary Group report 2012*

- Training of all those who come into contact with those at risk of dementia in the routine asking of questions to identify symptoms of dementia
- Commitment in the Prime Minister's challenge on dementia for regular checks for the over-65s should be widened to include regular checks for all groups at risk of developing dementia
- All health and social care professionals working in a general capacity with people at risk of dementia should have pre- and post-registration training in identifying and understanding dementia
- Support for the extension of mandatory GP training by at least one year and suggests that there should be a focus on dementia in the additional year
- Healthcare assistants (HCAs) and healthcare support workers should have appropriate training for their role and be sufficiently regulated
- Dementia should be a key focus for organisations co-ordinating the training of health professionals, including Health Education England, Universities and deaneries who set the curriculum for health professionals should ensure that the detection of dementia is represented on healthcare courses
- Royal Colleges should act on the plans regarding member training in the Prime Minister's challenge. The Royal College of GPs and members of the Dementia Action Alliance should compile and promote a list of available and effective training in dementia care for health and social care professionals. Service providers, including care homes, should commit dedicated time for training care workers in dementia care
- Issues with the assessment tools used by UK GPs and other primary care professionals should be explored and addressed
- Commissioners should invest in appropriate memory service resources to cater to the needs of their population, as well as being innovative in commissioning in order to meet the needs of their populations
- Strengthening the role of the Memory Services National Accreditation Programme (MSNAP), with accreditation for memory services being mandatory. MSNAP accreditation should include additional measures to ensure accurate recording of key data on memory services. MSNAP should strengthen strands of the programme that concern waiting times and community based work
- Adequate information and one-to-one support should be provided to patients and their families immediately following diagnosis and additional investment to develop the role of dementia advisers

In April 2013 NICE published quality standard guidance which contained a set of ten quality statements[15] which are aimed at supporting people to live well with dementia. These quality statements should also act as a benchmark for assessing the quality of care currently provided.

4. Local Strategic Context

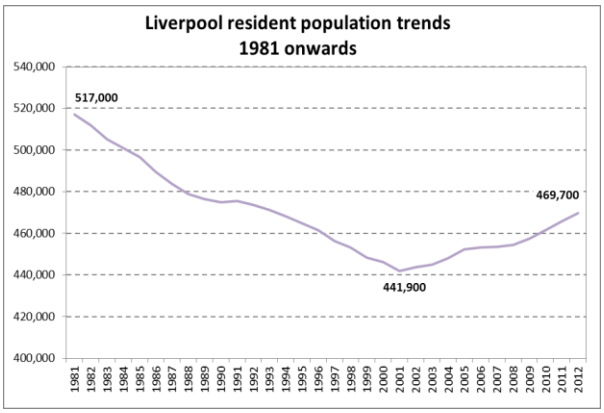
Dementia has been identified by Liverpool Clinical Commissioning Group (LCCG) as one of its priority programme areas. The organisation has identified a clinical and management lead to review and transform provision of care to meet the needs of older people in Liverpool, and more specifically those with dementia. Its portfolio of commissioned services includes those that support the needs of both patients and carers with dementia. Through LCCGs 'Healthy Liverpool Programme', dementia was identified as a priority area and joint work is underway with the Local Authority to develop an integrated model of dementia care for the city. This will include the establishment of a local Dementia Action Alliance, as recommended by the APPG. This will supersede the Year of Action on Dementia (YAD) 2013 group, whose role it was to increase awareness of dementia in Liverpool and ultimately work towards making the city a more 'dementia friendly' place.

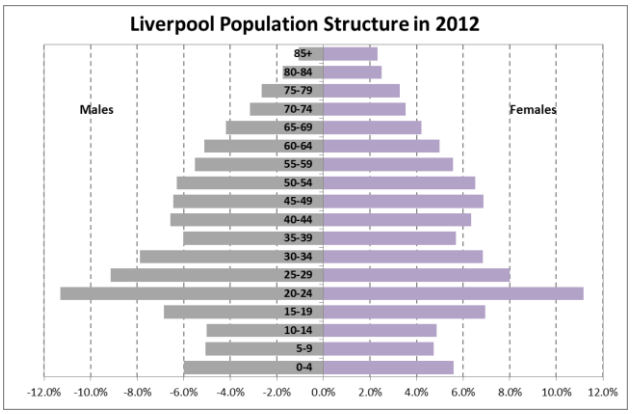
Liverpool City Council (LCC) has an integral role in delivering better outcomes for people with dementia and their carers'. LCC commission and provide generic and specialist services to support people with dementia and their carers by working with partners to design, procure, and monitor social care and housing-related support services. LCC work in partnership with LCCG to offer an integrated service and joint commissioning arrangements are in operation via a Section 75 agreement. This agreement allows the pooling of funds where payments can may be made towards expenditure incurred in the exercise of any NHS or 'health-related' local authority functions.

[15] *NICE (2013) Quality standard for supporting people to live well with dementia. QS30*

5. Demography of Liverpool

Figures for 2012 show there are an estimated 469,700 people living in Liverpool. While this is substantially down from the 517,000 living in the city in 1981, it represents a marked increase from the low point seen in 2001. Since that time the number of people in the city has increased by 6.3%.





Figures 1 and 2: Liverpool Population Trends & Structure, 2012

Source: ONS Mid-Year Resident Population Estimates

Figure 2 shows the current population structure in the city for both males and females. It clearly demonstrates the large student population within the city, with over 11% of people in Liverpool aged between 20 and 24 years old. The relatively large population of children and young adults in the city is reflected in the average age of its residents. At the time of the 2011 Census, the median (average) age in Liverpool was 35 years, compared to 39 years for England.

While the city has a relatively young population, the Office for National Statistics (ONS) project a substantial increase in the number of children and older people in Liverpool over the coming decade.

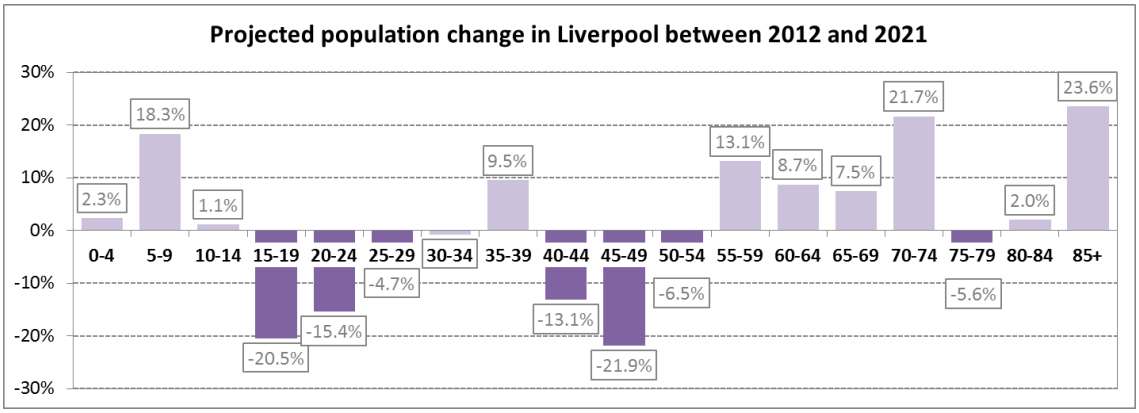


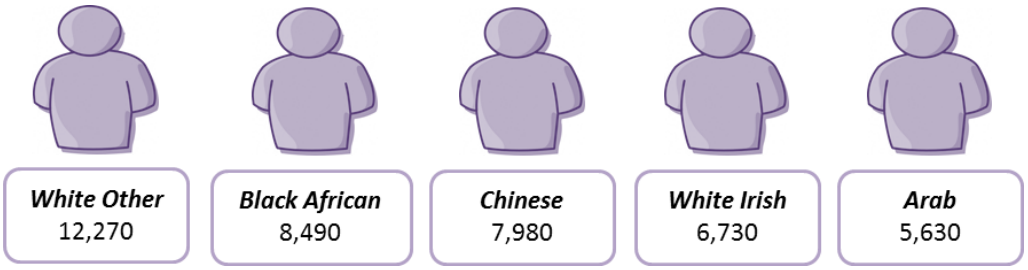
Figure 3: Liverpool Population Projections 2012 to 2021 by age band

Figure 3 clearly illustrates the fall in those of working age and a rise in the older population. This will have an impact of what is described as the 'old age dependency ratio'. This measures the number of people of State Pension Age and over for every 1,000 people of working age. This has implications in terms of increasing prevalence of dementia, but also the ability to meet the needs of those living with dementia, compounded by the decline in the working age population that would ordinarily provide care and economically support the ageing population.

By 2021, it is estimated that the number of people aged over 65 in Liverpool will increase by just over 9%, about 73,500 people. There will be particularly large increases in the number of people aged between 70 and 75, with that population group increasing by more than a fifth.

Figures from the 2011 Census indicate that 15.2% of the Liverpool population are from a minority ethnic group, i.e. non-white British, equating to almost 71,000 residents. This is slightly higher than the regional average (12.9%), but lower than England (20.2%).

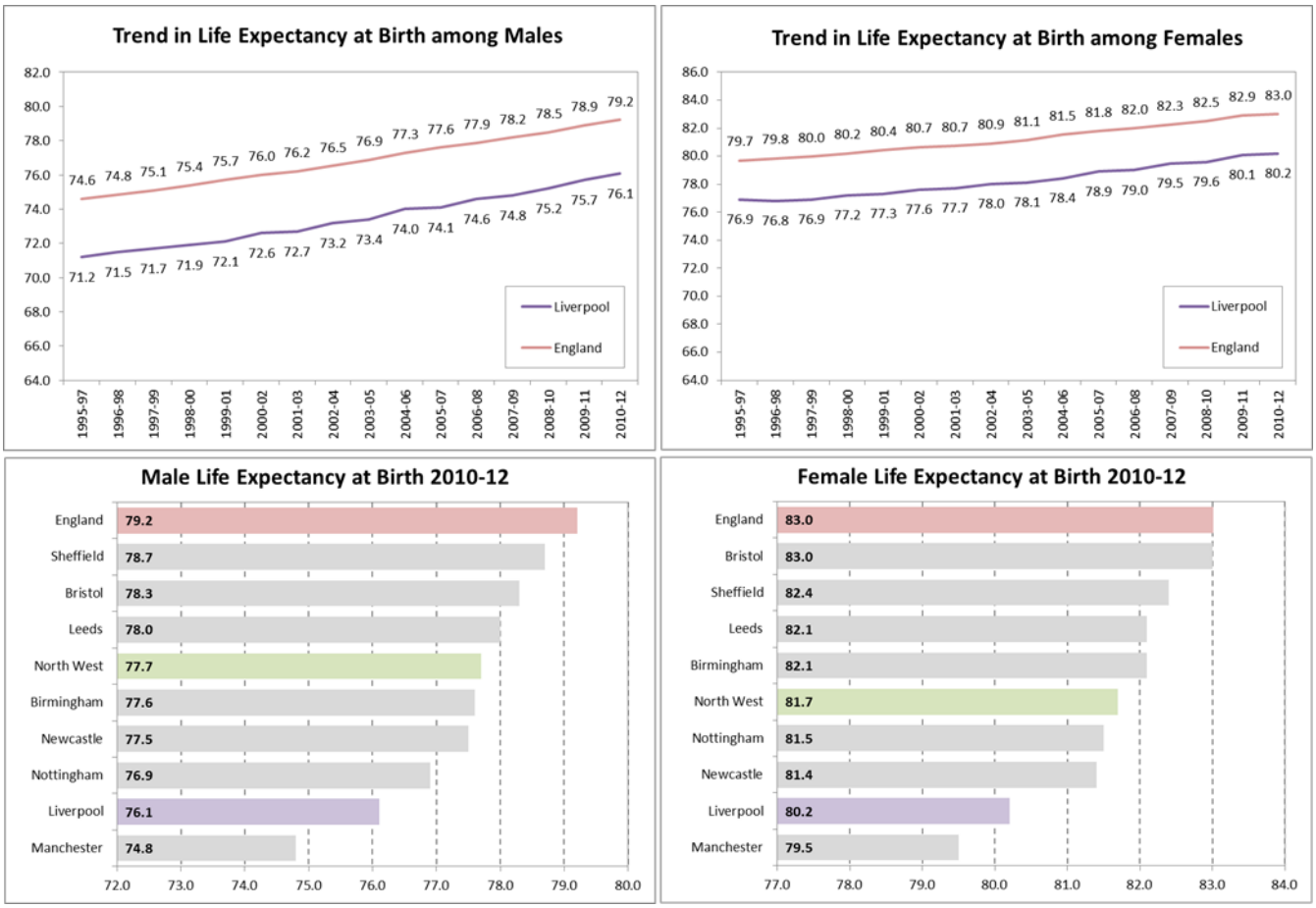
The top 5 ethnic minority groups in Liverpool are:



Between the 2001 and 2011 Census, the largest increase has been seen among the White Other group, followed by Black African and Indian. The change in numbers and age profile of these groups will impact on the need to provide culturally sensitive care for particular ethnic groups, with dementia likely to become a more significant problem as these populations age.

Life Expectancy

Life expectancy at birth is used as an overarching measure of the health of the population. Figures 6-9 below show how there has been a steady increase in life expectancy in Liverpool, with males expected to live 3.6 years longer than they were in 1995-97 and females 2.3 years longer. Data for 2008-10 show that Liverpool has the second lowest life expectancy of the eight core cities in England, slightly above Manchester.



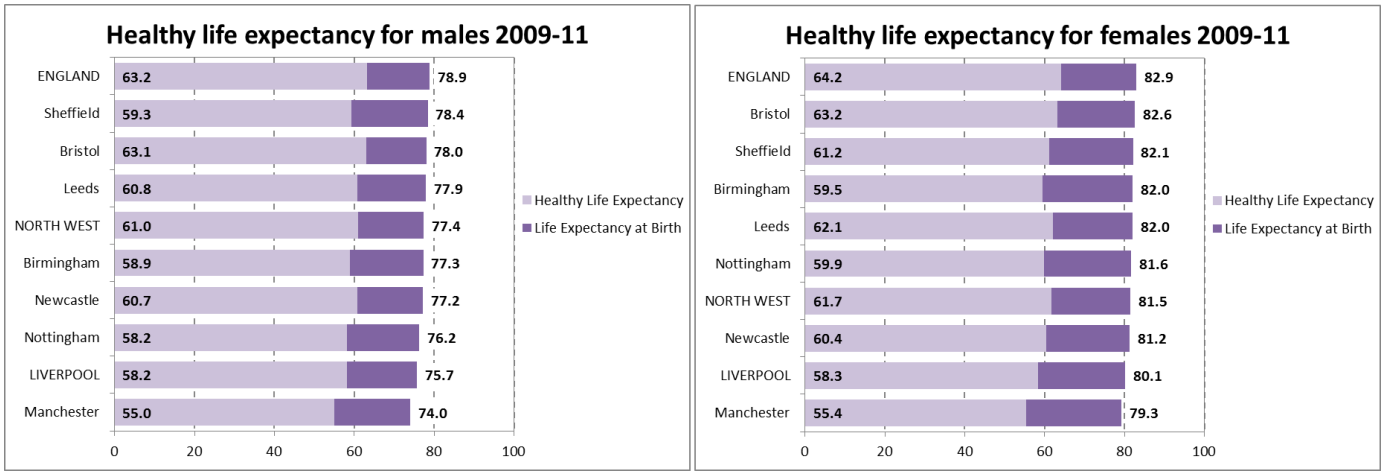
Figures 4 to 7: Life Expectancy at Birth in Liverpool, 2010-12.

The gap in life expectancy between Liverpool and England for men has narrowed by 8.8% since 1995-97, while remaining stable for females. Encouragingly, the gap between males and females within the city has narrowed substantially over the period, from 5.7 years in 1995-97 to 4.1 years in 2010-12 – a reduction of 28%.

Healthy Life Expectancy

Healthy life expectancy is often described as a measure of not just whether years are being added to life, but whether life is being added to years i.e. are people living healthier as well as longer lives. Work carried out by the Office for National Statistics suggest that while females in Liverpool live longer than their male counterparts, this does not translate into years of good health, with healthy life expectancy for both standing at around 58 years.

While there is a significant gap in overall life expectancy between Liverpool and England for both males and females, the gap increases further when looking at the number of years lived in good health. Nationally, males live an additional 5 years in good health when compared to Liverpool, with females living an additional 5.9 years. This burden of ill health within the city has significant implications in terms of demand for health and social care services.



Figures 8 & 9: Healthy Life Expectancy by Core City, 2009-11.

Main Causes of Death

Figure XX illustrates the main causes of death in Liverpool in 2011. Figures show that around 3 in every 4 deaths were due to Cancer, Circulatory Diseases or Respiratory Diseases – consistent with national patterns. Dementia deaths represented 292 (6.9%) of the total 4,232 deaths in Liverpool.

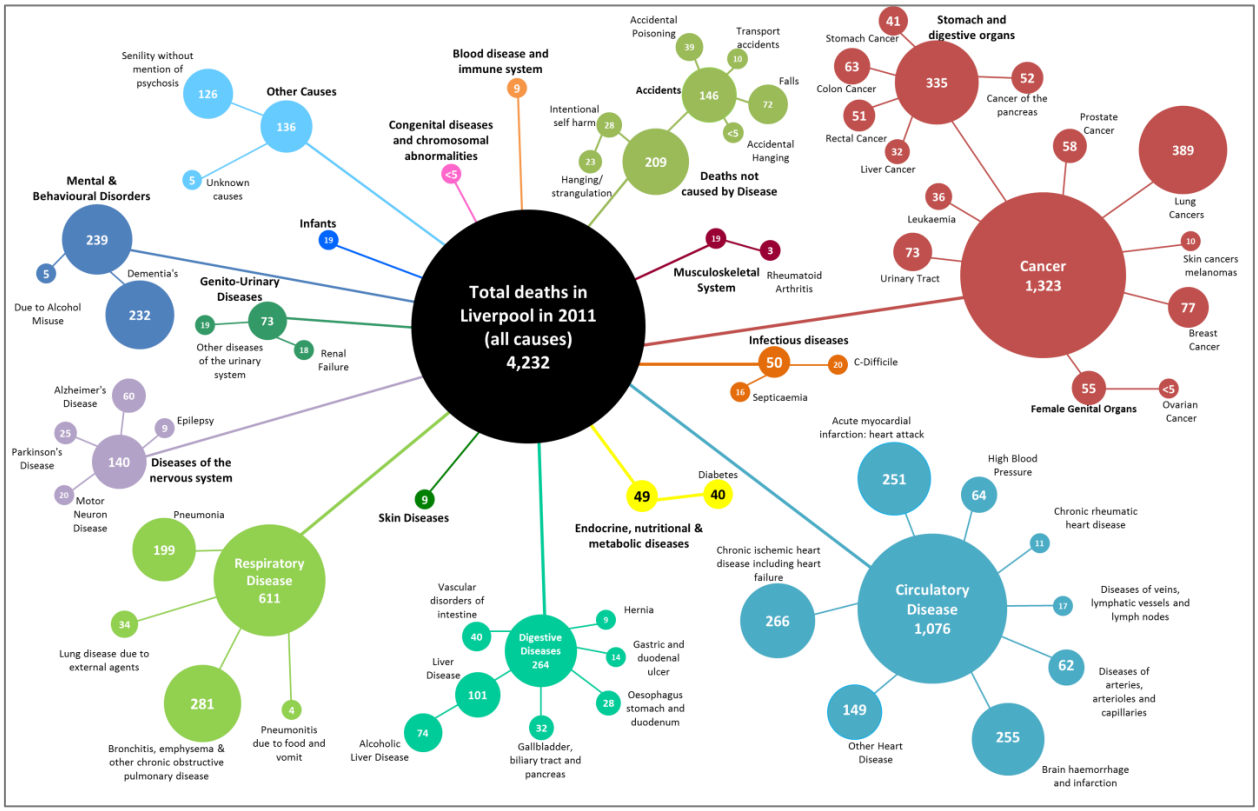


Figure 10: Main Causes of Death in Liverpool, 2011.

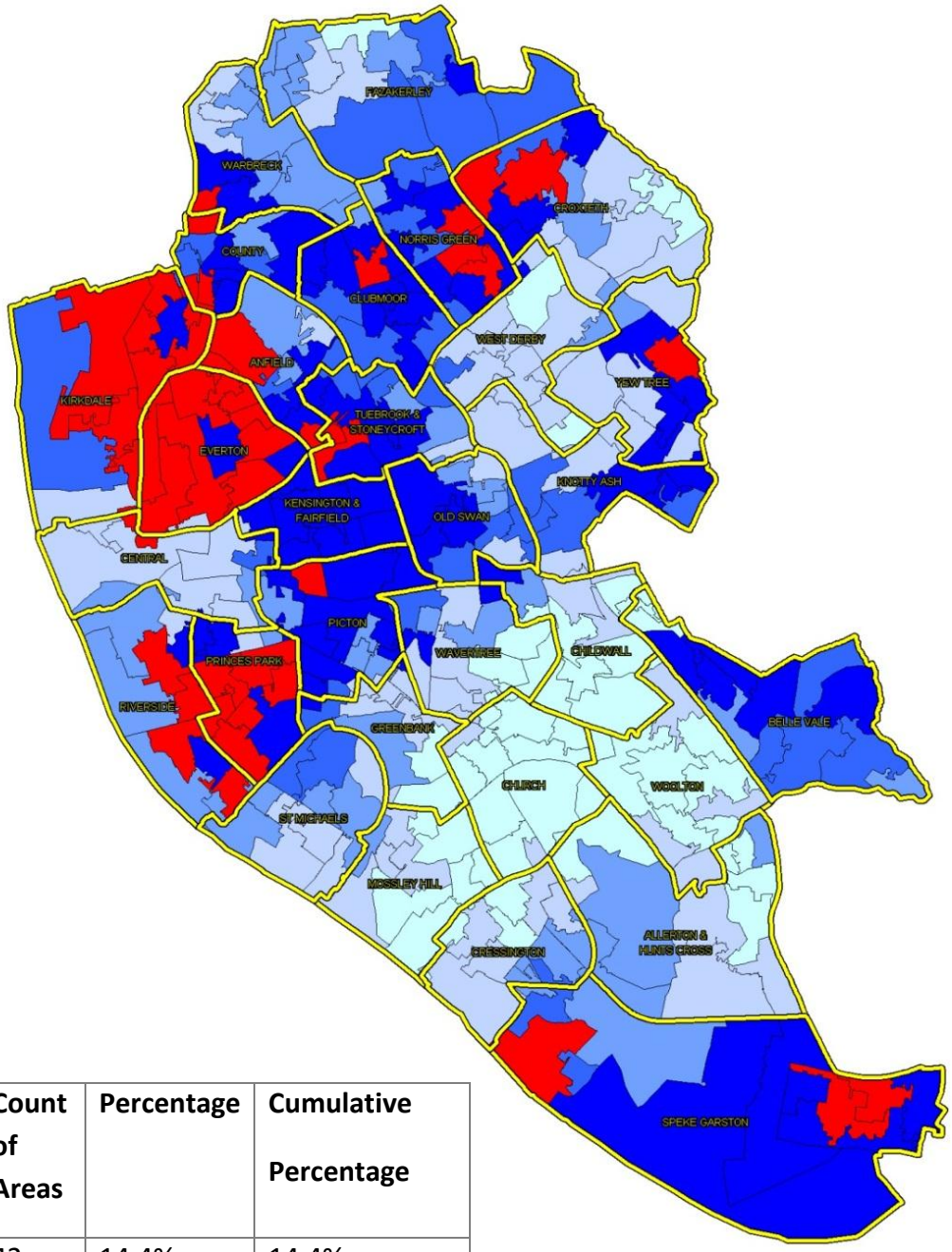
Deprivation

The English Indices of Deprivation 2010 (ID 2010) combine a range of economic, social and housing indicators to provide the most up to date and comprehensive picture of deprivation in England. They provide a measure of relative deprivation, i.e. they measure the position of areas against each other. Results show that Liverpool remains the most deprived local authority in the country, with its position unchanged from the 2004 and 2007 indices. (Figure 11)

City	Rank of Average Score	Average Rank	Extent	Local Concentration	Income	Employment
LIVERPOOL	1	5	4	2	3	2
Manchester	4	4	5	8	2	3
Birmingham	9	13	10	20	1	1
Nottingham	20	17	17	35	17	13
Newcastle	40	66	35	15	29	20
Sheffield	56	84	48	33	6	7
Leeds	68	97	59	44	4	4
Bristol	79	93	73	57	14	9
Note: 1 = most deprived, 326 = least deprived						

Figure 11: Indices of Deprivation, 2010

Levels of deprivation within Liverpool are particularly high in the north of the city, where virtually all of the neighbourhoods are ranked in the most deprived one or ten percent nationally. The map below shows that large areas of Everton, Anfield and Kirkdale are particularly deprived. This concentration of high deprivation also encircles the City Centre, this "inner core" area goes from Everton in the north through Kensington and on to Princes Park and Riverside to the south of the City Centre. Outside of the inner core, Speke Garston, Croxteth and Norris Green also have some of the highest levels of deprivation in the country. (Map 1)



Most Deprived Nationally	Count of Areas	Percentage	Cumulative Percentage
0-1%	42	14.4%	14.4%
1-5%	73	25.1%	39.9%
5-10%	33	11.3%	50.9%
10-20%	43	14.8%	65.6%
20-50%	60	20.6%	86.3%
50%+	40	13.7%	100%

Map 1: Levels of deprivation across Liverpool, 2010.

Income & Poverty

Low income and poverty are significant public health issues, impacting on both physical and mental health. Household income in Liverpool during 2012 was the second lowest of the eight core cities in England. Furthermore, household income in Liverpool fell by over £700 between 2011 and 2012, whereas many of the other core cities saw an increase.

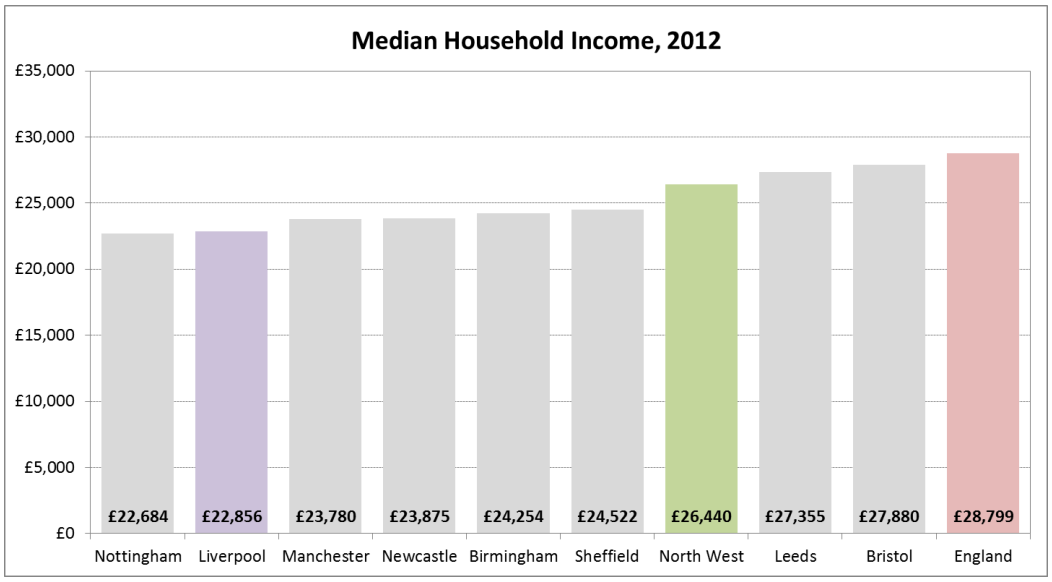


Figure 12: Median Household Income by Core City, 2012

Research by the Institute of Fiscal Studies[16] has shown the median household incomes in the UK fell in 2010-11 by over 3%, the largest one year fall since 1981. The reduction set average living standards back to below levels since in 2004-5. People are thought to live in relative poverty when their household income is less than 60% of contemporary median household income i.e. £17,279. Data from Consumer classification firm - CACI suggests that almost 40% of Liverpool households can be considered to be living at or close to the poverty line, with an income of less than £17,279. This measure does not take into account the number of people living in that household being supported by that income, therefore the higher the number of people in that household then the lower the standard of living. (Figure 13)

[16] *Institute of Fiscal Studies. Living Standards: Poverty & Inequality in the UK, 2012.* http://www.ifs.org.uk/comms/comm124.pdf

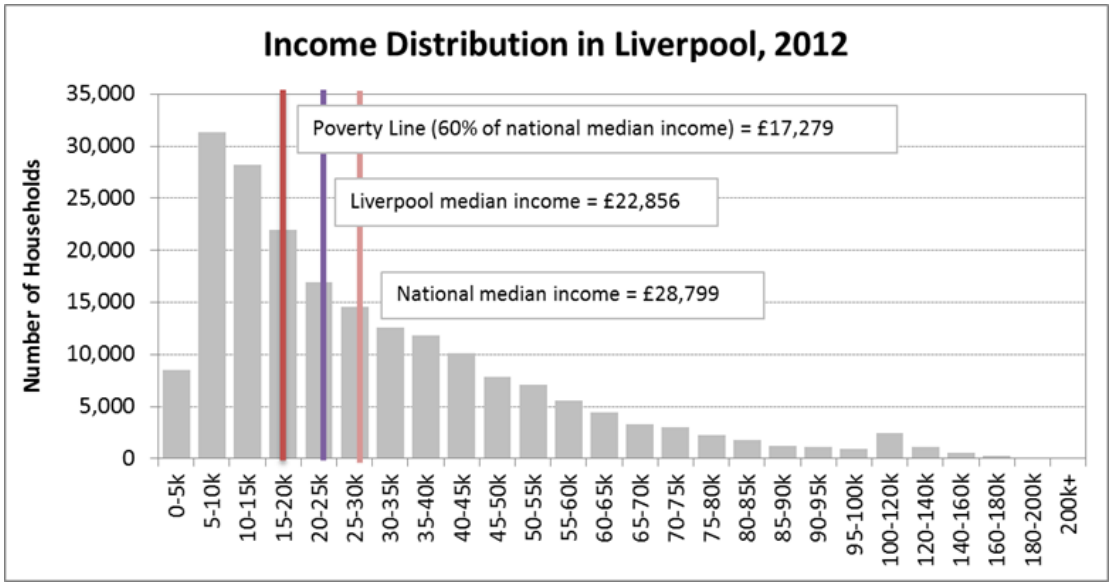


Figure 13: Household Income Distribution in Liverpool, 2012

Population Living Alone

The General Household Survey, which is based upon a sample of the general population resident in private households estimates that 20% of men and 30% of women aged 65-74 years live alone with rates increasing to 34% of men and 61% of women aged 75 and over. An increase of 6% is predicted in the number of people aged 65 and over living alone in the city between 2012 and 2021 (Source: Projecting Older People Population Information (POPPI) 2013).

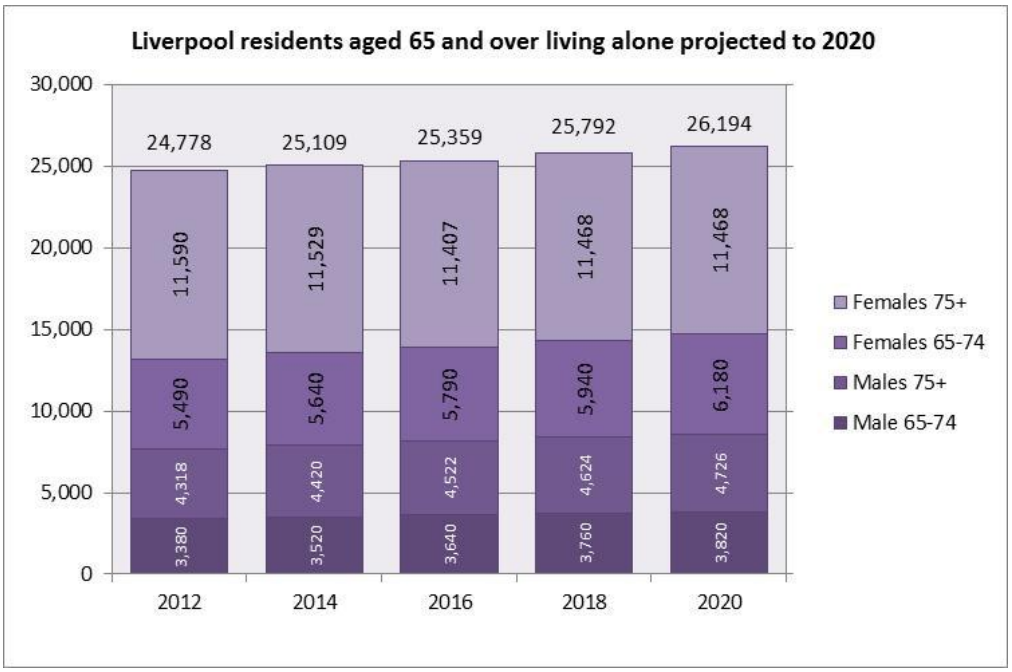
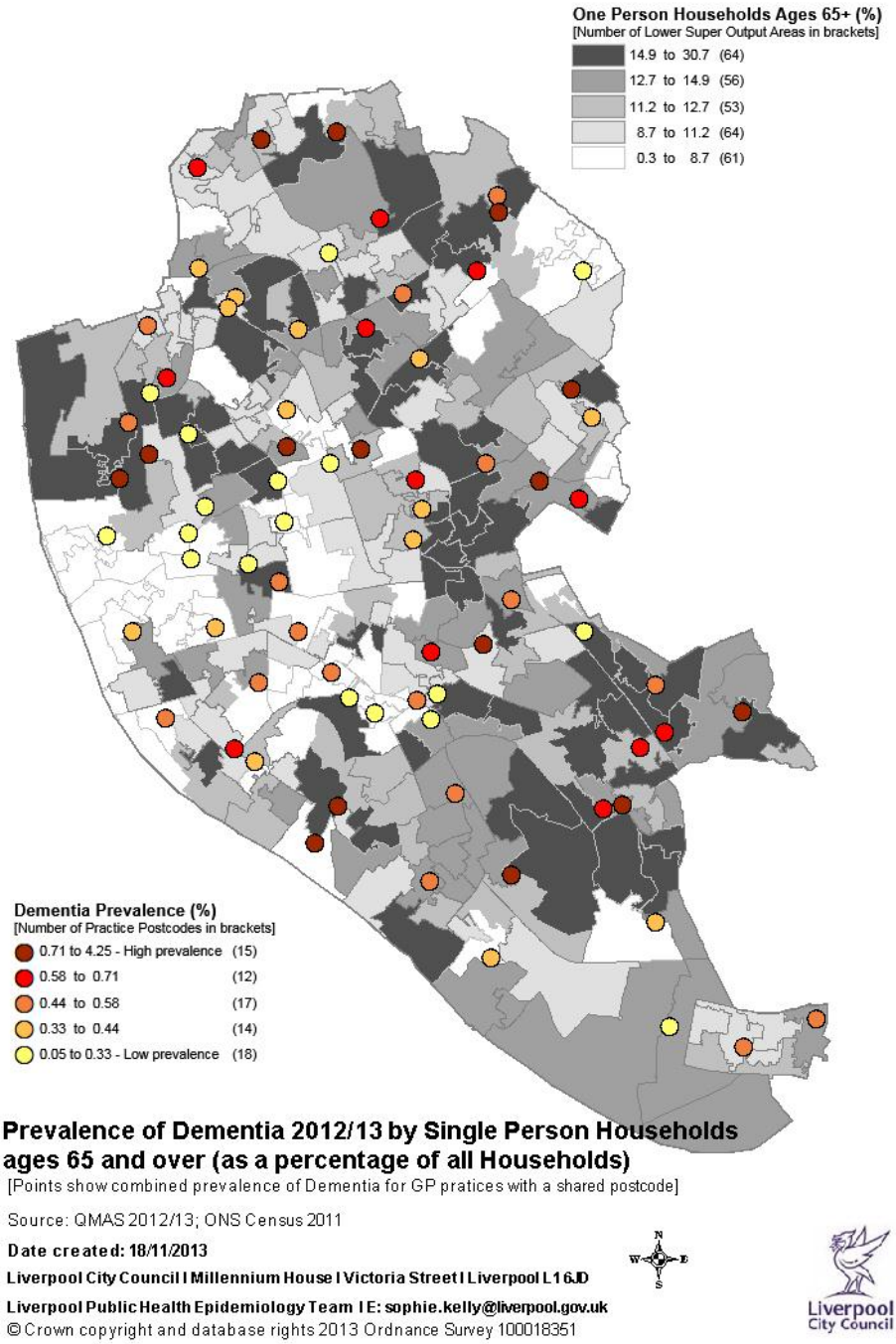


Figure 14: Liverpool residents aged 65+ living alone, 2012 to 2020

The map below illustrates the density of single person households in Liverpool. This data is then overlaid with dementia prevalence rates. There appears to be higher density of both single person households and higher dementia prevalence in the North of the city.



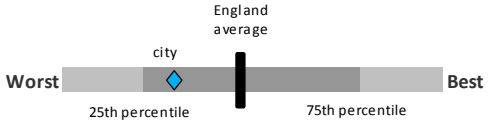
Map 2: Dementia prevalence 2012/13 and percentage of single person households, 2011

6. Epidemiology of Dementia

Keys:

- Significantly better than the England average
- Not significantly different to the England average
- Significantly below the England average
- No significance can be calculated

Improvement ▲
No change ◀▶
Decline ▼



Key Statistics for Liverpool CCG

The chart below shows how the dementia-related health of people in this city compares with the England average. The result for each indicator is shown as a circle. The England average is shown by the black line, which is always at the centre of the chart. The grey bar shows the range of results for local areas. Note: For indicators 1 & 2 a red circle indicates a significantly ageing population with increased dementia risk.

No.	Indicator	Number	Population	Liverpool rate		Previous rate	Rank out of 211 CCGs	England average	England worst	England range	England best	North West	Source	Value	Period	Previous Period
1	Male Population Ages 65+ %	31983	248890	▲	12.9	12.7	55	15.3	24.6		5.4	15.7	C&MCSU/ H&SCIC	%	Jun-13	Jun-12
2	Female Population Ages 65+ %	39674	247780	▲	16.0	15.9	57	18.4	27.6		6.8	18.9	C&MCSU/ H&SCIC	%	Jun-13	Jun-12
3	PCT Deprivation Score (IMD 2010)				43.4		150	21.7	45.3		8.8	27.2	DCLG	Mean	2010	n/a
4	DEM1 Dementia Prevalence %	2707	496221	▲	0.55	0.50	128	0.57	0.22		1.13	0.63	QOF	%	2012/13	2011/12
5	Actual versus Expected Dementia Prevalence %	2707	4883	▲	55.4	50.6	38	49.6	22.2		92.1	54.1	QOF	%	2012/13	2011/12
6	DEM2 The % of patients diagnosed with dementia receiving a care review	1986	2445	▲	81.2	79.5	167	83.2	76.0		91.1	83.4	QOF	%	2012/13	2011/12
7	DEM4 The % of patients with a new diagnosis of dementia from 1 April 2012 to have tests	348	498	▼	69.9	79.4	171	76.6	51.9		90.4	74.7	SUS	%	2012/13	2011/12
8	Memory Clinic (Mossley Hill & Walton) Referral Rate per 100,000	736	496934	▲	148.1	140.7	...		...		...		Mersey care	Rate per 100,000	2012/13	2011/12
9	Memory Clinic (Mossley Hill & Walton) Referrals Actual versus Expected	736	944	▲	78.0	74.0	...		...		...		Mersey care	%	2012/13	2011/12
10	Dementia Admissions Rate per 100,000 European Standard Population	2887	496934	▼	370.0	414.0	...		...		...		SUS	DSR per 100,000	2012/13	2011/12
11	Dementia Mortality Rate per 100,000 European Standard Population (5-Year Pooled)	3365	2434295	▲	84.6	81.5	...		...		...		OPEN EXETER	DSR per 100,000	2008-12	2007-11
12	Dementia Age-Standardised Years of Life Lost Under 75 Years per 10,000 population (5-Year Pooled)	1122.5	2247681	▲	4.7	4.6	...		...		...		OPEN EXETER	DSR per 10,000	2008-12	2007-11
13	Dementia Prescribing Unit Costs (per patient on the Dementia register)	£295,109	2707	▼	£109.02	£187.68	...		...		...		PCA SYSTEM	%	2012/13	2011/12

Figure 15: Key Statistics for Liverpool CCG – Dementia

		Neighbourhoods																		Locality			2012/13		2011/12	
Category	**KEY:** Red = Bottom quartile Amber = Mid-range Green = Top quartile	Aintree	Anfield	Belle Vale	Childwall	City Centre / Vauxhall	Croxteth	Dovecot & Old Swan	Everton / Great Homer Street	Garston / Allerton / Aigburth	Gateacre / Woolton	Kensington to Abercromby Neig	Norris Green	Picton	Riverside	Speke	Tuebrook / Stoneycroft	Walton	Wavertree	Liverpool Central	Matchworks	North	Liverpool	England	Liverpool	+/- % Annual Change
PREVALENCE	Deprivation Score (IMD)	34.5	58.9	42.8	24.2	41.1	40.4	40.1	64.1	27.4	25.5	56.0	54.3	56.7	40.7	57.4	49.3	55.6	24.4	49.0	32.2	45.8	43.4	21.7		
	DEM1 Dementia Prevalence %	0.77	0.43	0.69	0.56	0.20	1.06	0.62	0.53	0.79	0.66	0.34	0.47	0.52	0.55	0.38	0.62	0.40	0.30	0.45	0.63	0.65	0.55	0.57	0.50	10%
	Actual versus Expected Dementia Prevalence %	66.6	53.4	60.2	43.8	79.4	119.2	56.8	59.4	59.3	42.0	40.0	46.2	71.3	65.6	39.3	57.4	40.1	38.5	55.7	51.3	61.9	55.4	49.6	50.6	9%
PRIMARY CARE	DEM2 The % of patients diagnosed with dementia receiving a care review	76.5	78.5	87.0	81.1	77.0	89.4	82.5	83.9	76.2	82.1	81.7	87.8	84.5	71.2	80.0	79.5	89.5	88.6	80.9	79.6	84.0	81.2	83.2	79.5	2%
	DEM4 The % of patients with a new diagnosis of dementia from 1 April 2012 to have tests	83.6	57.9	38.5	82.5	78.6	53.8	50.0	63.6	77.3	83.8	50.0	90.0	36.2	67.0	76.9	74.4	78.6	76.9	53.4	80.2	77.6	69.9	76.6	79.4	-12%
	Memory Clinic (Mossley Hill & Walton) Referral Rate per 100,000	16.5	33.6	184.7	253.5	85.9	23.9	242.6	144.4	252.4	192.7	162.2	34.5	200.7	222.4	207.0	135.9	26.2	164.1	167.2	204.9	24.4	148.1	...	140.7	5%
	Memory Clinic (Mossley Hill & Walton) Referrals Actual versus Expected	8.7	17.7	97.2	133.4	45.2	12.6	127.7	76.0	132.8	101.4	85.3	18.2	105.6	117.0	109.0	71.5	13.8	86.4	88.0	107.8	12.8	78.0	...	74.0	5%
	Dementia Prescribing Unit Costs (per patient on the Dementia register)	£41	£54	£171	£187	£119	£22	£143	£55	£113	£162	£120	£92	£139	£115	£153	£99	£47	£177	£127	£134	£45	£109	...	£188	-42%
SECONDARY CARE	Dementia Admissions Rate per 100,000 European Standard Population	365.3	366.2	514.9	312.4	466.4	553.8	428.3	512.2	310.9	277.3	268.3	360.9	420.7	482.9	308.7	437.4	340.2	171.7	406.0	322.3	384.1	370.2	...	414.0	-11%
MORTALITY	Dementia Mortality Rate per 100,000 European Standard Population (5-Year Pooled)	78.0	61.6	77.3	66.6	122.5	219.1	86.6	78.9	98.2	52.9	57.6	62.1	128.4	139.9	57.3	94.0	57.8	59.3	87.2	79.7	88.4	84.6	...	81.5	4%

Figure 16: Key Statistics for Liverpool CCG by GP Neighbourhood

Figures 15 and 16 above give a comprehensive picture of some of the key indicators in relation to dementia care and support - the first chart benchmarks Liverpool against the national picture and the second chart illustrating performance at Liverpool GP neighbourhood (NBH) and locality level. Liverpool is performing above the national average in the actual versus expected dementia prevalence rates but performs below the national average in overall dementia prevalence, baseline screening of dementia patients, dementia patients receiving annual review, dementia mortality and years of life lost.

At locality level Matchworks performs most strongly against all of the indicators, at GP NBH level Gateacre and Woolton NBH have highest number so f indicators in top quartile, whilst Croxteth NBH have the highest numbers of indicators in the bottom quartile. These indicators will be further disaggregated in more detail.

Prevalence of Dementia

Prevalence of dementia increases with age and is estimated to be approximately 19.7% for males and 25.2% for females at 85 years of age and over, with prevalence higher in women due to their longer lifespan. Dementia prevalence in Liverpool is significantly lower than the England average (0.55% compared to 0.57% nationally). In 2012/13 there were 2707 registered patients in the city with a diagnosis of dementia, up 250 patients from 2011/12 (QOF, 2012/13). The Liverpool rate is the lowest on Merseyside and within the mid-range among the core cities.

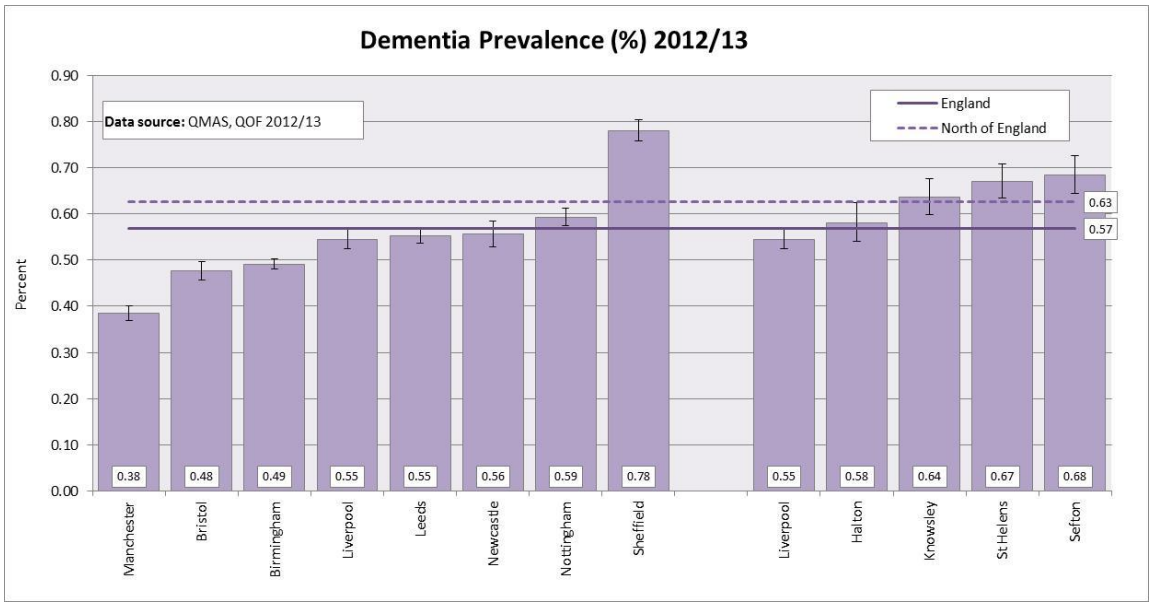


Figure 17: Dementia Prevalence by Core City, 2012-13

Between 2006/07 and 2012/13 there was a 33.5% increase in dementia prevalence. This compares to an increase in prevalence of 43.5% nationally over the same period. The number of patients with a diagnosis of dementia has increased by 745, up from 1962 registered patients in 2006/07 to 2707 registered patients in 2012/13, a 38% increase.

Using the latest available subnational population projections released by the Office for National Statistics in September 2012 and applying estimates of population prevalence of dementia by age and sex to practice registered populations we are able to predict the numbers of people expected to have dementia in 2021. The number of people with dementia is predicted to rise in the city by 19.5% for males (from 1769 to 2114), by 5.8% for females (from 3113 to 3293) and by 10.7% overall (from 4883 to 5407) between 2013 and 2021 largely due to increases in the older population.

When dementia prevalence was standardised by age and sex and analysed at GP neighbourhood level, Croxteth, City Centre/Vauxhall and Picton neighbourhoods were shown to have significantly higher prevalence of dementia than the Liverpool average. By comparison, prevalence was significantly lower in Belle Vale, Kensington & Fairfield, Wavertree, Walton, Speke, Gateacre/Woolton and Childwall neighbourhoods.

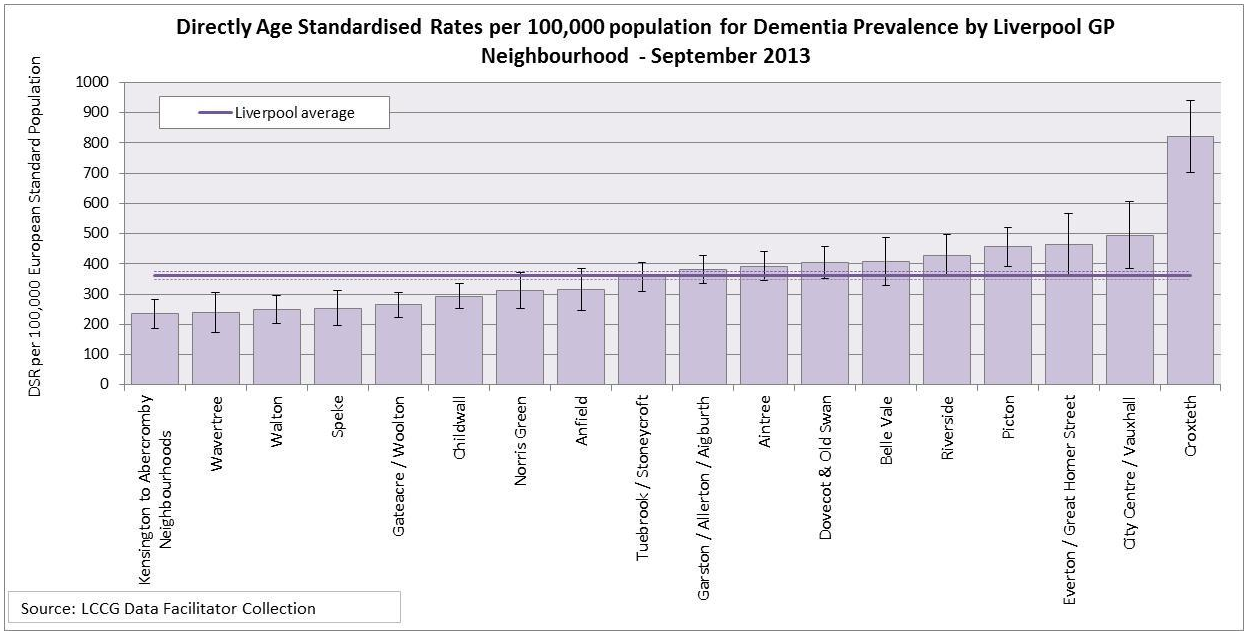


Figure 18: Age Standardised Dementia Prevalence by GP Neighbourhood, 2013

Actual Versus Expected Prevalence

The chart below illustrates the actual prevalence of dementia at GP neighbourhood level versus what we would expect using consensus estimates. The lowest achievement rate is in Wavertree neighbourhood (38.5%) and the highest in Croxteth neighbourhood (119.5%). Rates of achievement were significantly lower than the Liverpool average in Wavertree, Speke, Kensington to Abercromby, Walton, Gateacre/Woolton, Childwall and Norris Green

neighbourhoods and significantly higher in Riverside, Aintree, Picton, City Centre/Vauxhall and Croxteth.

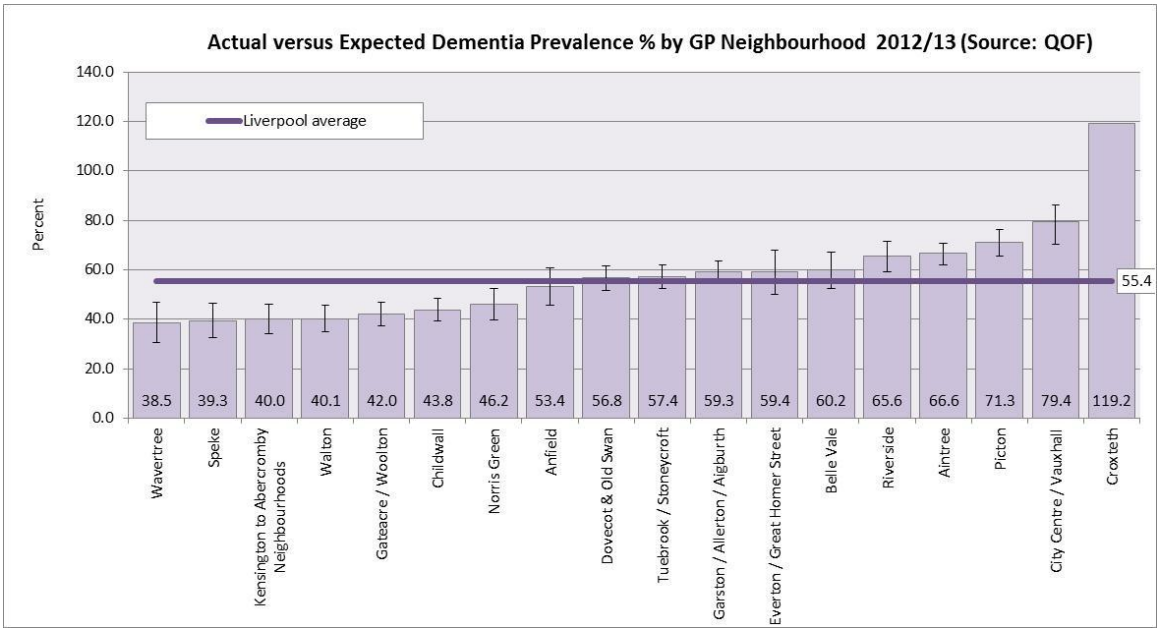


Figure 19: Recorded v Expected Prevalence of Dementia, 2013.

An audit of Liverpool GP clinical systems in September 2013 showed there were 2,776 patients with dementia, of which just under two thirds were females (64%). 5.4% of patients have a diagnosis of early onset dementia (approximately 150 patients aged under 65 years). Females aged 85 years and over accounted for just over one in four patients with dementia (27%) whilst one in ten patients were males aged between 80-84 years.

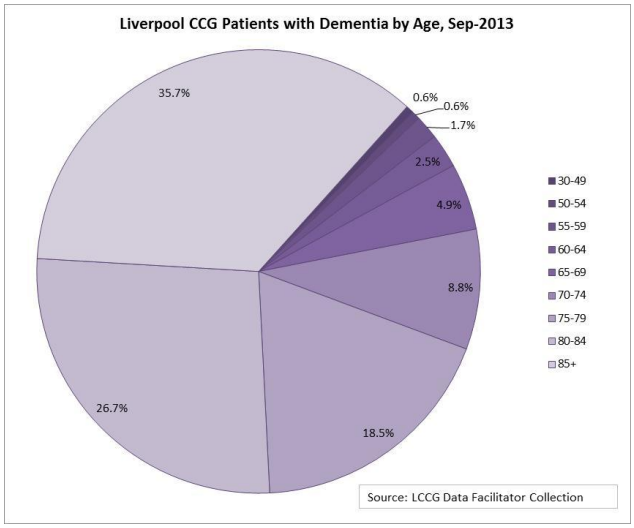


Figure 20: Dementia patients by Age, 2013

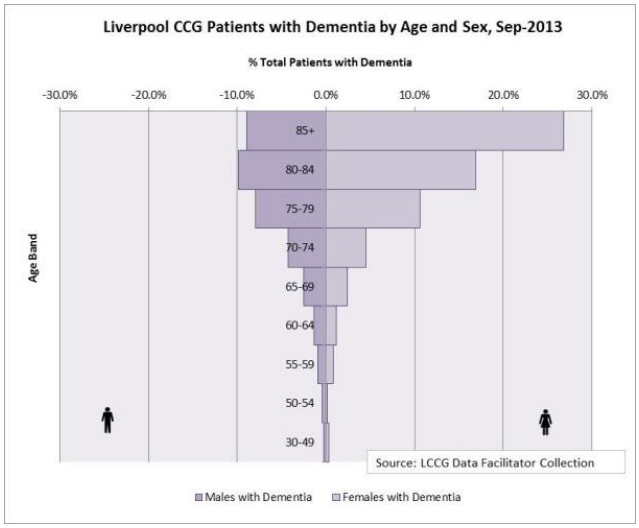


Figure 21: Dementia patients by Age and Sex, 2013

When dementia prevalence by age and sex was compared to consensus estimates of population prevalence of dementia there was an estimated shortfall of 2,107 patients. More patients than expected have been diagnosed with dementia among men aged between 60-64 and women aged between 55-59 and 60-64. The category with the greatest number of undiagnosed patients was women aged 85+.

It is estimated that in 2011 there were 25,000 people with dementia from black, asian and minority ethnic (BAME) groups in England and Wales[17]. This number is expected to double to 50,000 by 2026 and rise to over 172,000 by 2051. This is a nearly a seven-fold increase in 40 years, compared to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period.

The proportion of older people from BAME groups in the UK is increasing rapidly, as the numbers of older people from these groups increases. However, a report by the All Party Parliamentary Group[18] on dementia into dementia among people from BAME groups found they were under-represented in services and often diagnosed at a later stage of the illness, or not at all.

For those patients with dementia and for whom ethnic group could be provided: 93.5% were White British; 1.9% were White Irish; 1.5% were White Other whilst Mixed/Multiple Ethnic Groups, Asian, Black/African/Caribbean/Black British and Any Other Ethnic group accounted for the remaining 3.1% (Figure 22). When these figures are analysed against overall ethnicity figures, then those with dementia from BAME groups appear to be under-represented, as those from BAME groups make up 15.2% of the Liverpool population - this should be an area for further review.

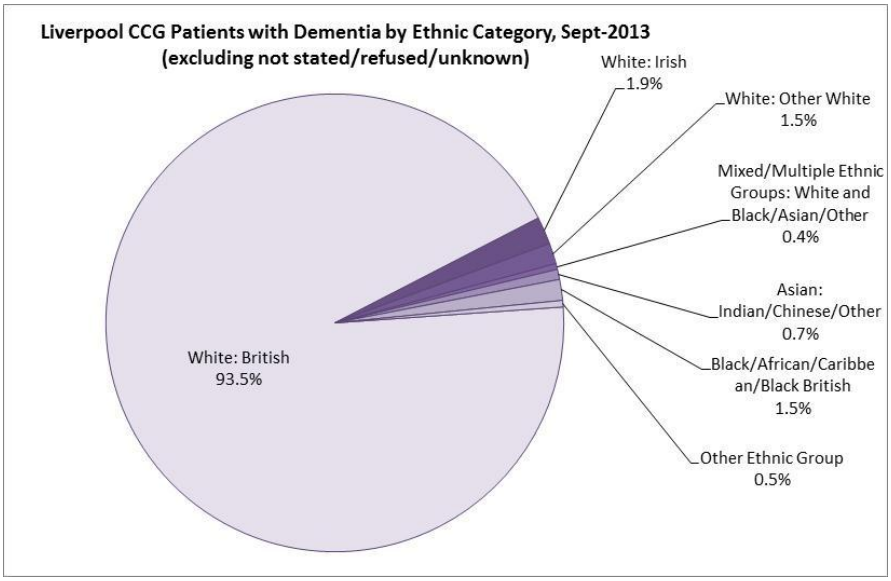


Figure 22: Dementia patients by Ethnic Group, 2013

[17] *The Alzheimer's Society. Accessed on 1st November at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=412*

[18] *APPG (2013) Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities. Accessed at: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1857*

Dementia UK[19] estimates that 63.5% of people with late onset dementia live in private households (in the community) and 36.5% live in care homes. The proportion of those with dementia living in care homes rises steadily with age, from 26.6% among 65–74 year olds to 60.8% among ages 90 and over. Based on these estimates of dementia, in Liverpool it is estimated that 3,161 people with dementia live in the community and 1,651 require a care home.

Age Group	< 65	65-69	70-74	75-79	80-84	85-89	90-95	95+	Totals
Living in Community	120	176	349	602	866	609	378	61	3,161
Living in Care Homes	0	88	88	279	279	375	375	167	1,651
Total	120	264	437	881	1145	984	753	228	4,812

Figure 23: Expected Place of Residence for people living with dementia in Liverpool

Source: NHS Dementia Calculator, Liverpool CCG, July 2013

Among people with late onset dementia (ages 65 and over), it is estimated that 55.4% (2,648) have mild dementia, 32.1% (1,570) have moderate dementia and 12.5% (598) have severe dementia. The proportion considered to have severe dementia increases with age, from 6.3% for those aged 65 to 69 years to 23.3% for those aged 95 years and over.

Severity by Age Group

Age Group	< 65	65-69	70-74	75-79	80-84	85-89	90-95	95+	Totals
Mild	60	163	274	502	650	534	368	97	2,648
Moderate	60	85	133	278	365	321	249	79	1,570
Severe	0	17	31	102	130	129	136	53	598
Total	120	265	438	882	1145	984	753	229	4,816

Figure 24: Expected Severity of Dementia in Liverpool by Age Group

Source: NHS Dementia Calculator, Liverpool CCG, July 2013

NB: Numbers may not sum due to rounding

[19] *Dementia UK (2007) A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society.*

Disability and Dementia

The Disability Adjusted Life Year (DALY) is a measure of the years of healthy life lost due to illness or injury and is calculated as the sum of both the years of life lost due to premature death and those lost due to disability. One DALY is considered to be one lost year of 'healthy' life. Applying estimates of DALYs for Alzheimer's and related dementias (WHO, 2004) by age and sex to the Liverpool registered population, we are able to approximate the number of healthy years lost due to dementia among diagnosed and undiagnosed patients.

It is estimated that in 2013 residents in the city will lose 2,324 healthy years due to dementia. As can be expected, the greatest burden falls among persons aged 60 and over who account for 92% of total Dementia DALYs. Among persons aged 60 and over in the city, healthy years lost due to dementia accounted for 8.99% of total DALYs for this age group.

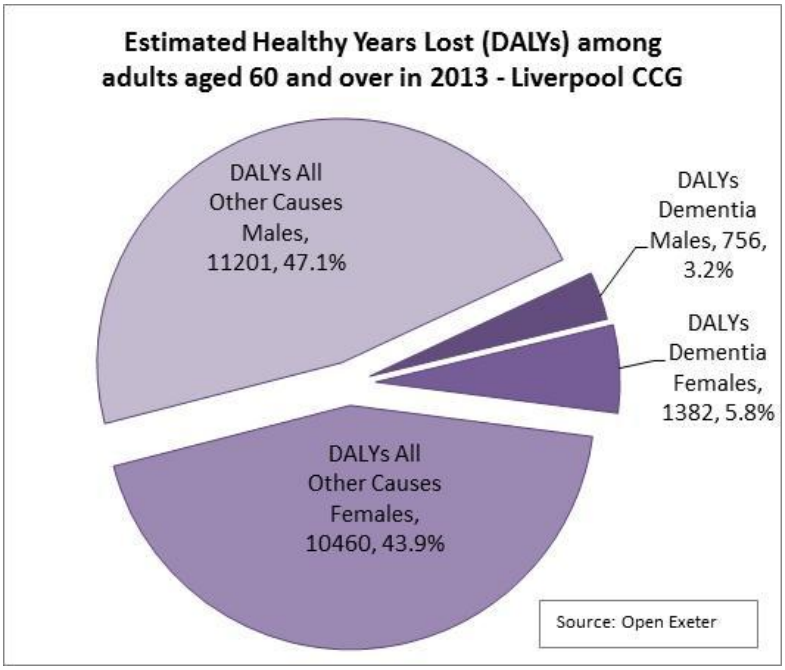


Figure 25: Disability Adjusted Life Years in Liverpool, 2013.

High Risk Groups

There are certain groups who are at greater risk of developing dementia. The characteristics of these groups are outlined below:

- Prevalence of early onset dementia is 2.2% for the UK population as a whole with rates of prevalence higher among BME communities at 6.1%. It is predicted that the number of people with dementia from BME groups will rise quickly as the population ages
- People with cardiovascular disease (CVD), stroke, peripheral vascular disease or diabetes are known to be at a higher risk of developing dementia. Examining disease prevalence

among a sample of patients aged 65 and over with a diagnosis of dementia shows patients with dementia have comparatively higher rates of heart failure, epilepsy, depression and coronary heart disease compared to the Liverpool population aged 65 years and over[20]

- Those with Down's syndrome have an increased genetic risk of developing dementia[21]. When people with Down's syndrome develop dementia, this is usually due to Alzheimer's disease. However there is a growing awareness that people with Down's syndrome can develop other forms of dementia. Studies have shown that the numbers of people with Down's syndrome who have Alzheimer's disease are approximately: 1 in 50 of those aged 30 to 39 years: 1 in 10 of those aged 40 to 49 years: 1 in 3 of those aged 50 to 59 years: more than half of those who live to 60 or over.

- People with learning disabilities may experience a higher risk of dementia because of premature ageing. Studies suggest the numbers of people with learning disabilities other than Down's syndrome who have dementia are approximately: 1 in 10 of those aged 50 to 65: 1 in 7 of those aged 65 to 75: 1 in 4 of those aged 75 to 85: nearly three-quarters of those aged 85 or over. These numbers indicate a risk about three to four times higher than in the general population. At present we do not know why this is the case and further research is needed. Genetic factors may be involved, or a particular type of brain damage associated with a learning disability could be a cause.

In 2012 there were 2,165 patients aged 18+ with a learning disability known to their GP, of those:

- 8.9% of the patients were aged 65+

- 623 (28.7%) patients had received a learning disability health assessment in previous 12 months

- An NHS Health Check Health Action Plan was completed for 252 (11.6%) of patients on the learning disability register up 0.5% on the previous year.

- People with long-term neurological conditions which have a known neurodegenerative element, for example, Parkinson's disease are known to be at increased risk of developing dementia.

- The Jewish community has a much larger percentage of older people than other communities; 40% are over 60, twice as large as the UK population average and it has the highest percentage of 90-95 year olds of any other group within the UK[22]. Merseyside Jewish Community Care (MJCC) provides support services to the carers of

[20] *Source: Liverpool GP clinical systems - March 2013*
[21] *http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103*
[22] *Jewish Care 2011*

clients with memory problems and dementia such as training sessions with Merseycare, carer's breaks and access to welfare benefits. MJCC is aware of 53 Jewish people with memory and dementia problems that affect their daily lives; this number has increased from 12 people in 2006. Of these, 13 are male (7 living independently in community and 6 living in a care home); 40 are females (17 living independently in community and 23 in a care home). Due to an ageing community this figure is likely to continue to increase.

- In a third of cases, dementia is associated with other psychiatric symptoms (depressive disorder, adjustment disorder, generalised anxiety disorder, alcohol related problems). Liverpool has one of the highest rates of alcohol related hospital admissions in England, although recent figures suggest these rates are beginning to plateau. A comprehensive review[23] by Smith & Atkinson (1995) suggested alcohol was a contributing factor in between 21% and 24% of all people of working age, presenting with dementia. Applying these estimates to people with dementia aged under 65 years, it is estimated up to 36 people in the city have dementia which is alcohol related (Figure 26). As these estimates are based on numbers of patients on the dementia register, true prevalence is likely to be higher due to undiagnosed cases.

	Males	Females	Persons
Number with non ARBD dementia aged under 65 (Sept-13)	60	54	114
Number with ARBD aged under 65 (Sept-13)	19	17	36
Total number with dementia aged under 65 (Sept-13)	80	70	150

Figure 26: Early Onset Dementia estimates, 2013

- Defined as cognitive decline greater than expected for an individual's age and education level, but that does not interfere notably with activities of daily life, Mild Cognitive Impairment should be regarded as a risk state for dementia - identification aids secondary prevention. There is debate as to whether individuals diagnosed with MCI should be reviewed regularly by primary care to monitor for development of dementia. Prevalence in population-based epidemiological studies ranges from 3% to 19% in adults older than 65 years[24].

[23] *Smith DM, Atkinson RM. Alcoholism and dementia. International Journal of Addiction 1995;(30):1843-69.*

[24] *Gauthier, S. et al (2006) Mild Cognitive Impairment. The Lancet. Volume 367. Issue 9518. Pages 1262 – 1270.*

7. Prevention

There is growing evidence that certain medical conditions - such as high blood pressure, diabetes and obesity - may increase the risk of dementia, whereas a healthy lifestyle may reduce the risk[25]. Other research suggests that the wider determinants of health may play a bigger role in determining the risk of developing dementia in later life, these include the number of years spent in education; having an intellectually-challenging job, and being socially engaged as you get older, can help reduce the amount of time you live without dementia[26].

The chart below shows that of the 206,515 households in Liverpool, 24,610 (11.9%) were single person households resided in by those aged 65+.

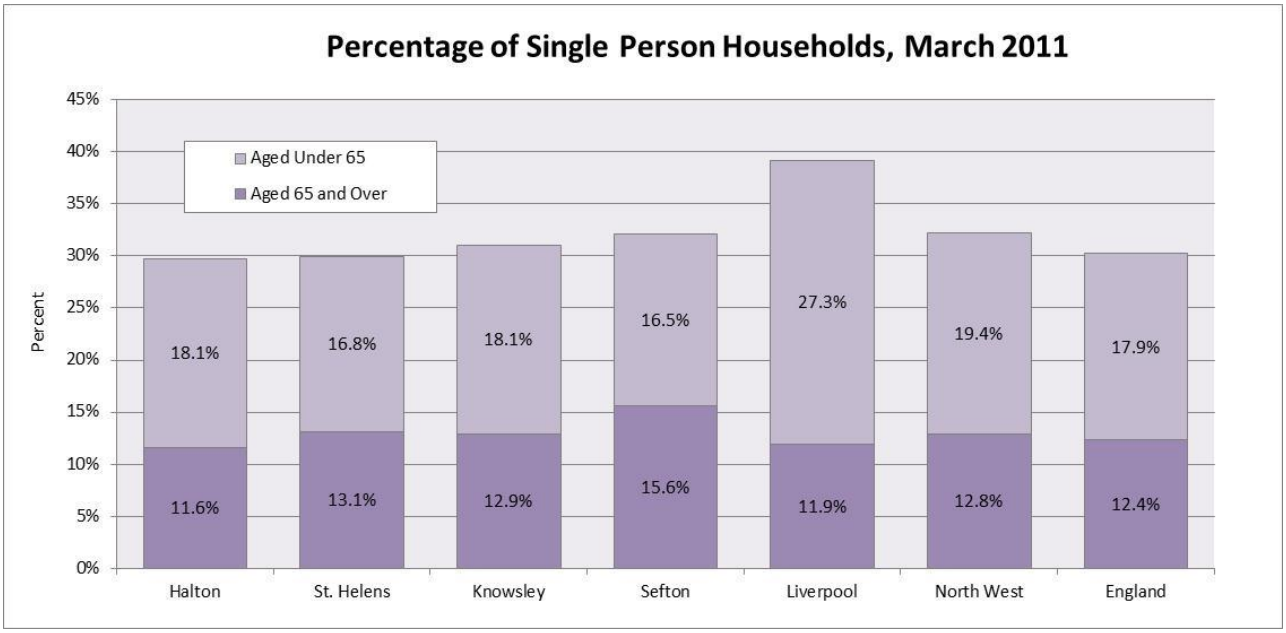


Figure 27: Percentage of Single Person Households across Merseyside

Source: Census 2011

[25] *Alzheimer's Society (2013) What is Dementia. Accessed at: http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1092*

[26] *Alzheimer's Research UK (2013) Annual Review 2011/12*

Figure 28 below suggests that Liverpool has the highest percentage of residents with no qualifications of its neighbours, regional and national comparators.

	No Qualifications	Level 1 Qualifications	Level 2 Qualifications	Apprenticeship	Level 3 Qualifications	Level 4 Qualifications and Above	Other Qualifications
Halton	26.9%	16.8%	18.6%	3.8%	12.5%	17.6%	3.7%
St. Helens	27.9%	14.3%	16.7%	4.4%	12.1%	20.9%	3.8%
Knowsley	34.7%	15.2%	16.1%	3.4%	11.8%	15.5%	3.4%
Sefton	25.1%	14.0%	16.6%	3.9%	12.5%	24.1%	3.9%
Liverpool	28.7%	12.5%	14.2%	2.5%	15.2%	22.4%	4.4%
North West	24.8%	13.6%	15.8%	3.9%	12.9%	24.4%	4.5%
England	22.5%	13.3%	15.2%	3.6%	12.4%	27.4%	5.7%

Figure 28: Highest Level of Qualification, All Usual Residents Aged 16+

Source: Census 2011

The Liverpool Lifestyles Survey[27] was designed to collect lifestyle indicator data across our population. The survey explored a range of behavioural and attitudinal factors, including general health, physical activity, diet and nutrition, alcohol consumption, smoking, disabilities, mental health status and attitudes towards life. A total of 4,793 interviews were conducted in-home with adults aged over 18 years and was carried out between 3 September 2012 and 27 January 2013. Those indicators which are associated with the development of dementia are outlined below.

A Body Mass Index (BMI) greater than 25 is considered overweight and above 30 is considered obese. More than half of residents in Liverpool fall into one of these two categories: 34% are overweight and 21% are obese. This is in-line with the average across

[27] *Liverpool Lifestyles Survey 2012/13*

Merseyside. Men are significantly more likely to be overweight than women. In total, 39% of men are classified as overweight, compared to 29% of women. However, there is little difference in the level of obesity (20% of women compared to 21% of men).

In Liverpool, half of people tend to add salt to their food during cooking (50%). This is higher than the overall Merseyside figure of 47%. The Liverpool figure is surpassed only by Halton, where 52% tend to add salt.

People with a long-term illness, disability or health problem are significantly more likely to be obese than those without (30% compared to 18%). Similarly, those who say their overall general health is poor are significantly more likely to be obese than those who consider their health to be good (32% compared to 16%).

The survey found that although older people were less likely to drink alcohol than younger people, those who do drink, do so more often. The proportion that drank at least once a week grows with age, ranging from 60% of 18-24 year olds to 76% among those aged 55 and over. This may have implications for future incidence of ARBD.

In Liverpool, 29% of adults currently smoke, which is marginally, but not significantly, above the Merseyside figure of 28%. Smoking is more prevalent in Liverpool than across England (20%). Smoking falls off significantly after the age of 55. Whilst 32% of those aged 18-54 smoke, this decreases to 23% of those aged 55 and over. Social renters are significantly more likely to smoke than private renters and owner occupiers (42% compared to 36% and 18% respectively). While 29% of people in Liverpool currently smoke, 41% have smoked at some point in their life (including current smokers), and this is slightly below the overall Merseyside figure of 44%.

Those with other diseases (Cardio-vascular Disease and Diabetes) are at an increased risk of developing dementia. Therefore optimal management of risk factors such as high blood pressure and cholesterol levels will support risk reduction. Analysis of The Quality and Outcomes Framework (QOF) for general practice in 2012/13 suggests that approximately 90% of patients registered with Coronary Heart Disease had a blood pressure of under 150/90 and 80% had a cholesterol level of at or below 5mmol/l. Approximately 83% of those with raised blood pressure were given lifestyle advice in the preceding 15 months.

8. Identification

Advice around early identification of those with dementia is mixed. The UK National Screening Committee policy on Alzheimer's disease screening in adults was carried out in 2010 and is due for review in 2014/15[28]. The current review recommends against screening the general population, whilst a more recent systematic review commissioned by The Alzheimer's Society found that there were no improvements in health outcomes as a result of screening[29]. Much of the literature points towards timely identification, with NICE recommending targeted screening of high risk populations (older people, those with learning disabilities).

In 2011 Alzheimer's International commissioned a report[30] which acknowledges that the effectiveness of health systems in identifying people with dementia depends upon the potential 'consumers', as well as the providers of health and social care. The report suggests that encouraging identification through awareness-raising is an essential component of any comprehensive strategy to close the treatment gap. However, increased demand needs to be met by adequately prepared and resourced services, trained and able to make accurate diagnoses in a timely and efficient manner, and to ensure that the diagnosis leads seamlessly to the provision of evidence-based care.

Liverpool Clinical Commissioning Group developed a target to increase diagnosis rates for dementia in those aged over 65 by 7% by 2014/15, with a target prevalence rate of 57.7% (using the 2012 baseline of 50.6%). This suggests an increase of 511 newly diagnosed individuals. Current initiatives to improve prevalence rates include incentivising organisations through the use of commissioning for quality and innovation (CQUIN) incentives and directly enhanced service (DES) schemes in primary care (Figure 29).

Further identification is anticipated through the addition of two dementia related questions to The NHS Health Check Programme which came into effect as of April 2013. It is too early to analyse the 'yield' in terms of numbers referred on for further assessment as a result of the programme.

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[28] *National Screening Committee (2010) The UK NSC policy on Alzheimer's Disease screening in adults. Accessed on 27th August 2013 at: http://www.screening.nhs.uk/alzheimers*

[29] *Brayne, C. (2013) Presentation to Alzheimer's Association International Conference, Boston. 17th July 2013.*

[30] *World Alzheimer Report (2011) The benefits of early diagnosis and intervention*

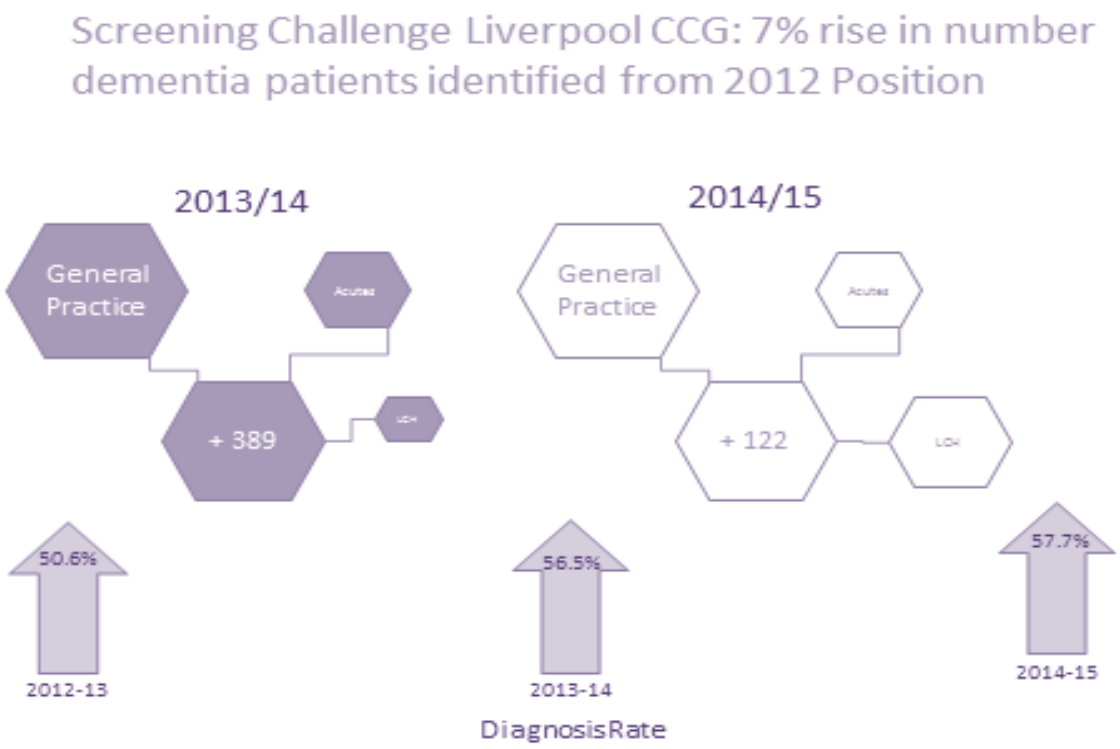


Figure 29: Liverpool Dementia Screening Challenge.

9. Diagnosis

There is evidence from economic modelling that the cost of an earlier dementia diagnosis and the downstream costs of providing evidence-based treatment may be more than offset by the cost savings accrued from the benefits of prescribing of anti-dementia drugs and caregiver interventions, delayed institutionalisation and enhanced quality of life for people with dementia and their carers'.

NICE[31] state that a diagnosis of dementia should only be made after a comprehensive assessment, including: history taking, cognitive and mental state examination, physical examination; review of medication to identify any drugs that may impair cognitive functioning. Possible dementia sufferers should be asked whether they wish to know the diagnosis and with whom it should be shared. If dementia is mild or questionable, conduct formal neuropsychological testing. At the time of diagnosis, and regularly afterwards, assess medical and psychiatric comorbidities, including depression and psychosis.

[31] *NICE (2013) Support for commissioning dementia care. Accessed at: http://publications.nice.org.uk/support-for-commissioning-dementia-care-cmg48/51-improving-early-identification-assessment-and-diagnosis*

Clinical cognitive assessment should include examination of attention and concentration, orientation, short- and long-term memory, praxis, language and executive function. Conduct formal cognitive testing using a standardised instrument, such as:

- Mini Mental State Examination (MMSE)
- 6-Item Cognitive Impairment Test (6-CIT)
- General Practitioner Assessment of Cognition (GPCOG)
- 7-Minute Screen.

Account should be taken of other factors that may affect performance, including educational level, skills, prior level of functioning and attainment, language, sensory impairment, psychiatric illness and physical or neurological problems.

NICE [32]suggest that memory assessment services offer a responsive service to aid the early identification of dementia, and include a full range of assessment, diagnostic, therapeutic and rehabilitation services. Memory assessment services ensure an integrated approach to the care of people with dementia and the support of their carers', in partnership with local healthcare, social care and voluntary organisations. They go on to state that they have been shown to significantly improve the quality of life of carers and people with dementia.

Once a diagnosis of dementia is given, a diagnosis of sub-type should be made by those with appropriate expertise in differential diagnosis using international standardised criteria[33] or by examination of cerebrospinal fluid in the case of suspected CJD.

[32] *NICE (2007) Memory assessment service for the early identification and care of people with dementia.*
Commissioning guide
[33] *NICE SCIE (2010) Guideline to improve care of people with dementia*

Type	Recommended Diagnostic Criteria
Alzheimer's disease	Preferred criteria: NINCDS/ADRDA. Alternatives include ICD-10 and DSM-IV
Vascular Dementia	Preferred criteria: NINDS-AIREN. Alternatives include ICD-10 and DSM-IV
Dementia with Lewy bodies (DLB)	International Consensus criteria for dementia with Lewy bodies
Frontotemporal dementia	Lund-Manchester criteria, NINDS criteria for frontotemporal dementia

Figure 30: Dementia Diagnostic Criteria

In England, less than half of all cases of dementia are routinely recognised, and when a diagnosis is made, it is often at a relatively late stage of the disease. According to the NHS Dementia Calculator[34] only 50.9% of dementia cases in Liverpool are diagnosed whilst numbers of cases are predicted to rise by 6% between 2011/12 and 2014/15 unless more is done to improve on current diagnostic rates.

	2011/2012	2012/2013	2013/2014	2014/2015	% Change 11/12 - 14/15
Dementia gap	2,421	2,477	2,527	2,575	6%
Dementia Register	2,507	2,564	2,616	2,666	6%
Forecast number of cases	4,928	5,041	5,143	5,241	6%
Diagnostic Rate (%)	50.9%	50.9%	50.9%	50.9%	0%

Figure 31: Dementia Diagnosis Forecasts for Liverpool

Source: NHS Dementia Calculator, Liverpool CCG, July 2013

[34] http://www.dementiaprevalencecalculator.org.uk/

NICE[35] recommend that any preliminary investigation of a suspected Dementia should include:

- Routine haematology
- Biochemistry tests
- Thyroid Function Tests
- Serum B12 and Folate levels

Liverpool figures for 2012/13 suggest that 70% of those with a new diagnosis of Dementia in Liverpool underwent routine screening as described above. Liverpool compares less favourably to its neighbouring CCGs Sefton and St Helens, the Core Cities and national and regional rates.

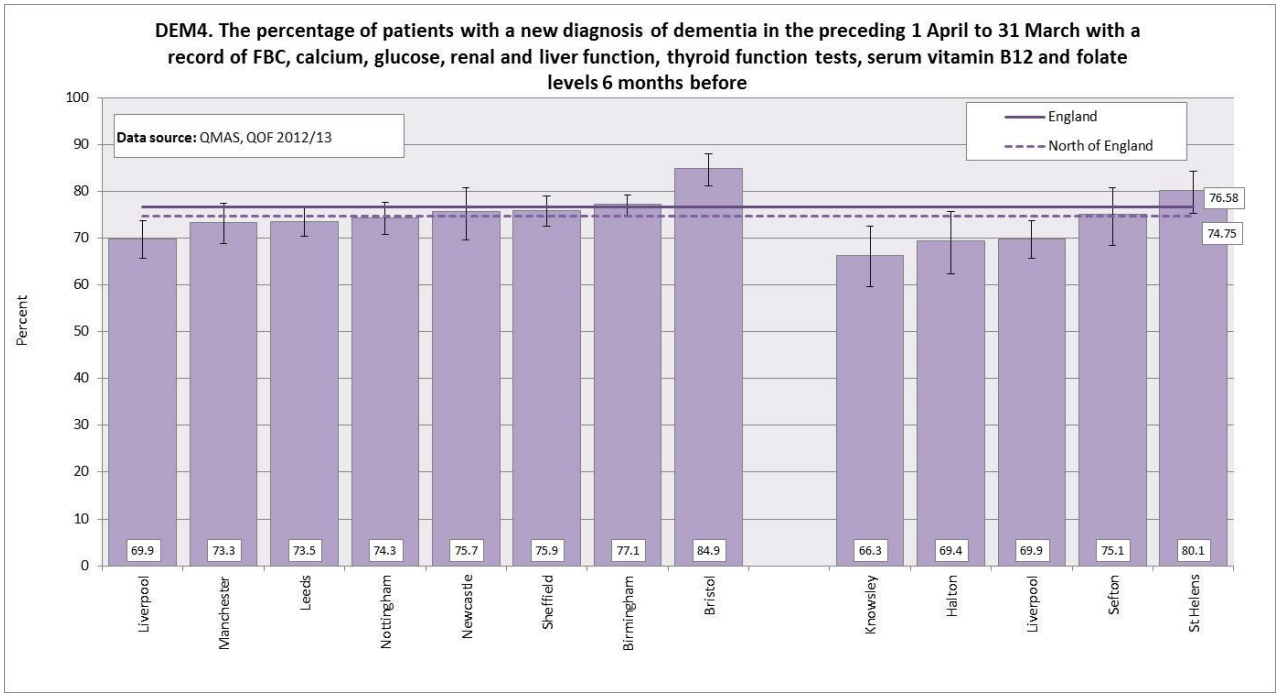


Figure 32: Primary Care Management of Dementia Patients – Routine Screening by Core City.

Source: QMAS, 2012/13

[35] *NICE (2013) Dementia Diagnosis and Assessment. NICE Pathways*

Memory Clinics

NICE[36] suggest the indicative benchmark rate for new referrals into a memory assessment service is 0.19%, or 190 per 100,000 population per year. Based on these estimates it is predicted that at least 936 registered patients in the city would have required referral to a memory assessment service in 2012/13 and 944 in 2013/14.

Therefore commissioners need to consider planning for increased activity to reflect current unmet needs of their population. NICE guidance suggests that around 54% of people attending memory assessment services are likely to have dementia, and 46% are likely to have other conditions such as mild cognitive impairment (MCI), depression or no illness.

The referral process for diagnosis in Liverpool varies depending on where you reside. Data was available for referral to memory clinics at Mossley Hill and Walton (those aged under 65 years). Therefore illustrated referral rates may be under-estimate the true figure.

In 2012/13 there were 736 referrals to the Mossley Hill and Walton memory clinics which represent a referral rate of 0.15% or 148 per 100,000 population. This was an increase of 5.3% on the 2011/12 rate (Figure 32). NB: This estimate includes referrals from patients registered at Liverpool practices who were referred to Mossley Hill and Walton memory clinics but does not include patients referred to the Royal Liverpool University Hospital memory clinic with no onward referral to Mossley Hill, so the true referral rate is likely to be higher.

Liverpool CCG Referrals	2011/12	2012/13	+/- Change %
Referrals to Mossley Hill Memory Clinic (LCCG)	665	705	6.0%
Referrals to Walton Memory Clinic (LCCG)	30	31	3.3%
Total referrals	695	736	5.9%
Referral Rate per 100,000	141	148.1	5.3%
Minimum expected no. of referrals	939	944	0.6%
Expected number of referrals gap	244	208	14.8
Minimum Expected Referral Rate per 100,000	190	190	0.0%
% Achievement (Actual / Expected)	70.8%	74.7%	5.4%

Figure 33: Liverpool CCG Referrals to Memory Clinics

[36] *NICE (2007) Memory assessment service for the early identification and care of people with dementia. Commissioning guide - Implementing NICE guidance*

Mossley Hill Memory Clinic Referrals	2011/12	2012/13	+/- Change %
Liverpool practices	665	705	6.0%
Practice code not applicable (V81998)	105	87	-17.1%
Practice outside Liverpool	35	34	-2.9%
Total Referrals	805	826	2.6%
Diagnosed with Dementia	501	573	14.4%
% Diagnosed with Dementia	62%	69%	11.5%

Figure 34: Diagnosis of dementia based on patients that are assigned to PBR Clusters 18 - 21 in the reporting period

In 2011/12 and 2012/13, GPs were responsible for 88% of all referrals to Mossley Hill memory clinics. The biggest increase in referral sources over the 2 year period came from Liaison Psychiatry services, an increase of 122.7% (Figure 35).

Referral Source	2011/12	2012/13	+/- Change %
Broadgreen Hospital	7	5	-28.6%
Cons. Non M. Health	12	11	-8.3%
Consultant at MCT	5	7	40.0%
General Practitioner	714	714	0.0%
Liaison Psychiatry Services	22	49	122.7%
Royal Liverpool University Hospital	8	13	62.5%
Whiston Hospital	3	4	33.3%
All other referral sources	34	23	-32.4%
Grand Total	805	826	2.6%

Figure 35: Liverpool Memory Clinic Referrals by Source

NB: Count of Referrals for Consultants Barnes, Metcalfe, Anderson, Chatfield Richman & the Pre Senile Dementia Team, Mossley Hill Hospital where Referral Problem = Cognitive Difficulties, Confusion, Memory loss or Memory Problems only

In 2012/13 the highest referral rate to Mossley Hill memory clinic for patients known to be registered with a Liverpool practice was from Childwall neighbourhood and the lowest rate was from Aintree neighbourhood. Statistically, Picton, Speke, Childwall, Garston/Allerton/Aigburth, Dovecot & Old Swan, have referral rates which were significantly higher than the Liverpool average (Figure 36). Aintree, Croxteth, Walton, Anfield, Norris Green and City Centre and Vauxhall neighbourhoods all have referral rates statistically significantly lower than the Liverpool average.

The data in relation to referral rates at GP neighbourhood level appears to run counter to previously described prevalence rates, whereby some neighbourhoods with the highest dementia prevalence are amongst the lowest in terms of referral rates to memory clinics. This is an area which requires further investigation.

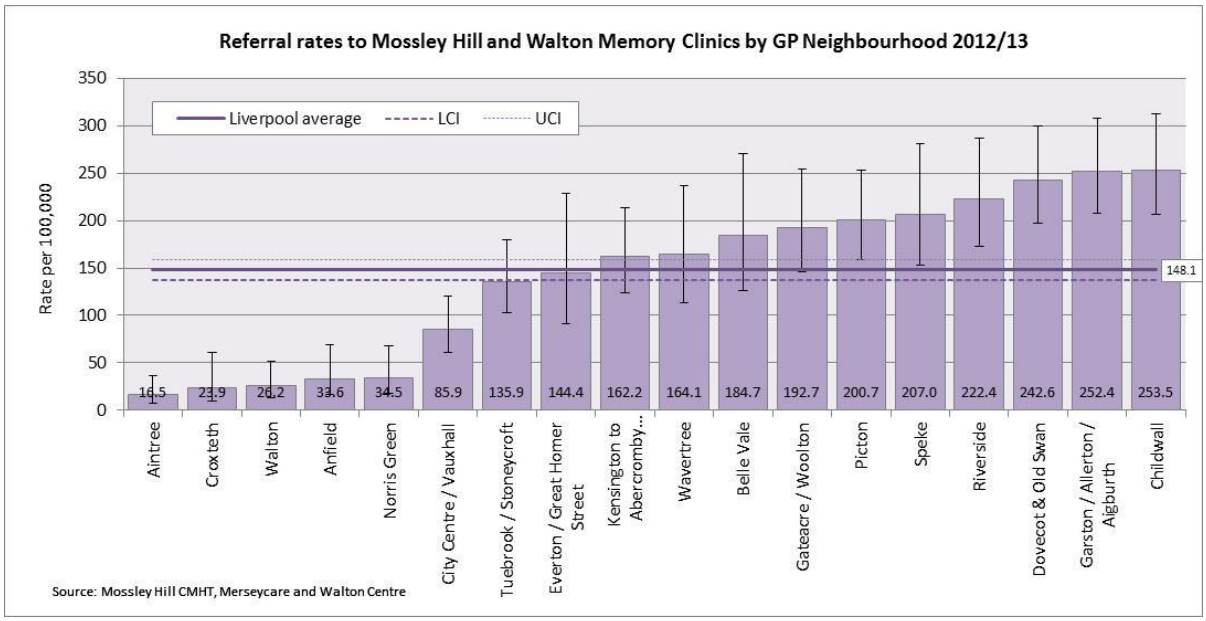


Figure 36: Referral rates to Memory Clinics by GP Neighbourhood, 2012-13

10. Post-Diagnosis Support

Prescribing

The three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine are now recommended as options for managing mild to moderate Alzheimer's disease. Memantine is recommended as an option for managing moderate Alzheimer's disease for people who cannot take AChE inhibitors, and as an option for managing severe Alzheimer's disease; combination treatment with memantine and an acetylcholinesterase inhibitor is not recommended. Only specialists in the care of patients with dementia (that is, psychiatrists including those specialising in learning disability, neurologists, and physicians specialising in the care of older people) should initiate treatment. Carers' views on the patient's condition at baseline should be sought.

If prescribing an AChE inhibitor (donepezil, galantamine or rivastigmine), treatment should normally be started with the drug with the lowest acquisition cost (taking into account required daily dose and price per dose once shared care has started). However, an alternative AChE inhibitor could be prescribed if appropriate taking into account adverse

event profile, expectations about adherence, medical comorbidity, possibility of drug interactions and dosing profiles.

People with dementia with Lewy bodies (DLB) with mild-to-moderate non-cognitive symptoms should not be prescribed antipsychotic drugs because they are at particular risk of severe adverse reactions. People with Alzheimer's disease, vascular dementia, mixed dementias or DLB with severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress) may be offered treatment with an antipsychotic drug after certain conditions have been met (see NICE guidance for further details).

Prescribing in Liverpool

Drug costs for treatment of Alzheimer's disease are decreasing as a result of donepezil (Aricept) and galantamine coming off patent early in 2012, rivastigmine coming off patent in July 2012 and memantine (Ebixa) in April 2014. NICE guidance estimates the reduction in price as generic drugs become available is between 30% and 80%. The table below shows prescribing costs for the city for dementia drugs in 2012/13 and 2011/12 by drug type as a percentage of total annual expenditure sourced from the Prescription Cost Analysis (PCA) system.

British National Formulary Classification	2012/13		
	Costs £	%	Unit Cost
Donepezil Hydrochloride	£123,927	42.0%	£45.8
Galantamine	£101,418	34.4%	£37.5
Rivastigmine	£43,016	14.6%	£15.9
Memantine Hydrochloride	£26,748	9.1%	£9.9
Total Annual Expenditure	£295,109	100%	£109.0

Figure 37: Liverpool Prescribing levels in 2012-13

The city has a prescribing rate of £109 per patient on the dementia register. The total prescribing cost for dementia drugs in 2012/13 was £295,109.19, down -41.9% on the previous year. The chart below shows a breakdown of prescribing rates by GP neighbourhood. The variation in prescribing rates needs to be looked at in the overall context of dementia prevalence.

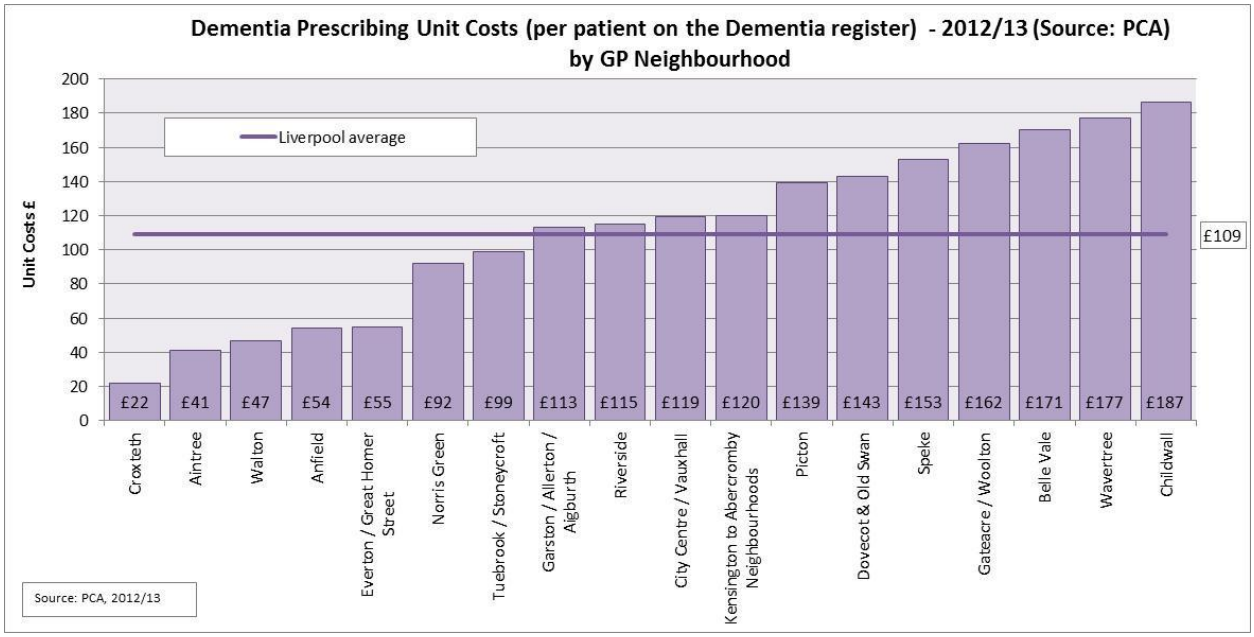


Figure 38: Dementia prescribing costs by GP Neighbourhood, 2012-13

Prescribing rates at neighbourhood level also appear to run counter to previous dementia prevalence rates, whereby those neighbourhoods with highest dementia prevalence have lowest prescribing costs, and some of those with lowest dementia prevalence have higher than average costs. This also requires further investigation as may indicate that patients who may benefit from dementia drugs are not being prescribed. In the case of those with higher costs and lower prevalence it may indicate inappropriate or less cost-effective prescribing.

Drugs for Non-Alzheimer Dementias and MCI

NICE (2013) state that unless as part of properly constructed clinical studies, do not use:

- AChE inhibitors or memantine for cognitive decline in vascular dementia
- AChE inhibitors in mild cognitive impairment

NICE guidelines recommend that antipsychotics should only be prescribed in the first instance to people with behavioural and psychological symptoms of dementia if the person is severely distressed or if there is an immediate risk of harm to the person or others. The Banerjee Report[37] commissioned by the Department of Health in 2009 called for urgent action to reduce the inappropriate use of antipsychotic drugs in dementia.

[37] *Banerjee, S. (2009)The use of antipsychotic medication for people with dementia: Time for action*

Prescribing of Antipsychotics in Liverpool

An audit of GP clinical systems in September 2013 showed that 390 patients with dementia had been prescribed anti-pyschotic drugs in the last 12 months (14%). The highest prescribing rates of antipsychotic drugs were found in North locality (17.3%), and the lowest in Matchworks (10.9%); whilst 14.7% of patients with dementia were prescribed anti-pyschotic drugs in Liverpool Central (Figure XX). It was not possible to calculate over what time period these drugs had been prescribed, it is recommended that further work is undertaken to determine this.

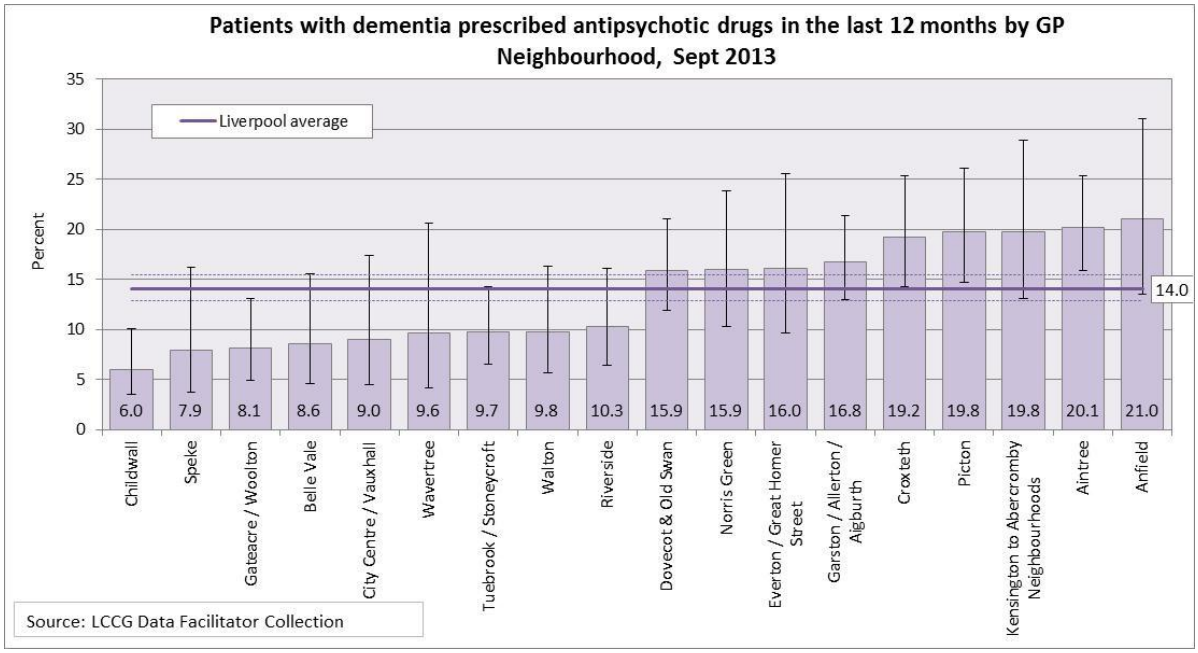


Figure 39: Dementia patients prescribed anti-psychotic drugs by GP Neighbourhood, 2012-13

Those with Alzheimers and non-cognitive symptoms and/or behaviour that challenges causing significant distress/harm to the individual may be offed an acetylcholinesterase inhibitor provided a non-pharmalogical approach has been tried or been ineffective and antipsychotic drugs are inappropriate or ineffective. Likewise provided all other non-pharmacological solutions have been tried people with moderate /severe Alzheimers who are intolerant of acetylcholinesterase inhibitors may be offered memantine.

Individuals with Dementia Lewy Bodies (DLB) with significant distress/challenging behaviour should be offered acetylcholinesterase inhibitor. However people with vascular dementia who develop non-cognitive symptoms or behaviour should not be prescribed acetlycholinesterase inhibitors.

Challenging behaviour, extreme distress, violence and aggression may need to be managed by de-escalation techniques without the use of sedation wherever possible. However, where drugs are necessary oral medication is preferred to parental (intramuscular) medication. Lorazepam, haloperidol or olanzapine should be used – preferably a single agent rather than a combination.

People with dementia who also have major depressive disorder should be offered antidepressant medication. The need for compliance, time of onset of action and risk of withdrawal effects should be explained at the start of treatment. In some instances where a person with dementia is severely disturbed and needs to be contained for his her own safety and/ or the safety of others s/he may need assessment under the Mental Health Act .

In all of these scenarios, access to specialist advice prior to treatment commencement is required. In Liverpool this is through secondary mental health services (Merseycare NHS Trust).

Once a person is diagnosed with Dementia, it is the responsibility of General Practice to undertake an annual health review. Figures for 2012/13 suggest that around 81% of those on a Dementia register received a review. Liverpool compares less favourably to its neighbouring CCGs (apart from Sefton), and to the core cities (apart from Manchester) and when compared to national and regional rates.

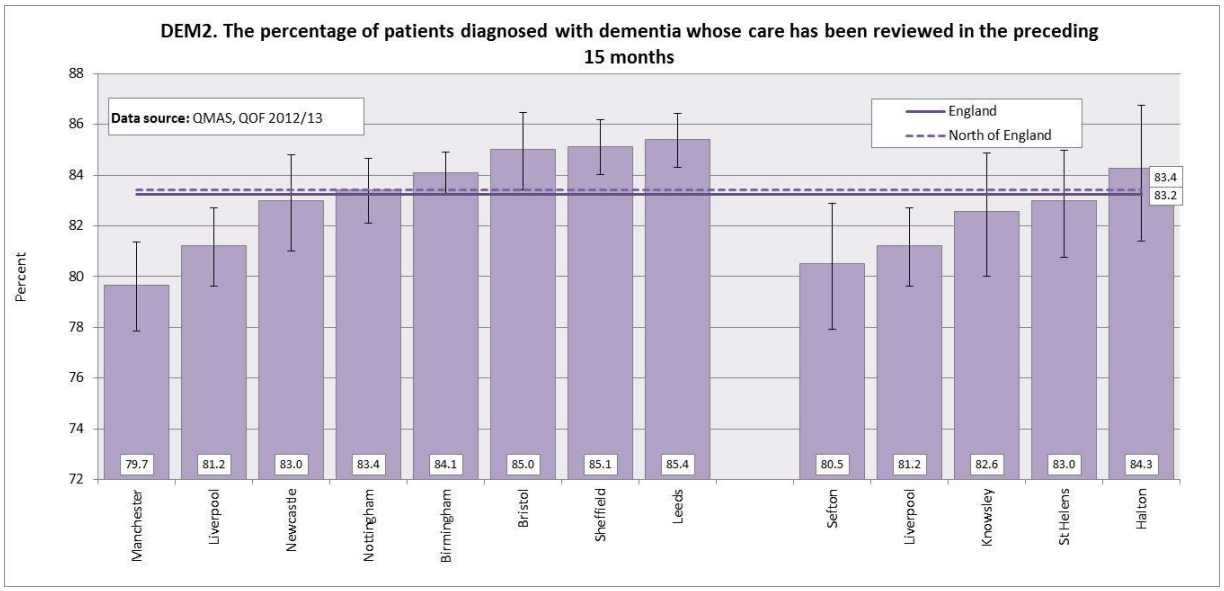


Figure 40: Dementia patients reviewed by Core City

Source: QMAS, 2012/13

There is variation at practice level with regard to some patients on the dementia register being 'exception-reported' or omitted from the number eligible for a care review, for example, if they are unsuitable for treatment, newly registered with the practice, newly diagnosed or in the event of informed dissent. As at March 2013, there were 262 patients in the city who were on the dementia register but exception reported from receiving a care review in the previous 15 months. There was 459 eligible patient(s) with dementia in the city who did not receive a care review in the previous 15 months. Analysis at practice within the context of other indicators should be undertaken, particularly in relation to the need for unplanned care with this cohort of patients.

Non-Pharmacological Interventions

The evidence base surrounding non-pharmacological interventions (NPI) to treat behavioural and psychological symptoms of dementia is scant and of variable methodological quality[38]. In a systematic review of the cost-effectiveness of NPI, cognitive stimulation therapy, tailored activity programme and occupational therapy were found to be more cost-effective than usual care. There was some evidence to suggest that respite care in day settings and psychosocial interventions for carers could be cost-effective. Coordinated care management and personal budgets held by carers have also demonstrated cost-effectiveness in some studies. The review found five barriers to achieving cost-effectiveness in this area of dementia care: the scarcity and low methodological quality of available studies, the difficulty of generalising from available evidence, the narrowness of cost measures, a reluctance to implement evidence and the poor coordination of health and social care provision and financing.

In Liverpool there are a range of organisations offering NPI: PSS offer a dementia befriending service: Alzheimer's Society provide "singing/dancing for the brain", peer support/carers groups: Local Solutions provide a Carers Centre as well as signposting and follow up services: Merseycare offer post diagnostic support groups: Age Concern provide a range of services and advice to elder individuals, including those living with dementia and their carers'. Work is currently underway to evaluate the effectiveness of these interventions locally.

Social Support

Social support is critical to maintaining an individual with dementia in their community and supporting their carer(s). Health and social care staff should ensure that care of people with dementia and support for their carers is planned and provided within the framework of care management/coordination. Care managers and care co-ordinators should ensure the coordinated delivery of health and social care including:

- A combined care plan agreed by health and social services which takes into account the changing needs of the person with dementia and his or her carers
- Assignment of named health and/or social care staff to operate the care plan

[38] *O'Neil ME, Freeman M, Christensen V, Telerant R, Addleman A, Kansagara D. (2011) A Systematic Evidence Review of Non-pharmacological Interventions for Behavioral Symptoms of Dementia. Department of Veterans Affairs; Evidence-based Synthesis Program Reports. Accessed at: http://www.ncbi.nlm.nih.gov/pubmed/21634073*

- Endorsement of the care plan by the person with dementia and/or carers
- Formal reviews of the care plan, at a frequency agreed between professionals involved and the person with dementia and/or carers and recorded in the notes

Care managers should explain to people with dementia and their carers that they have the right to receive direct payments and individual budgets. However, as many people with dementia and their carers may find this difficult to manage additional support should be offered. People with dementia and their carers should be informed about the statutory difference between NHS care and care provided by local authority social services (adult services) so that they can make informed decisions about their eligibility for NHS Continuing Care.

Social care and healthcare staff should identify the specific needs of people with dementia and the carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed by actions.

When people with dementia lack capacity, decisions made on their behalf under the Mental Capacity Act 2005 and should be made in line with the accompanying code of practice.

Social Support in Liverpool

Access to structured day care, individual access services, floating support, respite, residential and nursing home care and personal care is through assessment by social workers in the local authority utilising Fair Access to Care criteria (FAC). Individuals with dementia assessed with substantial and/or critical needs in relation to independent living can access a range of services commissioned by the local authority:

There are two levels of Elderly Mentally Ill (EMI) provision residential and nursing. Both require FAC assessment and EMI nursing provision requires referral by a psycho-geriatrician. In addition for individuals with very complex needs in relation to their dementia there is access through continuing healthcare budgets to a specialist resource (Paisley Court) which is run by Care UK. Liverpool CCG manages the continuing health care budget and this can be utilised to increase individual care packages e.g. one to one support for individuals over short periods of time. Individuals with dementia with savings of £25K will be required to self- fund residential provision, but health will contribute to additional nursing care costs.

Local services commissioned by LCC include:

- Sedgemoor dementia centre– Respite/reablement service,

- Short term reablement services in dementia "hubs" (Venmore/Sedgemoor/ Granby/Middleton Court
- Day services: Redholme/Bretherton House/ Brookside/ Norris Green, Sedgemoor
- Personal Care Services (7 providers) - subject to Fair Access eligibility criteria.
- Extra Care Housing Schemes
- Individual access services
- Floating support services

As of October 2013 there were 1328 service users (SUs) listed with LCC as having dementia. The table and charts below show the age and sex profile of people with dementia in receipt of a care package in 2013 (this data excludes people with dementia who are privately funded and for whom data is not available). Among services users with dementia, 2 out of 3 are females and almost half are aged between 81-90 years (46.5%) (Figure 41).

Age Band	SUs with Dementia			% of Total		
	Males	Females	Persons	Males	Females	Persons
30-50	6	5	11	0.5%	0.4%	0.8%
51-60	21	23	44	1.6%	1.7%	3.3%
61-70	49	41	90	3.7%	3.1%	6.8%
71-80	161	218	379	12.1%	16.4%	28.5%
81-90	167	451	618	12.6%	34.0%	46.5%
91+	29	157	186	2.2%	11.8%	14.0%
All Ages	433	895	1328	32.6%	67.4%	100.0%

Figure 41: Liverpool Service Users with Dementia by Age and Sex, 2013

It will be important to try to link this population with the GP registered population to ensure individuals are receiving the support they require. The LCC figure of 1,328 SUS listed with dementia, and the GP registered list of 2,776 represents a difference of 1,448 residents. Some of this shortfall maybe as a result of those who are privately fund their care, but could to an extent be due to a lack of awareness by the public of the support available. It may also pose an opportunity to case find as may be two entirely separate populations.

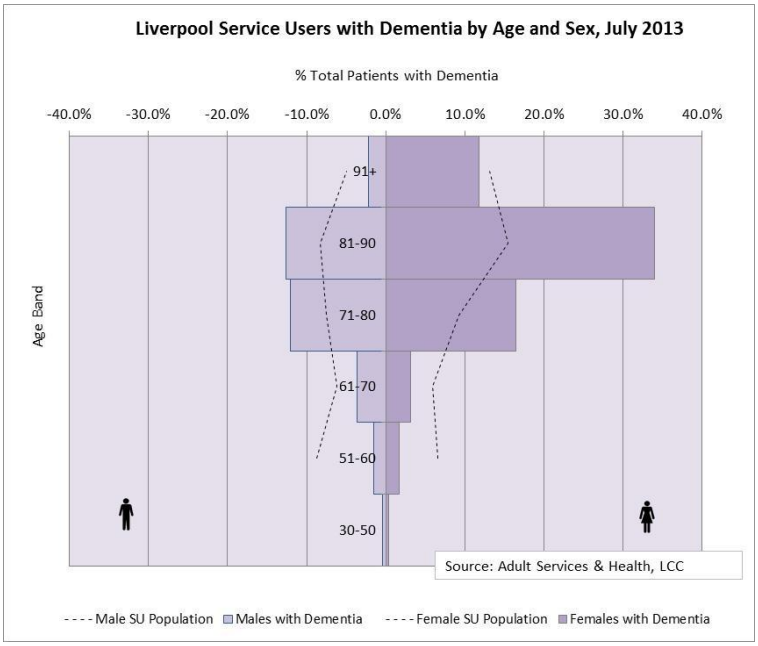


Figure 42: Liverpool Service Users with Dementia by Age and Sex, 2013

Among services users with dementia, 64% were receiving residential care, 16% domiciliary care, 7% day care and 6% direct payments whilst the remaining 7% were in receipt of either community support, occupational therapy or short term residential care (Figure 43).

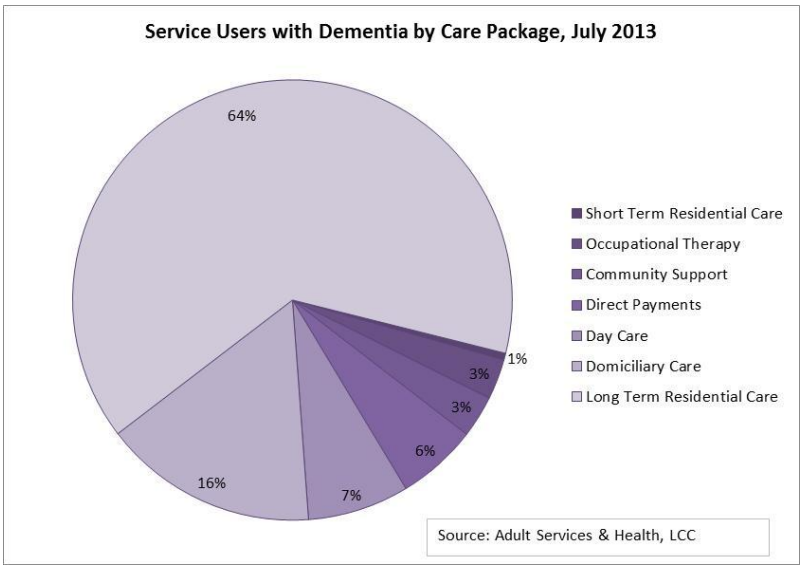
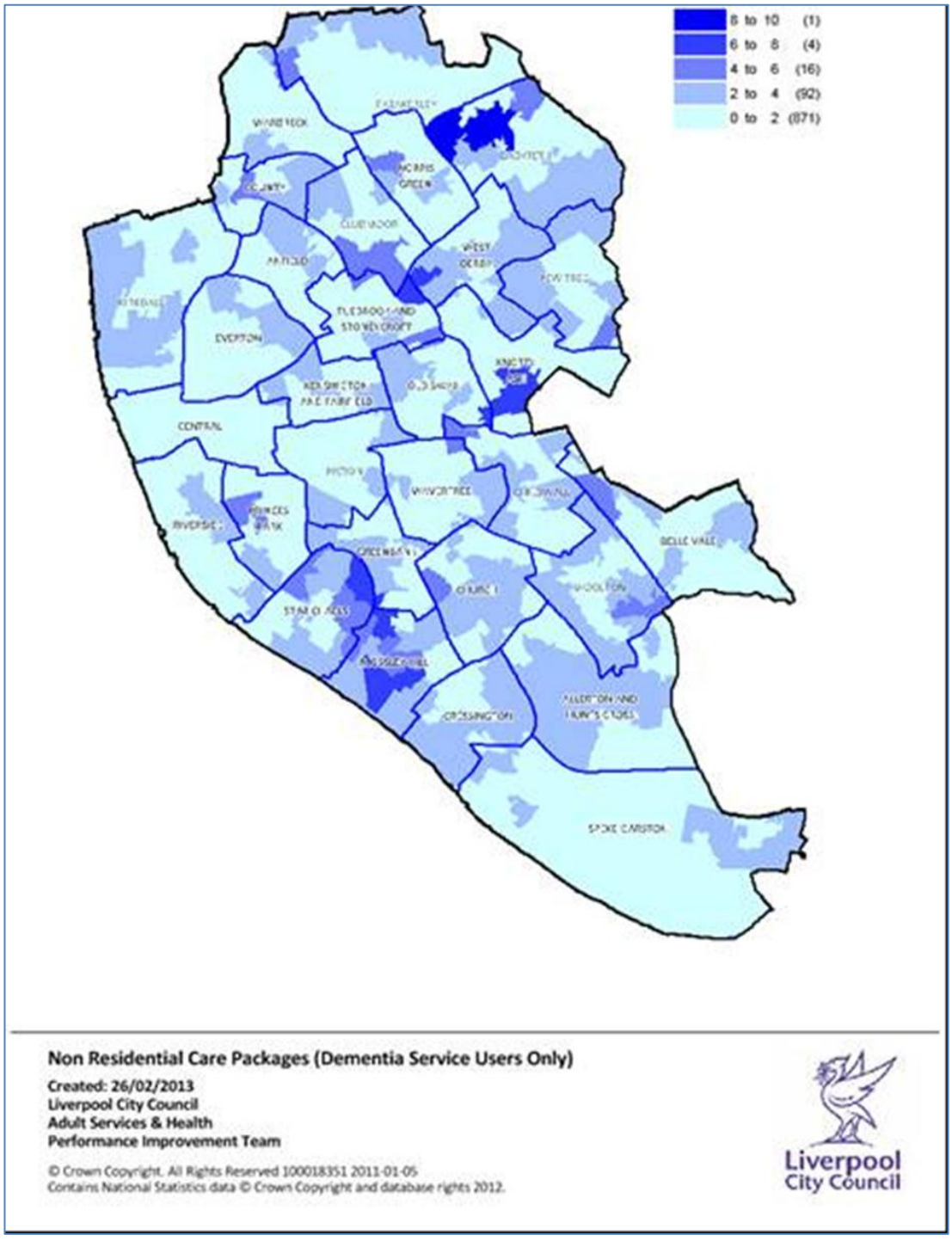


Figure 43: Liverpool Service Users with Dementia by Care Package, 2013

Non-Residential Care in Liverpool

The map below shows take up of non-residential care packages by super output area (excluding residential packages) by SUS with dementia. The darker colours are the areas with the highest take up of non-residential care packages in the city. Croxteth, Knotty Ash, Mossley Hill, St. Michaels and West Derby are those super output areas with higher than average levels of activity.



Map 3: Non Residential Care Packages for Service Users with Dementia

Residential Care in Liverpool

There are 923 residential and nursing home placements for service users with dementia (privately funded residents and residents funded by other local authorities are not included), with 133 (14%) of service users placements outside the city boundary. The chart below illustrates this breakdown by care home.

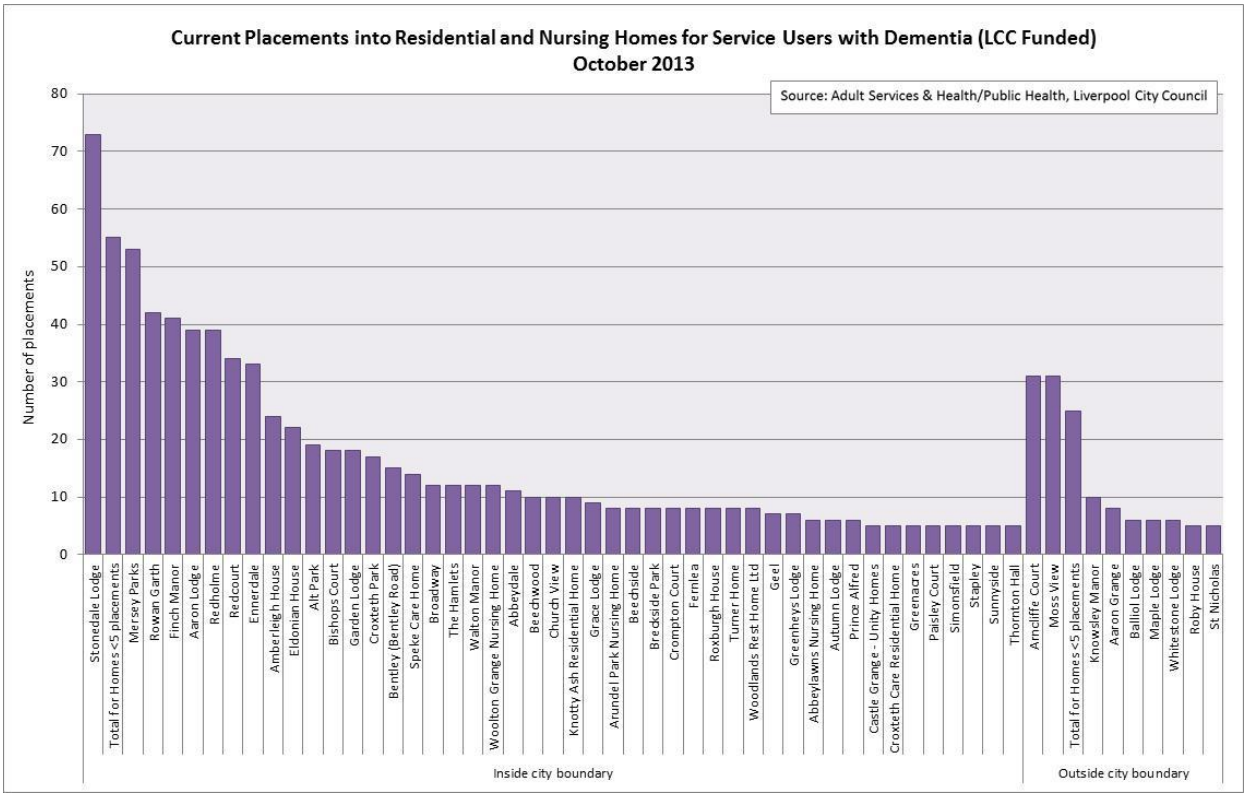
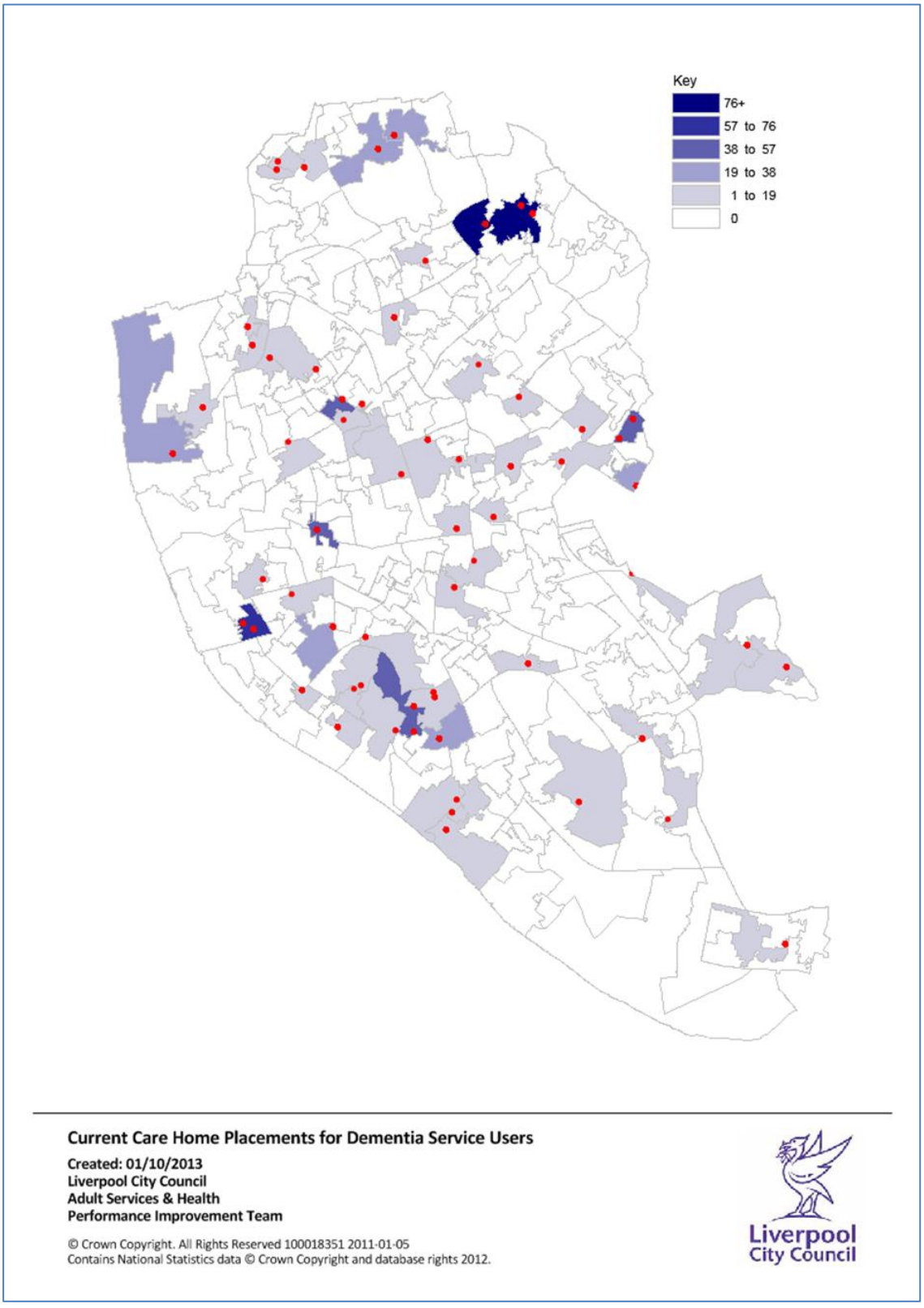


Figure 44: Care Home Placements for Service Users with Dementia, 2013

The map below illustrates the spread of current care home placements in the city. The red dots indicate the geographical location of care homes.



Map 4: Current care home placements for service users with dementia

The average length of stay in a residential or nursing home was 2 years from the date the resident was diagnosed with dementia. 44.2% of residents with dementia have a length of stay up to one year and a further 20% have a length of stay of between 1 and 2 years. 1.3% of residents with dementia have a length of stay longer than 10 years. These residents are likely to be younger, as the younger the person is diagnosed with dementia the slower the dementia progresses.

These figures are comparable to national data which suggests the median length of stay for a person with dementia in a residential home was 27 months and the median length of stay in a nursing home was 12 months. On average a person with dementia enters a care home 18 months before they die, whilst the majority of people with dementia enter 24 hour care before they die (76%). Other national data suggests that 80% of care home residents have dementia. Overall internationally there has been a reduction in the total numbers of people with dementia in 24 hour care (mainly residential) but a significant rise in the numbers in nursing care[39].

Advanced Care Planning and End of Life Care

The End of life care strategy[40] suggests 'although every individual may have a different idea about what would, for them, constitute a "good death", for many this would involve:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings
- being in the company of close family and/or friends'

Diminishing capacity becomes a particular problem in end of life care for people with dementia. In cases where a person still has capacity, they would be involved in the decision to shift from treating the condition to palliative care, along with decisions such as where they would like to die and what treatments they wish to receive. However, where capacity to make these decisions is lost, as is often the case for people with dementia, this is no longer possible and decisions will have to be made on their behalf.

[39] *Bowman C. Whistler J. and Ellerby M. (2004) A national census of care home residents. Age and Ageing Volume 33: 561 - 566.*
[40] *Department of Health (2008) End of Life Care Strategy: promoting high quality care for adults at the end of their life*

The clinical value of advance planning for end of life care is also clear. A recent study[41] found that advanced care plans drawn up in primary care could help reduce unplanned hospital admissions by 52%, as more was understood about the person's wishes should they need to be hospitalised.

Assessing pain at the end of life can be difficult[42]. Greater training and greater recognition is needed for health and care professionals in treating the person and carers of those with dementia as an individual.

The GMC guidance[43] states that artificial nutrition and hydration are medical treatments and that decisions about whether they should be used should be made in the same way as for other treatments, such as CPR. This includes whether the treatment is in the patient's overall best interest. The NICE-SCIE Guideline[44] on dementia states that artificial feeding and hydration should not commence if disinclination to eat or inability to swallow is considered to be part of the progression of the disease and will not change in future. Alzheimer's Society believes that when someone with dementia is close to dying the main issue of concern should be quality of life and quality of death, not length of life. Losing the ability to swallow can be part of the dying process in some cases and artificial nutrition and hydration in these cases may not be appropriate. However, it is important that there is honest and open discussion between medical professionals and the person with dementia's family, friends and carers when a decision is being made to withhold or withdraw treatment. It is essential that the quality of life and comfort of the person with dementia is paramount. There should be specialist palliative care, including pain relief and other palliative treatments available to the person at all times.

Research has suggested that the emotional and spiritual needs of people with dementia are disproportionately neglected[45]. While cognition declines and the person with dementia may become withdrawn, it is still possible for them to be distressed or upset. Depression can be difficult to recognise in advanced dementia. A holistic approach to care demands that there is an awareness of each person's wishes and needs as an individual. It is important that these needs are understood and met where appropriate. Making sure the person is comfortable and minimising distress is an important part of care. It is also important to consider whether the person would like spiritual support.

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[41] Baker et al (2012) Anticipatory care planning and integration: A primary care pilot study aimed at reducing unplanned hospitalisation. British Journal of General Practice, 62(595):e113-20.

[42] Health Service Ombudsman (2011). Care and compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people. The Stationery Office. London.

[43] General Medical Council (2010) Treatment and care towards the end of life: Good practice in decision making. General Medical Council. London.

[44] NICE-SCIE (2007) Dementia clinical guideline: supporting people with dementia and their carers in health and social care.

[45] Sampson, E. Gould, V. Lee, D and Blanchard, M,(2006). Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. Age and Ageing, 35(2):187-9.

The End of Life Care Strategy advocates that people should be supported to die in the place that they would choose. Often this choice is an individual's own home, or the care home in which they live, although many people with dementia still die in hospital.

The Palliative Care Funding review[46] suggests that people at the end of their lives and their carers should receive a holistic needs assessment and be supported by a care co-ordinator. Implementation of this proposal would greatly benefit people with dementia.

The Liverpool Care Pathway was developed from a model of care successfully used in hospices, the Liverpool Care Pathway for the Dying Patient (LCP) is a generic approach to care for the dying, intended to ensure that uniformly good care is given to everyone thought to be dying within hours or within two or three days, whether they are in hospitals, nursing homes, or in their own homes.

Because of substantial criticism of the LCP in the media and elsewhere Norman Lamb MP (Minister of State for Care Support), asked Baroness Julia Neuberger to chair a panel to review the use and the experiences of those using/involved in the LCP in England. The review[47] was to be kept independent of Government and the NHS. The Review considered evidence from many quarters: written submissions from members of the public and health professionals with experience of the LCP, as well as professional bodies and other organisations; a review of academic literature; a review of relevant hospital complaints; and surveys of health professionals. The panel also met members of the public at four sessions, to hear directly from them their experiences of the LCP. The review makes a number of recommendations to improve end of life care, its findings must be taken into account when caring for those with dementia.

End of Life Care in Liverpool

A report by The Alzheimer's Society suggests that two thirds of care home residents have some form of dementia. Only 60% of these individuals will be in dementia-registered beds (which are targeted at people with a high level of specialist needs) therefore it is vital that the whole sector is geared up to provide good dementia care.

Local work is currently underway to increase the numbers of care home residents with an ACP[48]. In Liverpool ACPs have been completed for 595 residents since November 2009. Of

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[46] Hughes-Hallet, T. Craft, A. and Davies, C. (2011). Funding the right care and support for everyone: Creating a fair and transparent funding system: The final report of the Palliative Care Funding review.

[47] The Liverpool Care Pathway Review: More Care Less Pathway. Accessed at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

[48] Bancroft et al (2013) Anticipatory Care Planning in Liverpool reduces hospital admissions at the end of life

these 250 have subsequently died – only 10 in hospital. In addition, the proportion of residents dying within 24 hours of hospitalisation has fallen by 52% to 13%. The main reason for implementation of an ACP was Advanced Dementia (50%). Relatives reported that having conversations about future prognosis and avoiding unnecessary distressing interventions is empowering, with care home staff feeling more confident about not sending frail residents into hospital when they are approaching the end of life.

In the absence of a valid advance decision to refuse resuscitation, the decision to resuscitate should take into account the wishes/beliefs of the person with dementia, their carer and the multi- disciplinary team.

Local work is also underway to develop 'Unified Do Not Attempt Cardio-Pulmonary Resuscitation' (DNACPR) Implementation. This is an initiative which has been led to date by North West Ambulance Service to provide clear guidance for local NHS staff and other organisations providing end of life care, about when resuscitation should and should not take place, taking into account the wishes of patients.

Approximately 18 months ago a steering group, led by NWAS and involving 25 organisations across the region, had formed to explore the gap in DNACPR policy between hospital Trusts and community care. This highlighted the work of the NHS South of England Central End of Life Care programme team on a regional DNACPR policy.

It was agreed in principle to work with the South of England policy given their two year audit review has demonstrated positive reviews. Their policy has been tweaked, but not fundamentally changed, for implementation across the North West and the final version of the North West DNACPR policy has been legally reviewed and approved.

During 2012 deaths related to Mental & Behavioural Disorders equated to 6.6% (281) of all deaths in Liverpool, of these deaths 6.5% (277) were dementia deaths. Deaths related to Dementia in Usual Place of Residence (UPR) have been increasing since monitoring began from 56% to 73%. The overall UPR for deaths related to dementia in Liverpool was highest in a residential setting (64% in 2012).

(Above fig of 281 deaths does not include ICD10 codes G30 Alzheimer's disease and R54 Senility)

Unplanned Care and Dementia in Liverpool

In 2012/13 there were 2,889 admissions in the city with a primary or secondary diagnosis of dementia[49]. The city has a directly age standardised admissions rate of 370 per 100,000 population, which is down 10.6% on the previous year. When the rates are broken down to GP neighbourhood there are 5 neighbourhoods with statistically significantly higher rates than the Liverpool rate, these were: Croxteth, Belle Vale, Everton and Great Homer Street, Riverside and Tuebrook/Stoneycoft. There were 5 neighbourhoods where admission rates are statistically significantly lower than the Liverpool rate, these were: Wavertree, Kensington and Abercromby, Gateacre and Woolton, Garston/Allerton/ Aigburth and Childwall. LCCG should look to investigate whether further resource is needed in those neighbourhoods with higher rates. Again some of these neighbourhoods were those with lower referral rates to memory clinics and the lowest prescribing rates of dementia drugs.

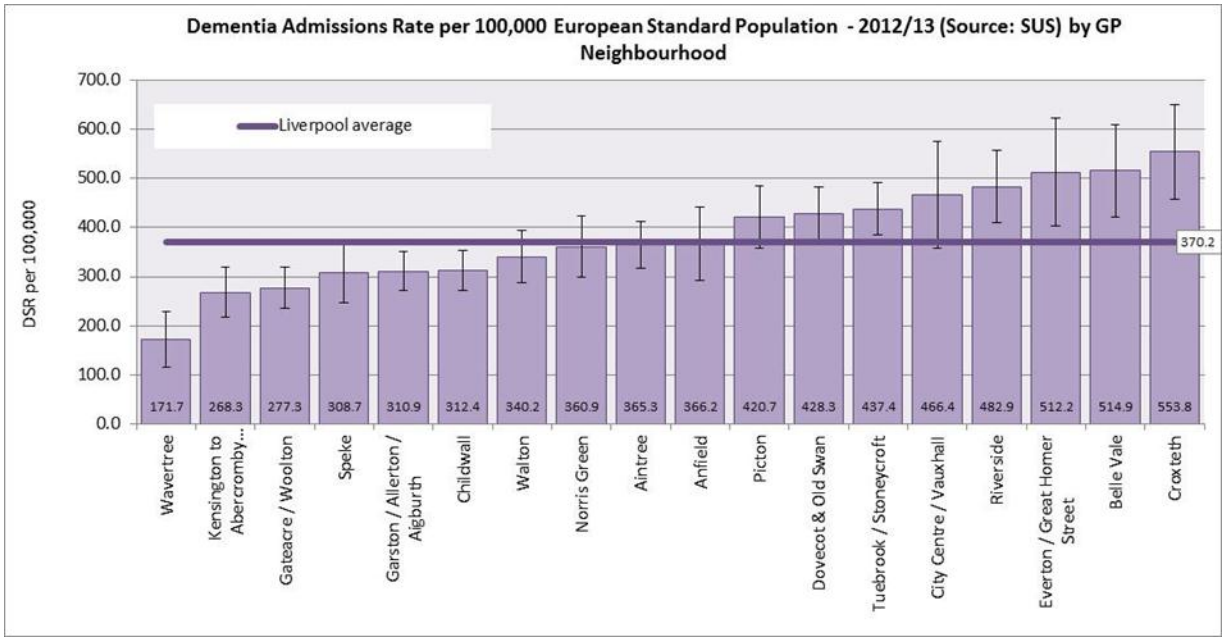

Figure 45: Hospital admissions for Dementia by GP Neighbourhood, 2012-13

When hospital admissions are analysed by source, almost 93% were from patient's usual place of residence (UPR). Those admitted from care homes will relate to those recently registered with a care home or those in short term or respite care, accounting for approximately 4% of patients. Other types of admission source account for around 3% of admissions and include temporary place of residence when usually resident elsewhere (hotel), penal establishments, court or police station or another NHS hospital provider (high security psychiatric accommodation , ward or A&E department).

[49] *Dementia is defined using ICD10 codes F00-F03 and G30 which include Alzheimer's disease, vascular and unspecified dementia, and dementia in other diseases such as Parkinson's, as well as R54 Senility which includes the physical symptoms of dementia such as loss of bodily functions and control, immobility and frailty.*

Admission Source	Admissions		Bed Days	Average LOS	Excess Bed Days	Total Cost (£)	Cost per Admission
	No.	%					
Usual place of residence	2,679	92.7%	27,963	10	3,326	£6,877,079	£2,567
Care Home (NHS and Non-NHS)	119	4.1%	1,791	15	86	£305,368	£2,566
Other	91	3.1%	3,492	38	96	£144,715	£1,590
All Admissions	2,889	100.0%	33,246	12	3,508	£7,327,162	£2,536

Figure 46: Hospital admissions for Dementia by source, 2012-13.

Hospital discharge destinations for the same cohort of patients reveal that those discharged to residential care/hospice increased by 84 individuals. This increase may indicate that those 84 individuals were previously living independently and were no longer able to do so following hospital admission. Whilst this group is small in numbers they account for the longest average length of stay.

Discharge Destination	Admissions		Bed Days	Average LOS	Excess Bed Days	Cost (£)	Cost per Admission
	No.	%					
Usual place of residency	1,818	62.9%	13,106	7	1,256	£4,045,108	£2,225
Not applicable/Not known[50]	500	17.3%	10,015	20	1,509	£1,800,672	£3,601
Residential/Care Home or Hospice	203	7.0%	5,667	28	429	£455,096	£2,242
Patient died	217	7.5%	1,986	9	162	£649,535	£2,993
Other destinations	151	5.2%	2,472	16	152	£376,751	£2,495
All Destinations	2,889	100.0%	33,246	12	3,508	£7,327,162	£2,536

Figure 47: Hospital discharges for patients with Dementia by destination, 2012-13

In 2012/13 almost a quarter of all dementia related admissions were due to symptoms, signs and abnormal clinical findings (ill-defined conditions such as nausea, headache, collapse where the primary cause is unknown at the point of admission).

[50] *The high percentage of not applicable/not knowns is due to the admissions data being extracted by date of admission rather than date of discharge and some patients may go on to have further episodes of care*

Primary Diagnosis	Admissions		Bed Days	Average Length of Stay	Excess Bed Days	Cost (£)	Average Cost of Admission
	No.	%					
Symptoms, signs and abnormal clinical findings	689	23.8%	5,988	9	756	£1,620,513	£2,352
Injury, poisoning and certain other consequences of external causes	505	17.5%	4,701	9	590	£1,244,522	£2,464
Diseases of the respiratory system	363	12.6%	3,654	10	210	£1,090,625	£3,004
Dementia	223	7.7%	7,229	32	662	£462,237	£2,073
Diseases of the genitourinary system	206	7.1%	2,566	12	236	£667,564	£3,241
Diseases of the digestive system	204	7.1%	1,776	9	113	£544,409	£2,669
Diseases of the circulatory system	184	6.4%	1,936	11	177	£484,204	£2,632
Certain infectious and parasitic diseases	82	2.8%	1,181	14	135	£301,752	£3,680
Diseases of the musculoskeletal system and connective tissue	72	2.5%	486	7	67	£145,464	£2,020
Neoplasms	64	2.2%	607	9	106	£201,413	£3,147
Endocrine, nutritional and metabolic diseases	60	2.1%	631	11	29	£159,156	£2,653
Diseases of the nervous system	56	1.9%	485	9	98	£92,744	£1,656
Factors influencing health status and contact with health services	48	1.7%	155	3	0	£22,547	£470
Diseases of the eye and adnexa	38	1.3%	18	0	0	£28,558	£752
Mental and behavioural disorders	36	1.2%	1,156	32	276	£84,427	£2,345
Diseases of the tissue and subcutaneous tissue	33	1.1%	414	13	16	£120,095	£3,639
Diseases of the blood and blood-forming organs	25	0.9%	257	10	37	£54,321	£2,173
Diseases of the ear and mastoid process	…	…	6	…	0	£2,611	…
All Conditions	**2,889**	**100%**	**33,246**	**12**	**3,508**	**£7,327,162**	**£2,536**

Figure 48: Liverpool Dementia Related Admissions by Primary Diagnosis. 2012-13

11. Dementia Mortality

Whilst deaths from dementia are relatively low when looking at underlying cause of death, the Alzheimer's Research Trust estimates that 1 in 3 people aged 65+ will have some form of dementia when they die. In Liverpool during the 5 year period 2008-12 there were 3,331 deaths among residents aged 65 and over where dementia was stated as a cause of death on the death certificate (19% of all deaths in this age group). This means almost 1 in 5 people in the city aged 65 and over have a form of dementia when they die, although this is likely to be higher due to undiagnosed cases.

Directly age standardised mortality rates (DSR) were calculated for the five year period 2008-12 using the European Standard Population which enable us to compare populations with different age structures to each other and over time. We included deaths where dementia was stated as a cause of death anywhere on the death certificate for patients registered at a Liverpool GP practice.

The city has a directly age standardised mortality rate of 84.62 per 100,000 population. Examining deaths by underlying cause of death, 1,791 patients in the city had dementia stated as the main cause of death on the death certificate. By comparison there were 3,365 patients with a diagnosis of dementia anywhere on their death certificate, up 5.7% on the previous year when there were 3,185 deaths.

12. Carers

The Royal College of General Practitioners (RCGP)[51] describe the impact that being a carer can have on an individual:

- Up to 40% of carers experience psychological distress or depression
- Carers have an increased rate of physical health problems. For example, providing high levels of care is associated with a 23% higher risk of stroke.
- Older carers who report 'strain' have a 63% higher likelihood of death in a year than non-carers or carers not reporting strain
- One in five gives up work to care, and
- More than half fall into debt as a result of caring.

[51] *RCGP (2011) Supporting Carers in General Practice Guide*

Furthermore, in England and Wales, those women working full-time and providing 50 or more hours of unpaid care per week were 2.7 times more likely to have 'not good' health compared with those providing no unpaid care and in full-time work. The corresponding value for men was 2.4.

The national strategy for carers was published in 2008[52]. It acknowledged the growing number of carers in the UK and set out a plan for meeting their need for information, care and support. The review of the strategy in 2010[53] set out the priorities for carers between 2010 and 2014. These included:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- Enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life
- Supporting carers to remain mentally and physically well

Carers in Liverpool

When someone is diagnosed with dementia, it has a profound impact, not just on them but also their family and others in their life. As a person's needs increase, family carers can become the most important source of support for them. It is vital those carers are supported throughout their journey. There are around 550,000 people in England acting as the primary carers for people with dementia. Carers for people with dementia save the nation nearly £7 billion every year[54].

Most family carers want to be able to support the person they are caring for at home, but they sometimes need more assistance in terms of information and advice on caring for someone with dementia while also looking after their own health.

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[52] *Department of Health (2008) National Strategy for Carers. HMSO: London*
[53] *Department of Health (2010) Recognised, Valued and Supported: Next steps for the carers strategy. HMSO: London*
[54] *Department of Health (2013 A State of the Nation Report on Dementia Care and Support in England*

According to the 2011 Census[55], over 50,100 people in Liverpool stated they provided unpaid care. While the number of people in the city providing unpaid care is comparable to regional levels, figures indicate that Liverpool has the greatest level among the eight core cities, in addition to being above national levels.

In 2012-13, 290 unpaid carers of people with dementia in Liverpool completed a carer assessment with Liverpool City Council. An audit of Liverpool GP clinical systems in September 2013 showed 386 patients with dementia had a registered carer recorded in the last 12 months (13.3%). Based upon the earlier Census figures, these figures are likely to under-estimate the true prevalence of carers for those with dementia in Liverpool.

The chart below shows the impact of caring in Liverpool to aspects relating to quality of life at assessment stage. The majority of carers of people with dementia state there is a 'serious' or 'significant' impact to the following:

- Ability to have time to yourself or to socialise / do things you value and enjoy
- Choice and control over daily life / spending time how you want
- Ability to have a good night's sleep
- Opportunities to take part in work, education or learning (carers over 65 are included in this)

[55] Nomis (2012) Census Table: DC3301EW. Accessed at: http://www.nomisweb.co.uk/census/2011/dc3301ew

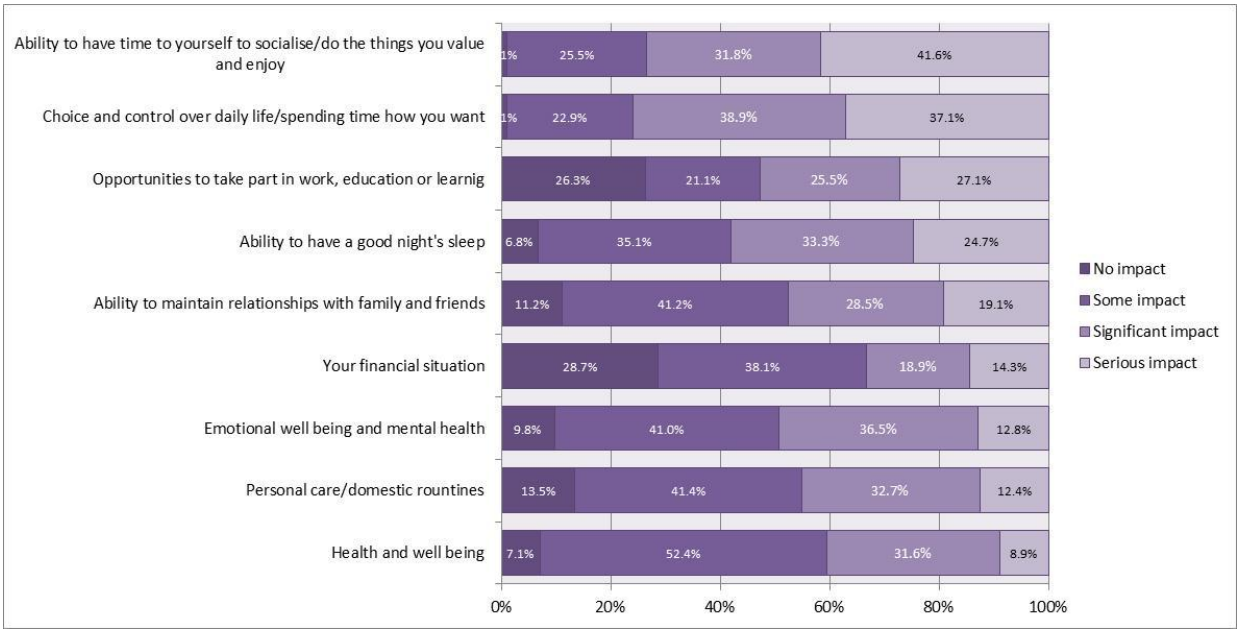

Figure 49: Liverpool Carer's Survey 2012-13

The majority of carers in Liverpool provide between 1 and 19 hours of unpaid care. The percentage of carers in the city providing greater than 20 hours of care (48%) is substantially above national levels, with the percentage providing more than 50 hours of care the highest among the core cities.

13. The Economic Cost of dementia in Liverpool

In 2011/12 Liverpool Clinical Commissioning Group spent an estimated £25million on dementia services, the majority of which is spent on secondary care in a hospital setting. The table below illustrates the breakdown of spend by service type by. In addition to local NHS spending Liverpool City Council spent an estimated £6.4m on dementia services (this is likely to be an under estimate of actual figure).

2011-12 Programme Budgeting Submission – Organic Mental Disorders		
Area	**Service**	**Amount £000's**
NHS & Foundation Trusts	Mersey Care NHS Trust	14,341
	South Staffordshire Healthcare Foundation Trust	1,052
	Royal Liverpool & Broadgreen University Hospitals NHS Trust	216
	Aintree Hospitals NHS Foundation Trust	153
	5 Borough Partnership NHS Foundation Trust	146
	Cheshire & Wirral Partnership NHS Foundation Trust	37
	St Helens & Knowsley Hospitals NHS Trust	28
	Lancashire Care Foundation Trust	7
	Liverpool Community Health NHS Trust	2
	Southport & Ormskirk Hospitals NHS Trust	1
	Non-contractual arrangements	2
Primary Care	GP Prescribing	532
	NHS Pharmacy Contract	134
Other Sectors	Paisley Court	1,841
	Funding Nursing Care	1,773
	Continuing Healthcare	1,723
	ESMI/EFMI - Grants	748
	Hospices	289
	Dementia funding	273
	Winter pressures funding	115
	CHC retrospective claims	93
	Complex Needs	35
Allocation of Non Healthcare costs		1,753
Total		**25,294**

Figure 50: NHS Programme Budgeting for Organic Mental Disorders, 2011-12

14. Models of Care

Once someone has received a diagnosis of dementia there will be a range of different types of support they and their families will need. If the condition is already advanced, some will be in need of health and care support straight away, while others may not have reached that point yet. However, everyone will need support, advice and help to understand what it means to have dementia, what they can do to live as well as possible with the condition and to enable them to plan for the future.

Examples of post-diagnosis help and support include:

- Information about available services and sources of support
- A dementia adviser to facilitate easy access to appropriate care and advice
- Peer support, such as befriending services, to provide practical and emotional support, reduce isolation and promote self-care.

Traditional models of dementia care are based on diagnosis being delivered by secondary mental health services through memory clinics. However there is increasing interest in delivering care co-ordination, advice and management within primary care[56] [57]. The table below gives an overview of 4 different approaches to supporting those with dementia.

[56] *Department of Health (2009) Demonstrator Site Programme. London: DH Website*
[57] *South West Dementia Partnership (November 2011) An evaluation of dementia support worker roles*

Title	Memory Nurse	Dementia adviser	Integrated care memory nurse	Admiral Nurse service
Location	Cornwall	Staffordshire	Cornwall	Worcestershire
Base	Primary care	Third sector	Secondary care	Secondary care
Function	Assessment towards diagnosis, education, proactive contact, signposting, enabling, development of care plans, leading complex care co-ordination, undertaking annual QOF dementia reviews. Case load held (180 per WTE). All dementia and MCI patients in area kept on caseload.	Signposting and six-monthly proactive information provision for patients and carers. Pre-diagnosis patients accepted. Information plan development. Case load held (200 per WTE). 6% of patients with dementia on caseload at any time.	Support service for GPs, co-ordinating care on basis of need, and providing opportunistic education for GPs. Provision of face to face contact with patients and carers for assessment of needs and information provision. No case load but awareness (by register) of patients with dementia at each GP surgery attached to.	Expert practitioner, patient advocate and facilitator. Variably commissioned depending on location. Complex needs assessments undertaken. Specific interventions offered such as psychotherapies. Caseload held (80 per WTE). 9% of patients with dementia on caseload.
Role	Band 6 nurse	NVQ3	Band 6 MHN	Band 6 or 7 MHN
Benefits	Patients and carers supported through journey from pre-diagnosis to end of live care. Delayed care home	Remain on caseload, no need to re-refer. Users report satisfaction of government	Reduced numbers needing CMHT or memory clinic input. Better signposting to appropriate service.	Patients remain at home for longer. Reduced acute hospital and care home admissions.

	placement. Reduced secondary care memory assessment (reduced costs). Crisis avoidance resulting in reduced hospital admissions. Data entered onto GP computers.	outcomes. Dementia awareness-raising amongst primary care staff.	Better GP liaison for education and support.	High intensity specialist support reduces need for CMHT, even for specific therapies. Improved care co-ordination. High carer satisfaction in surveys. Brand value for ready identification and fund-raising.
Risks	Cost. Control of workload with rising prevalence.	Stigma around 'dementia' in job title. Information-sharing with health and social care less easy.	No caseload: new problem requires re-referral by GP. Contact not pro-active unless patient is currently actively case-managed.	High-intensity interventions may restrict availability; however the service mitigates this risk by offering variable intensities of support to a wider range of service users.
Cost /100 patients	£30,254	£3,714	£102,600	£4,209

Figure 51: Dementia Models of Care

A more recent publication[58] suggests cost-effectiveness savings can be found by recruitment of "dementia advisors" based within primary care/general practice, with access to a consultant psychiatrist within the health centre. The dementia advisor receives referrals from the practice (any

[58] *Clark M, Moreland N, Jolley D, (2013) Putting personalisation and integration into practice in primary care. Journal of Integrated Care Vol.21 No 2 pp: 105-120*

practitioner who suspects memory impairment through health checks/vascular risk register or other regular check) and sees the individual in his/her own home with a relative or appropriate friend within a few days of referral, working to established protocols[59].

During the six years the model has been in operation only three referrals have been made to the local mental health service. The clinic is popular and inexpensive (£11,500 for a four partner practice, with an 8,000 practice population list) compared to secondary care (£133,000).

There are other examples of non-professionally trained co-ordinators and integrated care.[60] It seems what matters for the role is the motivation of the personnel involved (being dementia friendly and person centred), communication, facilitation, co-ordination and knowledge of community assets.

Models of Care in Liverpool

Currently Mersey Care NHS Trust delivers a 'care navigator' model from the Memory Clinic in Mossley Hill and one care navigator from Aintree University Hospital Trust. Each care navigator will have a caseload of approximately 200 people and deliver post diagnostic support groups. This model is accredited by The Royal College of Psychiatrists as excellent. Equitable access between those in the north and the South of the city needs to be addressed.

"Positive Care Pathways" (PCP) at Mersey Care NHS Trust is in the process of re-structuring their business model to provide one directorate with the aim of delivering one service for Liverpool, Sefton and Kirkby. Currently the North of the city delivers one post diagnostic programme and a memory service, rather than a clinic with follow up through the community mental health team. There is a shared care policy in place where GPs deliver prescriptions as assessed by the team and all follow up and reviews are delivered by the team. At the time of writing it is unclear as to how many GPs are signed up to the policy. The aim is to ensure that all prescribing for individuals with dementia is delivered by their GP and not by secondary services. It is recommended that shared care agreements are revisited which may improve access and support.

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[59] *Greening at al., (2009) and www.gnosallsurgery.co.uk/clinics-and-services.aspx?t=5.*

[60] *Thistlethwaite, P (2011) Integrating Health and Social Care in Torbay: Improving Care for Mrs. Smith. Kings Fund, London.*

15. The Lived Environment

The WHO criteria[61] for determining an 'age friendly city' includes housing which is affordable in areas that are safe and close to services and the rest of the community. It also lists:

- Affordable home maintenance and support services
- Well constructed dwellings which provide safe and comfortable shelter from the weather
- Interior spaces and level surfaces allowing freedom of movement
- Home modification options are affordable
- Sufficient and affordable housing for frail and disabled older people, with appropriate services provided locally
- Designated older people's housing located close to services and the rest of the community

The Mayor of Liverpool has pledged to transform Liverpool into an "Age- Friendly City" as specified by the World Health Organisation. A report to Cabinet (31st August 2012) outlines a plan to create an integrated housing, health and social care system for older people in a phased development. Phase 1 is to provide fully integrated extra care housing. The Cabinet has approved additional investment to develop an additional 5 integrated extra care schemes. Phase 2 is to develop integrated pathways through a "virtual network" of health and social care in order to meet the needs of older people in the community. Phase 3 is capital investment in additional housing for the ageing population, including people with learning disability and dementias. The aim of this initiative is to work in partnership with key stakeholders, including LCCG to deliver this ambition.

Housing design can play a key part in whether someone is able to stay independent or not. Issues such as good lighting, colour contrast and memory triggers are all very important. According to

[61] WHO (2007) Global Age Friendly Cities: A guide. Accessed at: http://www.who.int/ageing/age_friendly_cities_guide/en/index.html

research carried out by The University of Stirling people with dementia will do much better if you increase the light levels, including floor coverings.

Housing providers are really well-placed to help people to identify early signs of dementia and to get a diagnosis, to help people find their way around the system and well as to support positive risk-taking to help people live the lives they want to.

Being able to navigate easily is important, so all access points and pathways need appropriate light, considered use of colour, worded and pictorial signage for the presentation of essential information to assist way finding. Clear pathways around the building in same colours can offer directions additional clues such as potted plants pictures fish tanks can support way finding and act as reminders.

The Life Story Network has worked with housing providers in Merseyside to explore how to create the conditions to develop dementia friendly communities. The project confirmed the importance of being responsive to the needs of people with dementia and their family carers, not only those living in extra care and supported housing, but also those older residents who live in general housing stock who may not be in touch with support services or who may withdraw due to lack of confidence and support as their condition progresses. This situation can be self-perpetuating and can result in isolation and loneliness, which impact on physical and mental health.

In addition to housing support staff, tenants play an important role in identifying neighbours who may be exhibiting the early signs of dementia or other mental health difficulties, and in knowing how to support and seek help for them.

16. Technology

As part of the work in becoming an “Age friendly City”, there is an intention to develop a “virtual network” underpinned by increased focus on self-care and individuals taking more responsibility for planning their own health and well- being. In order to do this LCC and LCCG are working collaboratively to deliver the DALLAS (demonstrating assisted living lifestyles at scale) programme. The programme will invest in a range of initiatives to work with individuals, including older people with dementia to use technology in order to maintain their independence. The aim is to recruit 200 community champions who will raise the profile of the neighbourhood well- being assets, including assistive technology.

Telecare is currently delivered by LCC and includes a range of products in order to assist in maintaining independence, such as a telephone alarm systems in case of falls/ accidents, mattress pads to assist with continence, temperature sensors, user/carer alerts/ epilepsy alerts. There are a range of products which assist helping individuals feel more secure in their chosen environment. Currently there is a nominal charge for these solutions, but from April 2014 these will be assessed using the FAC criteria.

My Independence (Mi) offers a similar range of higher technological solutions for individuals and of their carers. At present these technologies are largely being tested by service users and carers. The aim of integration is to bring these two initiatives together to deliver solutions. Mi technology is also delivered at a cost so there is a price differential.

17. Workforce Education and Training

All health and social care staff involved in the care of people who may have dementia should have the necessary skills to provide the best quality of care. This should be achieved through effective training and continuous professional and vocational development in dementia.

The Prime Minister's Challenge on Dementia calls on the Royal Colleges to ensure all their members are capable and competent in dementia care. Health Education England (HEE) is the organisation responsible for overseeing education and training within the health and care system is working towards all NHS staff looking after patients with dementia undergoing foundation level dementia training, with HEE ensuring 100,000 staff have foundation level training by March 2014. This training will enable staff to spot the early symptoms of dementia, know how to interact with those with dementia and signpost staff to the most appropriate care.

HEE are to work with Skills for Health and Skills for Care to produce high quality training that can be used by people across health and social care. HEE also plans to complete research looking at the changes made in organisations and their people as a result of education and training. Every person joining the social care workforce will be expected to undertake the common induction standards which include aspects of dementia awareness. In addition to this, a number of units and qualifications at vocational levels two and three have been developed by Skills for Care and Skills for Health to support the development of the social care and health workforce working with people with dementia.

Local scoping work is currently supporting a better understanding of the scope of training on offer, and to provide a future system whereby the quality of training is assured.

18. Recommendations and Conclusion

The report has highlighted several areas where improvements can be made to reduce levels of unmet need and improve outcomes for older people. The recommendations should be used by commissioners to develop a strategy that is cost-effective in addressing need, reducing inequality and acceptable to the Liverpool population.

Prevention

The concept of 'healthy ageing' is vital in preventing or delaying the onset of dementia. Consideration should be given to the findings of the current reviews by NICE into dementia, disability and frailty in designing and delivering interventions to promote healthy behaviours. These interventions must consider the wider determinants of health and how the 'lived' environment (physical, social and economic) influences the choices people make.

Physical activity programmes should be tailored to support and appeal to older people. Local insight work with older people should help elicit their views on what is currently offered and how it could be improved.

There should be continued focus on the optimal management of conditions such as raised blood pressure, cholesterol management, diabetes and vascular disease. Reducing variation at neighbourhood level will support prevention and delays in onset of dementia.

Identification

The development of local population insight work and subsequent social marketing messages should be commissioned to support awareness-raising in the city. This will ensure that the messages used are consistent and resonate with the local population.

The establishment of a local Dementia Action Alliance should be tasked with raising awareness of dementia across the city and in targeting areas for improvement based on feedback from people living with dementia and carers. This should include a focus on the environment and transport, stimulating community based support such as memory cafes, peer support etc.

Targeted work with high risk populations should be used as a method to reduce the gap between actual and expected prevalence. This work will need to be supported by investment in services to meet the additional demand. High risk groups should include:

- BAME population
- CVD and diabetes population
- Down's Syndrome population
- Learning Disability population – improving rates of annual review
- Those with long term neurological conditions
- Those with psychiatric symptoms (depressive, adjustment and anxiety disorders)
- High risk and alcohol dependent drinkers
- Those with MCI

Diagnosis

Improvements in the routine preliminary screening of those with suspected dementia will support identification of other underlying disease.

Closing the gap between actual versus expected referral rates to memory clinics by reducing variation at GP neighbourhood level. Initial focus should be given to those neighbourhoods with lower rates than the Liverpool average.

Prescribing

Work to better understand the variation in prescribing rates for dementia drugs at GP neighbourhood level. Particularly in relation to those neighbourhoods with highest dementia prevalence but lowest prescribing rates. This should include revisiting shared care arrnagments for prescribing.

Work to better understand the prescribing of anti-psychotics to those with dementia. This should include both the individual context for use, adherence to guidance and care planning and review arrangements.

Non-Pharmacological Interventions

Consideration should be given to the findings of the local evaluation of NPIs in Liverpool. This will support investment in those interventions which are found to be cost-effective.

Primary Care

Improving variation in numbers of patients on a dementia register having received a review in general practice will support early intervention and may reduce future need for unplanned support.

Social Support

Further investigation of the variation in service users with a diagnosis of dementia at Liverpool City Council and those at GP level may support in case finding those with unmet need. A data linkage exercise across the two organisations will support our understanding of the true picture of unmet need.

Unplanned Care

Further investigation is needed to better understand the variation in unplanned hospital admission rates. This work should consider associated analysis of referral rates to memory clinics, prescribing rates, ACP and social care data linkage.

An understanding of the 'conversion rate' from unplanned admissions from UPR and discharge to care homes may allow for better planning of rehabilitation and reablement services. An audit is recommended to look at this particular cohort.

End of Life Care

The local work around ACP should be expanded to move beyond those in residential care to the wider registered population. This will support improvements in the care of those nearing the end of life and reduce the need for unplanned care.

The findings of the LCP review should be considered in developing dementia services and built into related workforce and education plans.

Carers

Improvements should be made to identify and support the carer population. This will be achieved through developments from population insight work, improvements in recording and reviewing the needs of carers in the city and involvement of third sector partners. The current intelligence highlights the need for additional support to allow carers time that is independent of their caring responsibilities and support at night. Improved support for carers will result in improved outcomes for all.

Models of Care

An evaluation of current post-diagnostic support demonstrating outcomes will support service improvement and redesign. Particular attention should be given to geographical inequity of access to support (North/South provision). This should be done in conjunction with modelling of a shift towards management of those with dementia in a primary care setting based upon the emerging evidence base.

The Environment

Liverpool partners should continue with their work to become an 'age friendly' city. The work of The Dementia Action Alliance should coordinate and support improvements in community based solutions and support for those living with dementia.

Technology

The role of technology has an important role to play in supporting people with dementia to remain as independent as possible. It is important to find solutions that can be integrated into the person's normal routine with minimum disruption and always involve the person in decisions about which product or solution to use, and take their opinions on board. The Alzheimer's Society suggests there is a higher chance of success if you can introduce assistive technology when the dementia is still at an early stage, so that the person can gradually get used to the new way of doing things.

Housing

Consideration should be given to the planning and design of new and refurbished housing stock to incorporate dementia friendly design and technology.

Workforce

Commissioners should work to align dementia training and awareness programmes with accredited standards. This should include general awareness training, as well as bespoke training for health and social care staff.