Dementia

JSNA Report

January 2016

This report

This report has been prepared jointly by Knowsley Council, the Clinical Commissioning Group (CCG) and partners of the Knowsley Health and Wellbeing Board (HWB).

Purpose and scope of this report

The purpose of this overarching strategic assessment is to identify the needs and gaps in provision for people with and at risk of dementia in Knowsley, and their carers, to support future commissioning decisions.

This needs assessment covers a wide range of data relating to Knowsley adults diagnosed with and at risk of dementia. It presents analyses of the prevalence of Dementia in Knowsley, relative comparisons with the national picture and variations across the borough. Where possible, the analysis looks at the historical trends to see whether needs have increased or decreased over the past year, and whether this is part of a sustained trend. Data was also looked at by localities to see whether there are differences in health for different areas of the borough. Given that demographic and health changes at the population level are slow moving any trends must be treated cautiously.

Quality of data and intelligence available

Data can sometimes lead to constructing misleading pictures, and some data is more vulnerable to misinterpretation than others. Some cautionary notes are included to highlight where data is not always fully complete, up to date, or is perhaps compiled by means of people self-reporting their behaviour.

This is one of a series of reports that comprise Knowsley's Joint Strategic Needs Assessment (JSNA).

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Further information

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1. Introduction to Dementia

Dementia is not a disease in itself, it is a word used to describe a group of symptoms that occur when brain cells stop working properly. This happens inside specific areas of the brain, which can impact upon memory loss and create difficulties with thinking, problem-solving or language. Dementia is progressive, which means the symptoms will gradually get worse. There are a variety of forms of dementia, each with unique impacts upon an individual and their need for care.

Types and Causes of Dementia

Alzheimer's Disease

This is the most common cause of dementia. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells.

Vascular dementia

If the oxygen supply to the brain fails, brain cells may die. The symptoms of vascular dementia can occur either suddenly, following a stroke, or over time, through a series of small strokes.

Dementia with Lewy Bodies

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

In fronto-temporal dementia, damage is usually focused in the front part of the brain. Personality and behaviour are initially more affected than memory.

Rarer causes of dementia

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. Prions are infectious agents that attack the central nervous system and

then invade the brain, causing dementia. The best-known prion disease is Creutzfeldt-Jakob disease, or CJD.

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

Diagnosing dementia

Diagnosing dementia is often difficult, particularly in the early stages, this makes it difficult to assess the full extent of prevalence in Knowsley and elsewhere. Initial referral, often through primary care to specialist assessment, should enable the right support and treatment, critical to improved outcomes and planning.

Assessments can include conversations with the person being diagnosed and those close to them, a physical examination, memory tests and/or brain scans. The Mini Mental State Examination (MMSE) is the most commonly used test for complaints of memory problems or when a diagnosis of dementia is being considered.

Becoming forgetful does not necessarily mean that someone has dementia. Many people notice that memory becomes less reliable as they get older. It can also be a symptom of stress or depression. In rare cases, dementia-like symptoms can be caused by vitamin deficiencies or a brain tumour.

2. Impact, Prevalence and Variation

Impact of the disease

Dementia impacts upon people and families in a number of ways, the most obvious impacts relate to an individual’s ability to function in relation to key tasks, something which deteriorates over time although initially may not prevent an individual functioning well.

There are significant impacts upon partners, families and loved ones, especially those with carer responsibilities, again these impacts escalate over time although some aspects of behaviour may be significant at earlier stages of disease progression.

Other impacts include the financial impacts where functioning is impaired and employment is affected, the psychological impact upon the individual and their families and relatives. The safety of the individual, especially where activities that had previously been taken for granted, such as driving, may be affected and, finally, issues such as planning for end of life, including making wills for example, may prove difficult if not undertaken before disease progression becomes acute.

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 and related 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.

The number and characteristics of people affected by dementia

National

Over 1.5 million people in the UK, including both people with dementia and their carers, would benefit from dementia treatment and support. There are 850,000 people living with dementia in the UK today (1.3 per cent), including over 700,000 people in England, over 45,000 in Wales, nearly 20,000 in Northern Ireland and 70,000 people in Scotland[2]. By 2025 the number is expected to rise to over one million and by 2050 it is projected to exceed 2 million[3]. In the UK it is estimated that 62 per cent of people with dementia are female and 38 percent are male[4].

Dementia is the leading cause of death among women in the UK with 12.2 per cent (31,850) of deaths per year attributed directly to the condition[5]. In the UK over 40,000 people under 65 years of age have dementia with the Department of Health estimating that 59% of people with dementia in England have a formal diagnosis.

Knowsley

Local prevalence for Knowsley was reported to be 69.3% of those expected to have a diagnosis with a formal diagnosis (September 2015). Prevalence of dementia as reported via the Quality Outcomes Framework for 2014/15 tells us that nationally circa 0.75% of the population has dementia, in Knowsley the prevalence is 0.70% of the population which places the CCG in the third quartile ranking it 137 out of 209 CCG's.

Comparison with national and regional averages and statistical neighbours

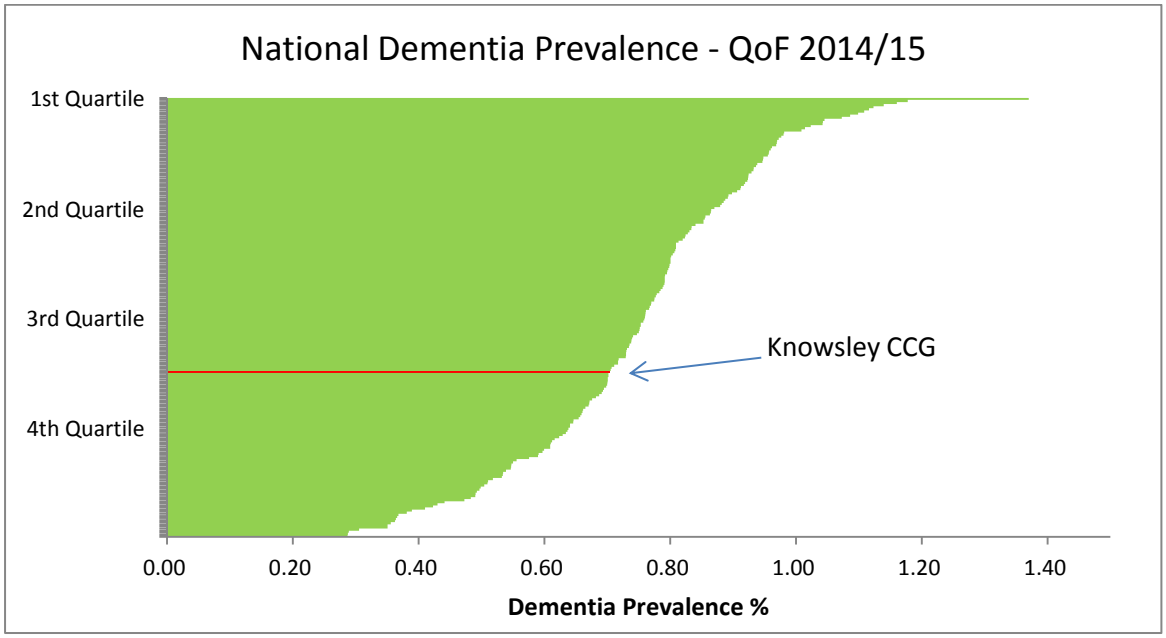

Figure 1: Dementia prevalence 2014/15 by quartiles

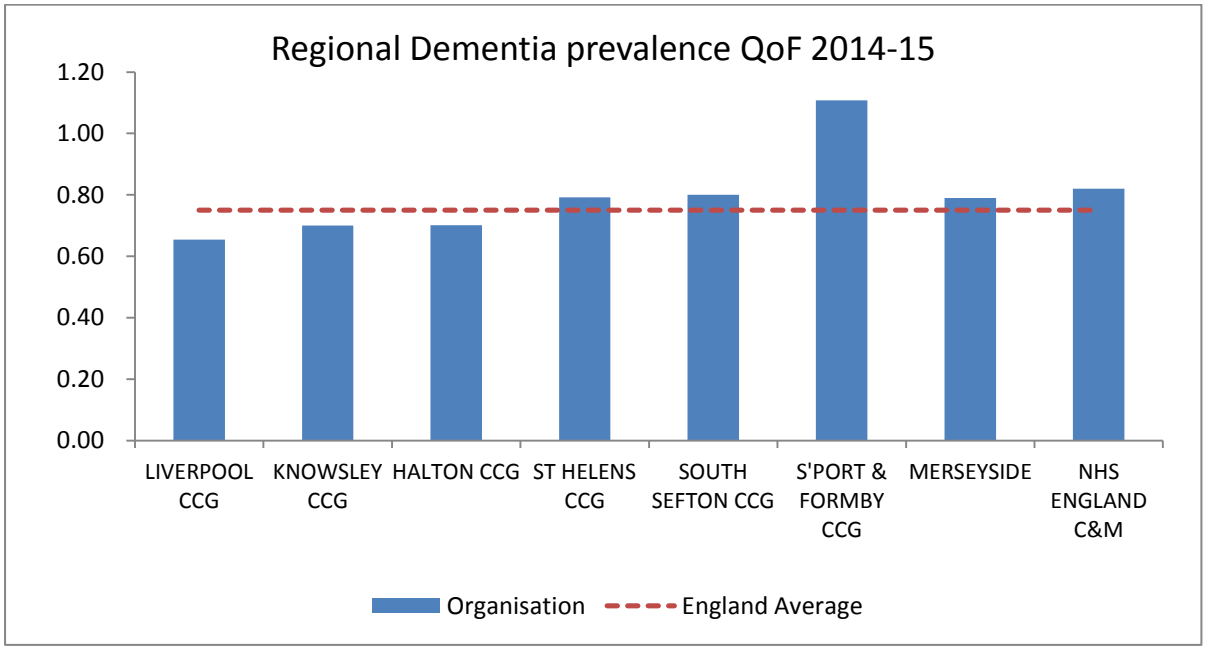

Figure 2: Regional comparison of Dementia prevalence 2014/15

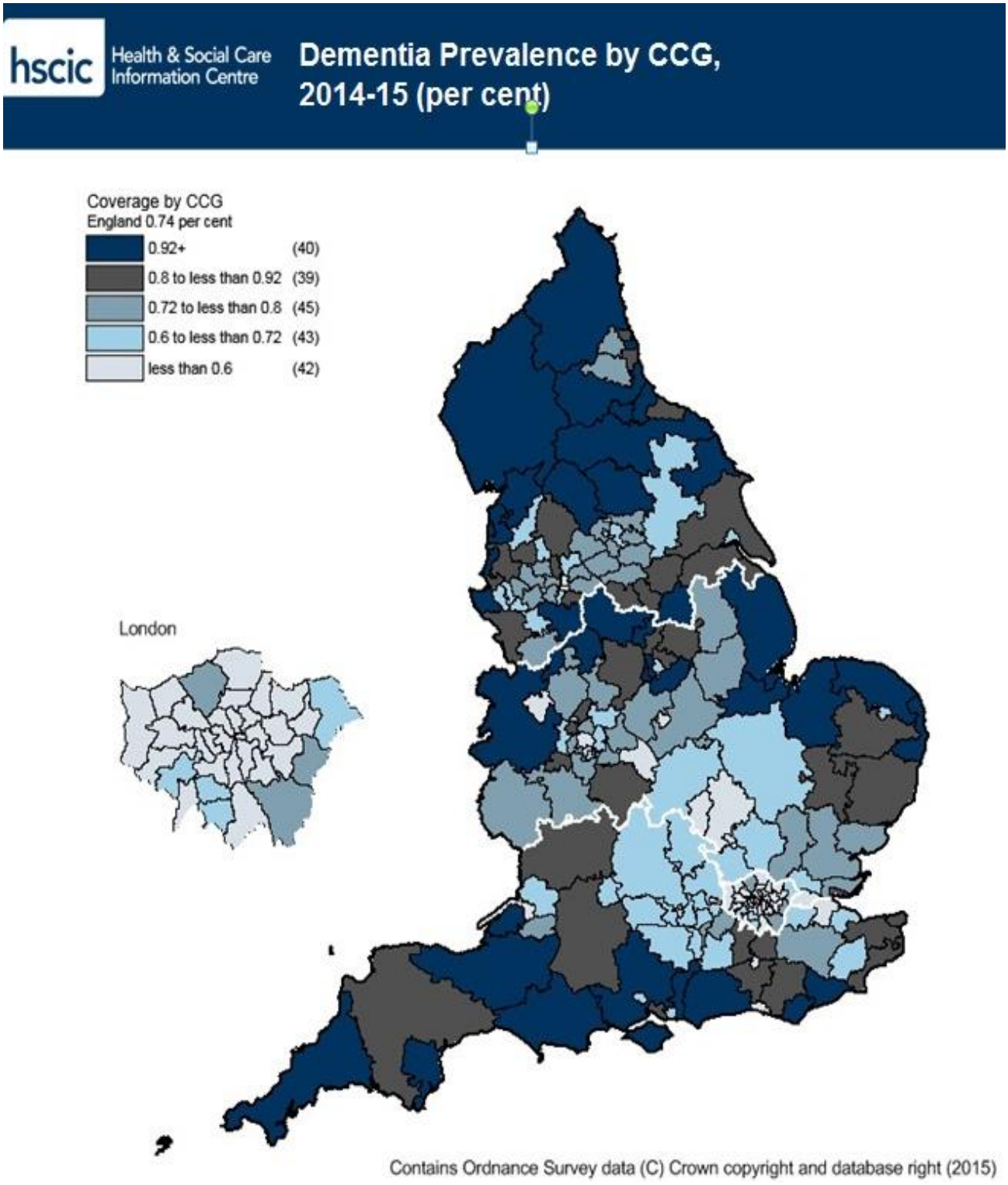

Figure 3: Dementia prevalence by CCG 2014/15

The map (figure 3) indicates that dementia prevalence tends to be higher in rural and coastal areas, this reflects population structures and the higher incidence of care home and retirement destinations in such areas.

Figure 4 indicates the rate of diagnosis for Knowsley which has risen steadily in recent years. Whilst the CCG has increased dementia diagnosis rates over the last few years to place it in the upper part of the third quartile of those patients diagnosed

with dementia nationally, there is still a gap (March 2015) between the expected number of those diagnosed and the actual numbers diagnosed.

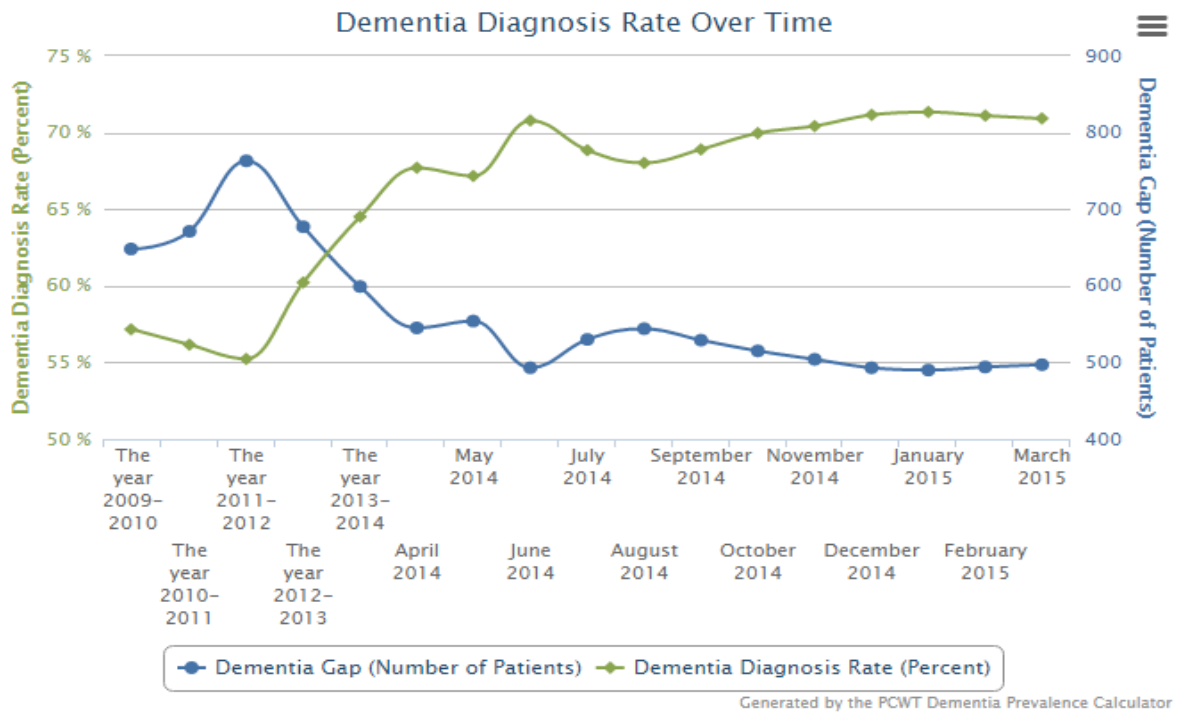

Figure 4: Dementia diagnosis rate and gap

This dementia gap has remained steady in recent years (figure 5)

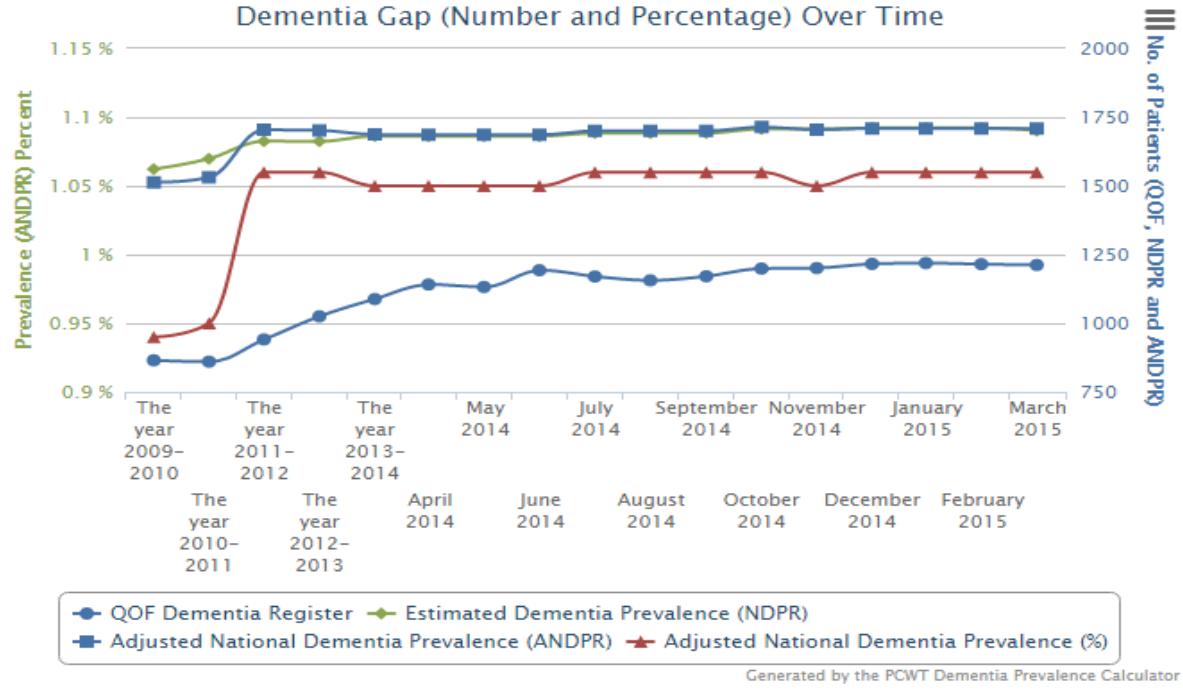

Figure 5: Dementia Gap over time

Figure 6 indicates the numbers of Knowsley patients with dementia as indicated on the QOF registers, shown against the numbers of dementia patients in care homes and overall practice list sizes.

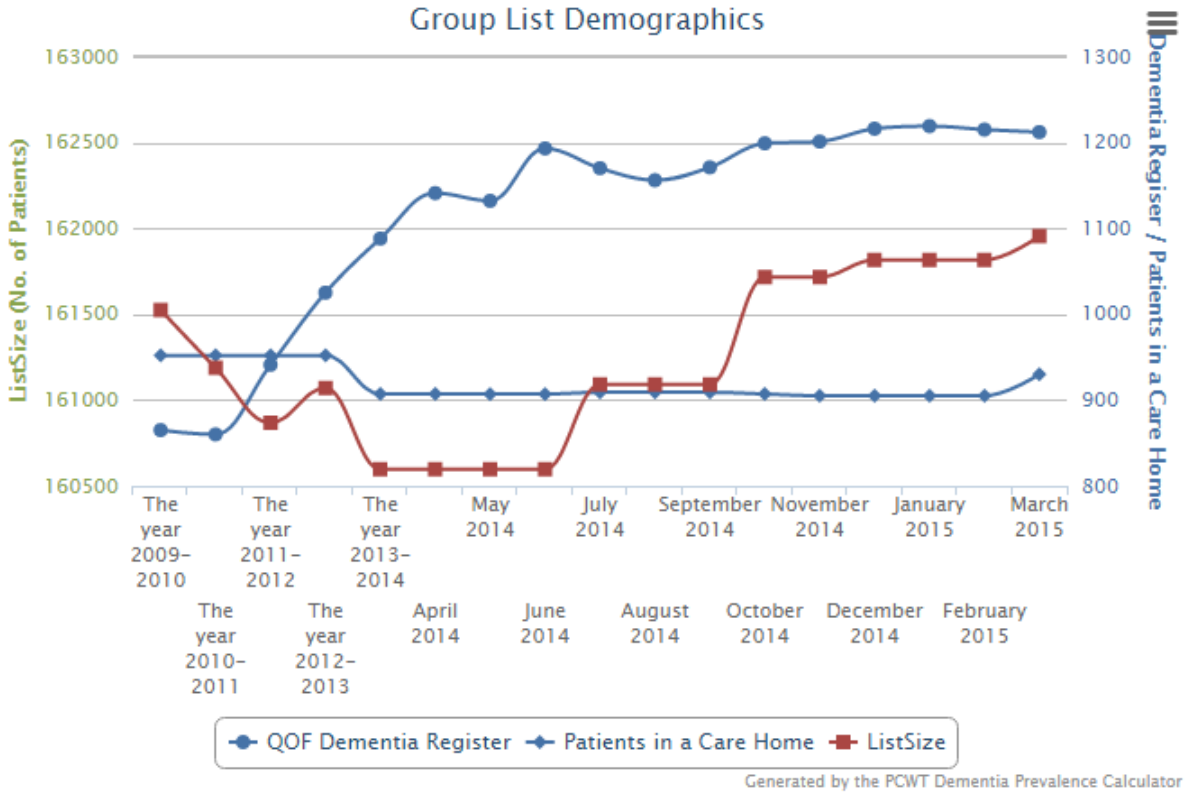

Figure 6: Demographic list growth and comparable growth in Dementia registers

Future projections

There are about 800,000 people in the United Kingdom (UK) with dementia. 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.

The changing demographic profile of Knowsley suggests 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' with implications in terms of increasing prevalence of dementia, the ability of commissioning bodies 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.

Population shifts are expected to bring with them a shifting burden of disease and, alongside an expected rise in the numbers of very elderly, an increase in the number of people with dementia.

Table 1: People aged 65+ predicted to have dementia, by age and gender, projected to 2020					
Knowsley	2012	2014	2016	2018	2020
People aged 65-69 predicted to have dementia	83	88	96	93	97
People aged 70-74 predicted to have dementia	150	147	150	169	180
People aged 75-79 predicted to have dementia	296	301	283	265	265
People aged 80-84 predicted to have dementia	459	459	459	469	456
People aged 85-89 predicted to have dementia	367	406	461	506	522
People aged 90 and over predicted to have dementia	240	299	357	416	447
Population aged 65 and over predicted to have dementia	1,594	1,699	1,805	1,917	1,966

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

Factors influencing the numbers with Dementia

Risk Factors

The biggest risk factor for dementia is age, the older people are the more likely they are to develop the condition, but it is not an inevitable part of ageing. About two in 100 people aged 65 to 69 years have dementia, and this figure rises to one in five for those aged 85 to 89. Evidence suggests this appears to be true for Dementia With Lewy Bodies (DLB) also, however, there is very little evidence about the risk factors for this disease.

Research continues into the identification of other factors which may be involved and research is underway to learn more about whether there is a genetic basis for risk. Alzheimer's is a common disease which means it is quite common for people to have a relative with the condition, but this does not mean people inherit the condition. Some research has suggested that if there is a parent or grandparent with Alzheimer's and they developed the disease over the age of 65, then the risk of developing it may be slightly higher than someone with no family history. Research has identified some genes that may be associated with a higher risk of late-onset Alzheimer's in some people. This is helping the understanding about the causes of Alzheimer's.

People who have developed mild memory problems, which do not interfere with normal daily activities, are at increased risk of developing Alzheimer's. This is often referred to as mild cognitive impairment (MCI). However, many people with MCI do not develop Alzheimer's and some even regain normal memory function. People with Down's syndrome are at increased risk of developing Alzheimer's, and are more likely to develop the disease at an earlier age.

In terms of vascular dementia a number of factors may increase the likelihood of damage to blood vessels in the brain. These include:

- Smoking
- High blood pressure (known as hypertension)
- High cholesterol
- Type 2 diabetes
- Obesity
- Circulatory system problems.

For this reason, all of these factors can increase a person's risk of vascular dementia. In exceptionally rare cases, vascular dementia can be caused by an inherited genetic disorder. Although some of these risk factors can have a genetic basis, managing high blood pressure and high cholesterol might help to lower the risk of vascular dementia. Some research suggests that regular exercise and a healthy diet, especially in midlife and beyond, might help to lower risk.

Support after diagnosis

Once diagnosed a range of support is available, depending upon the progression of the disease. Figure 7 gives an indication of the % of patients who have had reviews which is lower than near neighbours with the position in Knowsley and St. Helens deteriorating in 2014/15 and the group average as indicated by the dotted line

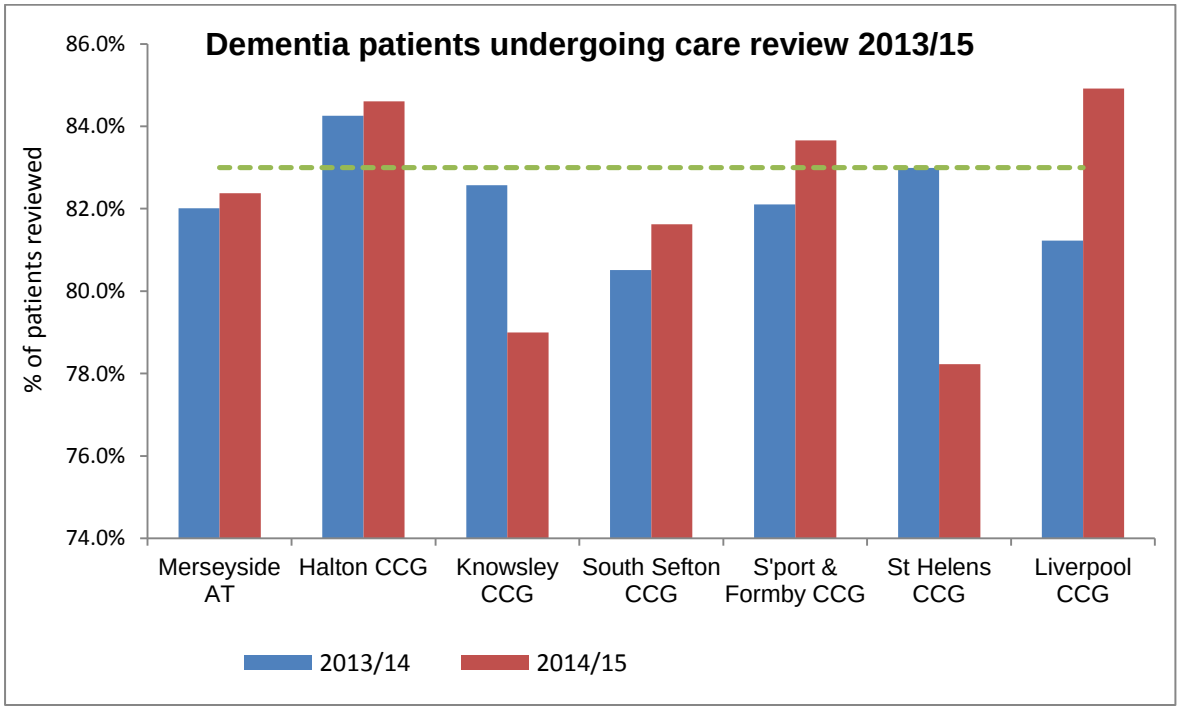

Figure 7: Dementia patients undergoing a care review (QoF 2013-15)

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. Dementia HNA 7 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.

Carers and support

A significant element of caregiving is provided informally by spouses, children, other family members and friends, all of 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. 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

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 is critical to maintaining an individual with dementia in their community and supporting their carer(s). Health and social care staff should ensure that the 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 a co-ordinated approach to the delivery of health and social care.

Evidence has suggested that the emotional and spiritual needs of people with dementia are disproportionately neglected. 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 this is 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.

Mortality

In terms of mortality and diagnosis – whilst pneumonia, cardiovascular disease and pulmonary embolus are often the direct cause of death,because dementia is unlikely to be direct cause of death, so to better understand the impact we need to consider dementia as an underlying cause.

A study on influence of type of dementia on mortality reported that the risk ratio was 2.0 (95% confidence interval 1.5–2.7) for Alzheimer's disease and 3.3 (95% confidence interval 2.0–5.3) for vascular dementia. The gender, age, pre-morbid physical conditions, severity of dementia and institutional accommodation seem to have a strong influence on the mortality pattern among patients with dementia.

Within the first year of being diagnosed as having dementia in a primary care setting, patients have adjusted mortality rates more than 3 times higher than those without dementia, a rate that is much higher than in populations actively screened for this condition, according to a new comparison cohort study from England.

Among people with dementia, men, older people, and those with pre-existing comorbid conditions have decreased life expectancy and survival, which is often dependent on timely diagnosis and treatment.

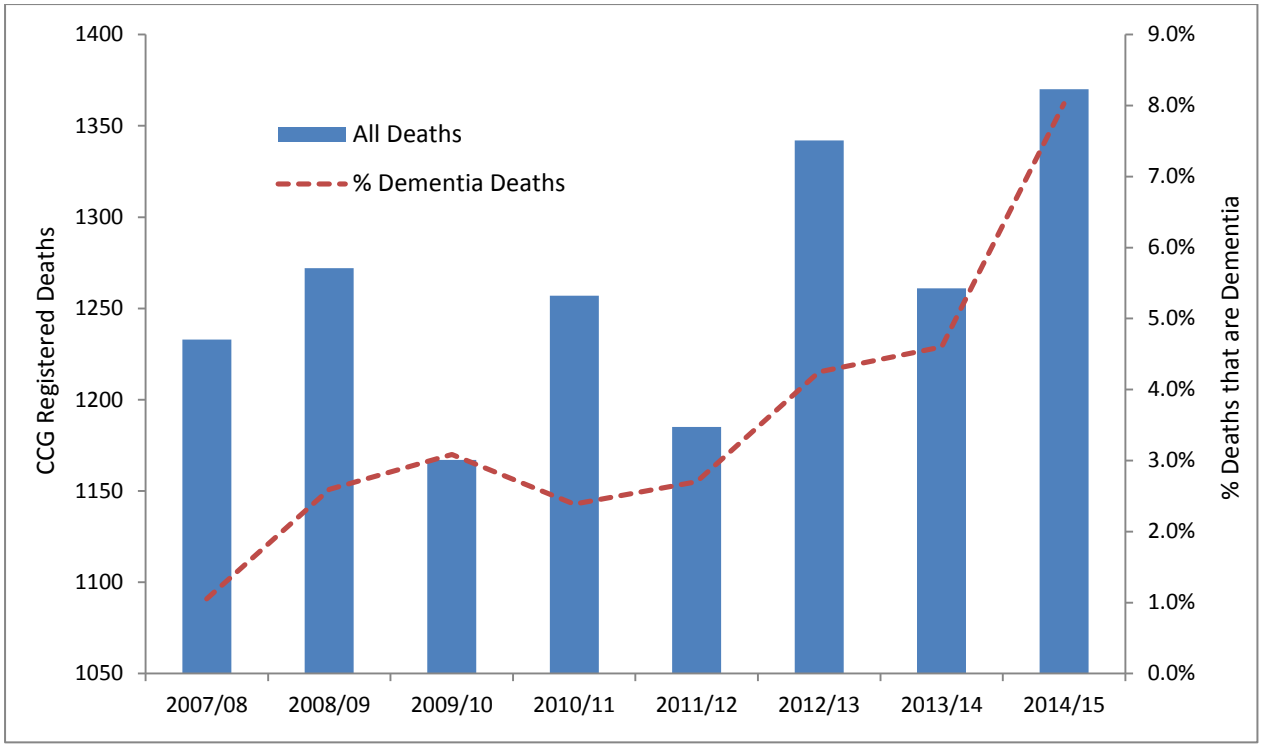

Figure 8: Mortality where Dementia is an underlying cause by year. – Source Primary care Mortality database

End of Life Care

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

Advance care planning is a key element of effective end of life care for dementia patients, especially given the progressive loss of mental capacity during disease progression. 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.

The clinical value of advance planning for end of life care is also clear. Evidence suggests 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.

Service provision and action

Local service provision is primarily based around the following providers and services.

- Later Life and Memory Services, Kirkby (Mersey Care NHS Trust), Knowsley other than Kirkby (5 Boroughs Partnership NHS Foundation Trust),
- Admiral Nurse Service (5 Boroughs Partnership NHS Foundation Trust)
- Diagnosis and support in primary care
- Social Care
- Carer Support
- Care Homes
- Acute Hospital Provision
- Support services through local Alzheimer's Society

Evidence and guidance around what works

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 anti-dementia drugs and caregiver interventions, delayed institutionalisation and enhanced quality of life for people with dementia and their carers. NICE guidelines 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 may be asked whether they wish to know the diagnosis and with whom it should be shared. If dementia is mild or questionable, formal neuropsychological testing may be undertaken and at the time of diagnosis, and regularly afterwards, there is also a need to assess medical and psychiatric comorbidities, including depression and psychosis.

Models of Care

Once someone has received a diagnosis of dementia there are 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 coordination, advice and management within primary care.

National Transformation Framework

NHS England have produced a transformation framework for Dementia which is made up of five key areas.

1. Preventing Well

'The risk of people developing dementia is minimised'

*Standards covered**;*** Prevention, risk reduction

2. Diagnosing Well

'Timely diagnosis, integrated care plan and review within first year'

*Standards covered**;*** Diagnosis, memory assessment, discussion of concerns, investigation, information provision, care plans.

3. Living Well

'People with dementia can live normally in safe and accepting communities'

*Standards covered**;*** Integrated services, supporting carers, carer's respite, co-ordinated care, promoting independence, relationships, leisure, safe communities

4. Supported Well

'Access to safe high quality health and social care for people with dementia and their carers'

*Standards covered**;*** Choice, BPSD, liaison, advocates, housing, hospital treatments, technology, health and social services

5. Dying Well

'People living with dementia die with dignity in the place of their choosing'

*Standards covered**;*** Palliative care and pain, end of life, preferred place of death

Dementia Friendly Areas

The WHO criteria for determining an 'age friendly area' 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

CCG Mental Health 4 year Strategy

The CCG has developed a four year plan for Mental Health with Dementia as one of the key elements of plans, this will involve ensuring diagnosis and post diagnostic support services are in place and that Knowsley is supported to become a dementia friendly borough, involving a wide range of partnerships supporting those with a diagnosis as well as their carers. Supporting quality in care homes provision and encouraging advance care planning for patients and families/carers will also form part of the approach.

Links to other Knowsley priorities

Interdependencies with Council, CCG and wider Partnership priorities

Prevention-Reducing the risk of Dementia

Whilst there can be no change in the ageing process there is currently no way we can completely prevent dementia. However, there are lifestyle changes which will help lower our risk and therefore prevalence in Knowsley.

Risk factors for cardiovascular disease (like heart disease and stroke) are also risk factors for dementia. Leading a healthy lifestyle and taking regular exercise will help lower risk of cardiovascular diseases, and it is likely that will lower risk of dementia too, particularly vascular dementia.

In this sense there is a link between programmes relating to;

- Smoking
- Exercise

- Weight management
- Healthy diet
- Alcohol
- Cholesterol and blood pressure.

Key areas to focus on in the early detection of dementia therefore include developing enhanced education and training in primary care; developing more integrated, collaborative systems of care at the primary-secondary care interface and the interface with other relevant services; and ensuring that both policy makers and commissioners plan services that reflect the effects of dementia on primary care and other services.

Service provision priorities

Other Knowsley priorities strongly linked to dementia include;

- The range and quality of care home provision
- Intermediate care provision
- Reducing hospital admissions
- Psychiatric liaison in hospitals
- Support for carers
- Safe and supported hospital discharge
- End of life care

References:

1: Lewis et al (2014), The Trajectory of Dementia in the UK – Making a Difference, report produced by OHE for Alzheimer's Research UK (calculated by combining the numbers of people with dementia and the number of people who care for them)

2: Alzheimer's Society (2014), Dementia 2014: Opportunity for change

3: Lewis et al (2014), The Trajectory of Dementia in the UK – Making a Difference, report produced by OHE for Alzheimer's Research UK

4: Lewis et al (2014), The Trajectory of Dementia in the UK – Making a Difference, report produced by OHE for Alzheimer's Research UK

5: ONS (2014) Mortality Statistics: Deaths Registered in England and Wales (Series DR), 2013 Release