Needs and Evidence Base Review of Dementia

Public Health
Lincolnshire County Council

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Executive Summary

This report was written to inform the updating of the local Dementia Strategy in 2014 through a review of the evidence around dementia, the effectiveness of treatment and prevention at different stages, and the efficacy of screening tools for dementia. Local dementia information was also obtained with future projections and trends in Lincolnshire. Despite over 20 years’ research, firm conclusions cannot be drawn around effective early diagnosis, treatment or association of any modifiable risk factors for prevention. Non pharmacological interventions however have the potential to reduce frequency and severity of behavioral and psychological symptoms of dementia for dementia patients, and may delay the requirement for nursing/residential home placements/home care support. The benefits of early screening/diagnosis allow the patient to discuss the nature of disease, prognosis, planning around healthcare and personal matters. The possible anxiety and distress caused by knowing this information needs due consideration. This makes it imperative that post-diagnosis support services for both people who have dementia and their carers are established and easily accessible across the county. These include the new Dementia Toolkit established by NHS England in late 2014 alongside locally commissioned support services.
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1. BACKGROUND AND SCOPE

This needs assessment was designed to inform the re-development of the Lincolnshire Dementia Care Strategy and to support the development of joint commissioning plans for service delivery for local people.

The needs assessment is focused on a strategy for people with dementia, rather than being a strategy for dementia persé. The main effect on scope of the needs assessment and subsequent work on strategies and plans is that the information used to determine needs is limited to the latter stages of the dementia pathway. In practice this means looking at needs from the point of diagnosis (including how to address under-diagnosis) forwards.

It is clear from literature review that the majority of earlier preventative interventions to delay or prevent onset of dementia lie in the promotion of good lifestyles that help avoid vascular disease related dementia. The need for these interventions at population and individual level are being addressed elsewhere in the Lincolnshire Joint Health and Wellbeing Strategy (Theme 1).

1.2 What is Dementia?

Dementia is a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function, NICE (2011). Ageing of the population has been accompanied by a dramatic increase in the prevalence of dementia, along with a high burden of suffering for patients, their families and the annual societal cost of dementia is very high, Boustani et al (2003). Dementia is associated with complex needs, particularly in the later stages, and has high levels of dependency and morbidity. These complex needs often challenge the skills and capacity of families and service providers.

Dementia is caused by a number of diseases that affect the brain. Different types of dementia affect the brain at different rates in different ways. The way in which the disease progresses is unique to each individual. Defining a person's disease stage helps care professionals determine the best treatment approach and aids communication between providers and caregivers. Stages can be referred to as "early stage", "middle stage" or "late-stage" dementia, but often a more exact stage is assigned, based on a person's symptoms.

Alzheimer’s disease – is the most common form of dementia. In most cases of Alzheimer’s disease the brain shrinks, which damages the brain’s structure and how it works. An area of the brain known as the cerebral cortex is particularly affected by this atrophy. The cerebral cortex is the layer of grey matter covering the brain. Grey matter is responsible for processing thoughts. Clumps of protein, known as ‘plaques’ and ‘tangles’, also start to form in the brain. The plaques and tangles start to destroy more brain cells, which makes the condition worse. They also affect the chemicals that carry messages from one brain cell to another, slowing and disrupting brain function.
**Vascular dementia** is caused when the brain’s blood supply is interrupted. If the supply of blood is restricted or stopped, the brain cells will begin to die, resulting in brain damage. If the blood vessels inside the brain narrow and harden the brain's blood supply can gradually become interrupted. The blood vessels usually narrow and become hard when fatty deposits build up on the blood vessel walls, restricting the flow of blood. This is called atherosclerosis. If the brain's blood supply is interrupted rapidly during a stroke, this can also damage the brain cells, but not everyone who has a stroke will develop vascular dementia.

**Lewy bodies (Dementia)** – are small, circular lumps of protein that develop inside the brain. It is not known what causes them. It is also unclear how they damage the brain and cause dementia. One theory suggests that dopamine and acetylcholine play a role in regulating brain functions i.e. memory, learning, mood and attention. This type of dementia is closely related to Parkinson’s Disease (physical symptoms include involuntary shaking, muscle stiffness and slowness of movement).

**Fronto-temporal dementia** involves shrinkage of the temporal and frontal lobe and usually occurs in people under 65 years of age. In an estimated 20% of cases this form of dementia is caused by an inherited gene disorder.

**Motor neurone disease** is also sometimes associated with fronto-temporal dementia. It is a rare condition that progressively damages the nervous system, causing the muscles to waste away.

1.3 How is Dementia Classified in the People Affected?

The global deterioration scale for assessment of primary degenerative dementia (GDS) is one of the most commonly used staging scales for dementia. It divides the disease process into seven stages based on the amount of cognitive decline. The GDS is most relevant for people who have Alzheimer’s disease, since some other types of dementia (i.e. fronto-temporal dementia) do not always include memory loss. (See table below).

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Stage</th>
<th>Signs and Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Dementia</td>
<td>Stage 1: No Cognitive Decline</td>
<td>In this stage the person functions normally, has no memory loss, and is mentally healthy. People with NO dementia would be considered to be in Stage 1.</td>
</tr>
<tr>
<td>No Dementia</td>
<td>Stage 2: Very Mild Cognitive Decline</td>
<td>This stage is used to describe normal forgetfulness associated with aging; for example, forgetfulness of names and where familiar objects were left. Symptoms are not evident to loved ones or the physician.</td>
</tr>
<tr>
<td>No Dementia</td>
<td>Stage 3: Mild Cognitive</td>
<td>This stage includes increased forgetfulness, slight difficulty concentrating, decreased work performance. People may get lost more often or have difficulty finding the right words. At this stage, a person's loved ones will begin to notice a cognitive decline. Average duration: 7 years before onset</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Stage</td>
<td>Signs and Symptoms</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Decline                         | Early-stage                                     | **Stage 4: Moderate Cognitive Decline**  
This stage includes difficulty concentrating, decreased memory of recent events, and difficulties managing finances or traveling alone to new locations. People have trouble completing complex tasks efficiently or accurately and may be in denial about their symptoms. They may also start withdrawing from family or friends, because socialisation becomes difficult. At this stage a physician can detect clear cognitive problems during a patient interview and exam. Average duration: 2 years |
|                                 | Mid-Stage                                       | **Stage 5: Moderately Severe Cognitive Decline**  
People in this stage have major memory deficiencies and need some assistance to complete their daily activities (dressing, bathing, preparing meals). Memory loss is more prominent and may include major relevant aspects of current lives; for example, people may not remember their address or phone number and may not know the time or day or where they are. Average duration: 1.5 years |
|                                 | Mid-Stage                                       | **Stage 6: Severe Cognitive Decline (Middle Dementia)**  
People in Stage 6 require extensive assistance to carry out daily activities. They start to forget names of close family members and have little memory of recent events. Many people can remember only some details of earlier life. They also have difficulty counting down from 10 and finishing tasks. Incontinence (loss of bladder or bowel control) is a problem in this stage. Ability to speak declines. Personality changes, such as delusions (believing something to be true that is not), compulsions (repeating a simple behaviour, such as cleaning), or anxiety and agitation may occur. Average duration: 2.5 years |
|                                 | Late-Stage                                      | **Stage 7: Very Severe Cognitive Decline (Late Dementia)**  
People in this stage have essentially no ability to speak or communicate. They require assistance with most activities (e.g., using the toilet, eating). They often lose psychomotor skills, for example, the ability to walk. Average duration: 2.5 years |

Reisberg, et al., 1982; DeLeon and Reisberg, 1999)

There are a number of other prevalent systems for describing the stages of dementia in people affected. Some are functionally based, as above, whilst others look at the syndrome from an intervention view point.
2. METHODOLOGY

A range of methodologies have been utilised in completing this needs assessment and make recommendations for action in Strategy and Commissioning Plans.

These include:

- Structured literature review of evidence base for dementia interventions;
- Collection and analysis of routinely available information on dementia prevalence;
- Forecasting future dementia prevalence at sub-County levels, based on forecast age profile changes;
- Assessment of impact on services of current numbers of people with dementia from activity data in health and social care;
- Involvement of service users, carers, advocates and service providers in identifying felt need; and
- Triangulation of the findings and report with an expert staff ‘Core Group’ and associated stakeholders who were involved in its production.

3. SUMMARY OF FINDINGS

This section is presented under three broad headings: the current and future prevalence of dementia the ‘felt need’ of people affected by dementia and the evidence base for possible interventions.

3.1 The Current and Future Prevalence of Dementia

Lincolnshire population structure

Lincolnshire is one of England’s biggest counties covering an area of nearly 6000 square kilometres. The population is 714,800 according to the 2011 Census. The majority of the population live in rural areas, and the average density is approximately 120 people per square km.

Around 21% of the population are aged 65+, which is higher than the figure for England which is 16%. The proportion of over 65s is projected to increase to 24% by 2021.
The proportion of over 65s varies from district to district with the highest in East Lindsey (26%) and the lowest in Lincoln (14%).

ON5 2011 Mid-Year Population Estimates
The map below highlights the areas with the highest number of elderly residents. It is clearly noticeable that many older residents live in the rural, sparsely populated regions and within some areas of higher levels of deprivation (East Lindsey coast).

Fig. 3 - Population of people aged over 65 in Lincolnshire

As well as having a high proportion of older people, Lincolnshire also has a high proportion of single person households aged over 65: 13.7% compared to 12.4% in England. According to the 2011 Census, 9500 people aged over 65 in East Lindsey are living alone.

**Estimated dementia prevalence and projections**

It is estimated that only around 40% of dementia cases are diagnosed and registered nationally. Due to this, the national rates established by Alzheimer’s Society in 2007 were used in order to estimate the dementia prevalence and future projections in Lincolnshire.
Tab. 1 - The National Dementia Prevalence Rates (NDPR)

<table>
<thead>
<tr>
<th></th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85-89</th>
<th>90+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.5%</td>
<td>3.1%</td>
<td>5.1%</td>
<td>10.2%</td>
<td>16.7%</td>
<td>27.9%</td>
</tr>
<tr>
<td>Females</td>
<td>1.0%</td>
<td>2.4%</td>
<td>6.5%</td>
<td>13.3%</td>
<td>22.2%</td>
<td>30.7%</td>
</tr>
</tbody>
</table>

*Source: Alzheimer Society, Dementia UK, 2007*

The table above only lists rates for later onset of dementia (ages 65+). The rates are also available for people aged below 65 and those vary from 0.01% for the age group 30-34 to 0.2% for 60-64.

We have applied the above rates to the total population in each of the age/gender groups. Using this estimate, the number of dementia cases across Lincolnshire in 2011 was over 10,300 people. An estimated 200 people in Lincolnshire are affected by dementia before reaching their 65th birthday.

We have also applied the NDPR to the ONS population projections in order to project future prevalence of dementia in the county. The number of dementia cases is expected to increase in all districts. The numbers of people affected by dementia will remain highest in East Lindsey.

Fig. 4

![Projected numbers of dementia cases by district](image)

*Source: LCC PH Intelligence team, based on ONS 2011 population projections and NDPR*

In Lincolnshire, 3,900 more people are expected to suffer from dementia in 2021 than in 2011, which gives an increase of nearly 38% in 10 years.

The estimated number of dementia cases is expected to grow most rapidly in West Lindsey. It is estimated that the number of cases will increase from around 1250 in 2011 to 1800 in 2021; a 45% increase in 10 years.
As well as providing the national prevalence rates, Alzheimer’s Society has also created the estimated severity rates for specific age groups.

Tab. 2 - Severity rates

<table>
<thead>
<tr>
<th></th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85-89</th>
<th>90-95</th>
<th>95+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>61.66%</td>
<td>62.50%</td>
<td>56.97%</td>
<td>56.80%</td>
<td>54.32%</td>
<td>48.89%</td>
<td>42.30%</td>
</tr>
<tr>
<td>Moderate</td>
<td>32.03%</td>
<td>30.37%</td>
<td>31.49%</td>
<td>31.86%</td>
<td>32.60%</td>
<td>33.00%</td>
<td>34.43%</td>
</tr>
<tr>
<td>Severe</td>
<td>6.31%</td>
<td>7.13%</td>
<td>11.54%</td>
<td>11.34%</td>
<td>13.08%</td>
<td>18.11%</td>
<td>23.27%</td>
</tr>
</tbody>
</table>

Source: Alzheimer society, Dementia UK, 2007

Using those rates we have estimated that around 1250 cases of dementia in 2011 were severe cases (12.2% approximately). The number of severe cases in Lincolnshire is expected to increase to nearly 1800 by 2021. The projected increase in severe cases (42%) is higher than the increase in all dementia cases (38%). This is a reflection of projected change in the population structure (aging of the society).
Estimated diagnosis rates for CCGs\textsuperscript{vii}

National Dementia Prevalence Rates can also be applied to the Clinical Commissioning Groups (CCG) registered population. The table below shows the numbers of registered patients, the proportion of people over 65, and the estimated dementia cases (NDPR). Comparing the estimated cases to registered cases from the Quality outcome Framework 2011/2012, we were able to calculate the estimated diagnosis rates, which are also presented in the table below.

Tab. 3 - CCGs population, estimated dementia cases and diagnosis rate, 2011/12.

<table>
<thead>
<tr>
<th></th>
<th>Registered</th>
<th>Proportion of population aged 65+</th>
<th>Expected Dementia Cases (NDPR)</th>
<th>Sum of Dementia register (QOF 11/12)</th>
<th>Dementia Diagnosis rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lincolnshire East CCG</td>
<td>240,624</td>
<td>23%</td>
<td>3,784</td>
<td>1,544</td>
<td>41%</td>
</tr>
<tr>
<td>Lincolnshire West CCG</td>
<td>223,217</td>
<td>18%</td>
<td>2,868</td>
<td>1,396</td>
<td>49%</td>
</tr>
<tr>
<td>South Lincolnshire CCG</td>
<td>154,909</td>
<td>21%</td>
<td>2,278</td>
<td>1,012</td>
<td>44%</td>
</tr>
<tr>
<td>South West Lincolnshire CCG</td>
<td>128,329</td>
<td>20%</td>
<td>1,774</td>
<td>771</td>
<td>43%</td>
</tr>
</tbody>
</table>

Source: Dementia Partnership, Dementia Prevalence Calculator for Clinical Commissioning Groups

Lincolnshire West CCG has the highest diagnosis rate of 49%, which is higher than the national average of 46%. More detailed and updated analysis including prevalence and diagnosis rates for individual GPs can be found in the Dementia Prevalence Calculators available from Dementia Partnership’s website: [http://www.dementiapartnerships.org.uk](http://www.dementiapartnerships.org.uk). NHS England has launched a new [Dementia Toolkit](http://www.dementiapartnerships.org.uk) aimed at helping GPs make the early diagnosis and, importantly,
what they can do in terms of vital post-diagnostic support. NHS England's target is to go from under half of people currently to two thirds of people with dementia getting a diagnosis by 2015.

In terms of case severity, South Lincolnshire CCG is estimated to have the highest percentage of severe cases - 15%, which is higher than for example Lincolnshire East, despite the fact that the East has higher estimated dementia prevalence in general. Those differences are caused by the fact that people in the south have a higher life expectancy and a longer life increases the chances of developing severe dementia.

It is important to remember that all the estimates and projections in this chapter are purely based on the population age structure. For simplicity, none of the health conditions or lifestyle choices which are known to increase the risk of developing dementia was taken into account.

3.2 The Evidence Base for Interventions in Dementia

Whilst dementia has, and is being, much researched as a serious disease in developed countries, much of the evidence base for interventions remains relatively low down the hierarchy of evidence. This appraisal of the evidence base has looked broadly across interventions specific to dementia rather than examining evidence base for more generic health and social care interventions for vulnerable people.

3.3 Pharmacological Interventions

A breakthrough dementia drug would treat the underlying disease and stop or delay the cell damage that eventually leads to the worsening of symptoms. Despite a large body of research that has provided an important insight into the nature of dementia, evidence is insufficient to support the use of pharmaceutical agents to treat or repair the brain damage that underlies dementia.

Currently approved drugs help manage the symptoms of dementia, but do not treat the disease. All systematic reviews, literature reviews and meta-analysis on treatment and prevention state that large scale population based studies and RCTs are critically needed particularly in the area of prevention.

Mild to moderate dementia

Guidance from the National Institute for Health and Clinical Excellence (NICE) 2011 recommends that three drugs be made available for treatment of mild to moderate dementia. These are donepezil, rivastigmine and galantamine all of which are acetylcholinesterase inhibitors (working by blocking the actions of an enzyme called acetylcholinesterase which destroys an important neurotransmitter for memory called acetylcholine). These drugs are available as part of NHS care for people with mild-to-moderate dementia. There are also now several studies (Bond et al 2012),– including work supported by Alzheimer's
Society – which suggest that cholinesterase inhibitors may also help people with more severe Alzheimer's disease. However, the above drugs are not licensed in the UK for the treatment of severe Alzheimer's disease and are not universally approved or available.

Treatment of people with mild and moderate cases of dementia with these medicines is effective in between 40 and 70% of people and may only improve symptoms temporarily, between 6-12 months in most cases. People who benefit report improvements in motivation, anxiety levels, and confidence in daily living, memory, and thinking.

**Moderate to severe dementia**

A drug called Memantine is licensed in the UK for the treatment of moderate to severe Alzheimer's disease. It may temporarily slow down the progression of symptoms, including deterioration of everyday function in people in the middle and later stages of the disease. There is evidence that Memantine may also help behavioral symptoms such as aggression and agitation. Again, Memantine is not suitable for all people and delays rather than prevents progression of disease.

Anti-depressants are effective for treating depressive symptoms among community dwelling elderly persons with mild to moderate dementia but it is not clear if these drugs modify the progression of dementia, Seitz et al (2011).

### 3.4 Non-pharmacological interventions

Systematic reviews and meta-analysis of effectiveness of interventions reveal that some non-pharmacological interventions have the potential to reduce frequency and severity of behavioral and psychological symptoms of dementia, Brody and Arasaratnam (2012).

Activities such as exercise, music, animal therapy and multi-sensory stimulation can reduce apathy.

Caregiver training and involvement are very important in determining the success and sustainability of care for people affected. Research evidence is limited in this area with small study designs, however, limited evidence indicates that intensive multicomponent interventions to support caregivers may delay nursing home placements for people with dementia.

### 3.5 Interventions recommended by NICE (2011)

In the most recent NICE advice on provision of care pathways for people with dementia, a range of recommendations about the components of good, cost effective interventions and practice are made. The main components recommended are:

- The development of individual care plans.
For co-morbid agitation, consider interventions tailored to the person’s preferences, skills and abilities and monitor response and adapt the care plan as needed.

Depending on availability, the options to consider include:

- Aromatherapy, as there is some evidence that suggests certain oils can help people with dementia relax and certain oils may improve cognition in AD, specifically lemon balm, lavender oil; however there is insufficient evidence to state this categorically.

- Multi-sensory stimulation, as Multisensory Environments (MSEs) utilising advanced sensory stimulating equipment targeting the senses, have been successfully used in dementia care, severe learning disabilities and palliative care. Collier (2007) demonstrated that MSE does significantly improve motor performance with participants with moderate/severe dementia and improved mood and behaviour.

- Music/dancing, as this can have a powerful effect to improve a person’s sense of wellbeing. Review of music therapy for dementia concluded that based on available evidence it's unclear whether it is beneficial for dementia patients.

- Animal assisted therapy is gaining popularity as part of therapy programmes in residential aged care facilities. Humans and pets respond to quiet interaction with a lowering of blood pressure and increase in neurochemicals associated with relaxation and bonding. Effects may be of benefit in ameliorating behavioral and psychological symptoms of dementia. (Review of literature Filan & Llewellyn 2006).

- Massage, as there is much anecdotal evidence that massage can help manage symptoms associated with dementia such as anxiety, agitation and depression, but studies have not been sufficiently rigorous to provide solid proof. It does seem likely that massage interventions may well be beneficial, but further research is required.

If a person with dementia develops distressing non-cognitive symptoms or behavior that challenges, offer an early assessment to identify factors that may influence the behavior include:

- physical health and depression
- possible undetected pain or discomfort
- side effects of medication
- individual biography
- psychosocial factors
- physical environmental factors
- behavioral and functional analysis in conjunction with carers and care workers

### 3.6 Prevention
Despite published studies declaring the immediate need for appropriate lifestyle measures to prevent the development of dementia, there is a lack of randomised control trials. Most trials note that there are certain variables that increase an individual's likelihood of developing dementia that are not open to intervention, the most important of these are genetics and age.

There are some proven links between certain lifestyle factors and increased likelihood of dementia. These are predominantly related to the development of vascular forms for dementia and some evidence exists to support the promotion of lifestyle change as a secondary prevention intervention i.e. in people with early indicators of dementia.

There is insufficient evidence to support the use of pharmaceutical agents or dietary supplements to prevent cognitive decline. However, individuals diagnosed with mild cognitive impairment should address risk factors (diet, physical activity) to delay existing deficits from progressing. On-going larger population based studies that include anti-hypertensive medications, omega 3 fatty acid, physical activity and cognitive engagement may provide new insight into prevention or delay of cognitive decline but the evidence bases for these remains inconsistent.

Systematic reviews of evidence demonstrate that:

- Fruit and vegetable consumption has been associated with lower risk of dementia and slower rates of decline in cognition in older age, but evidence for this association is lacking, Loef and Walach (2012).


- Anti-hypertensive medication could reduce risk of vascular dementia and any dementia, but not for Alzheimer’s Disease, cognitive decline and cognitive impairment, Chang Quan et al. (2011).

- Cholesterol lowering drugs cannot be recommended as a preventative treatment for dementia. Muangpaisan et al. (2012).

- Whilst cognitive and memory training in those at risk of dementia has shown moderate to large beneficial effects on memory related outcomes, the evidence is not yet strong enough to infer a direct causal relationship. Gates et al (2011).

3.7 Screening for Dementia

Who should be screened?

Although routine use of standardised assessment instruments are recommended, they are not diagnostic instruments, the diagnosis of dementia, delirium and depression is eventually a clinical one that uses all available evidence.
NICE concluded on the basis of a systematic review that there is no simple accurate and cost effective method for identifying people with early dementia through population screening, although there may be a case of targeted screening of sub-populations (Down’s Syndrome, learning disabilities (LD), after a stroke and Parkinson’s disease).

The British Psychological Society (2009) recommend that services for people with LDs should establish a baseline for every adult with Down's Syndrome while they are healthy, provide reactive screening and undertake prospective screening for adults with Down's Syndrome at intervals from age 40 or 50 onwards.

If there is suspected dementia, testing should include examination attention, concentration, orientation, short and long term memory, praxis, language and executive function. As part of the assessment formal cognitive testing should be undertaken using a standardised instrument.

Factors that are known to affect performance including educational level, skills, prior level of functioning and attainment, language, sensory impairments, psychiatric illness or physical/neurological problems should be considered by those interpreting scores. An individual with low education levels may score low and not have dementia and a more educated individual could score highly and have dementia.

The key to the reliable identification is to integrate three components: observation of the patient; collateral account from a carer; and the results of standardised tests for immediate and on-going management. Young and Meagher (2011)

Which screening tools should be used?

There are a range of screening tools available and in common use. They all offer benefits and dis-benefits, including:

- How accurate they are;
- How specific they are in finding dementia as opposed to other causes of functional under-performance;
- How costly they are to administer.
- Their cost effectiveness in reducing future cost to the person and to care organisations.

Additionally, the above section in prevention identifies that there are few proven interventions available to support the person identified as at risk or with functional deterioration except at the latter stages of disease.

The primary reason for screening lie in the social rather than the clinical interventions and may promote planning for the future including advance directives for future care when capacity may be lost.
4. ANALYSIS OF FINDINGS

4.1 Forecasting Volume of Need

The data are clear. Lincolnshire has an older population than average, and the population is set to age more quickly than the average. The longer term risk of dementia is not universally distributed throughout our population, with different communities having a greater or lesser proportion of the risk factors associated with dementia.

The risks of vascular based (or exacerbated) dementia are more prevalent in populations that are more challenged around their lifestyle choices and these populations are predominantly in lower social class groups. Current indications and forecast of shorter term effects of poor lifestyles like obesity and type two diabetes indicate that the problem of higher risk lifestyles is increasing rather than decreasing.

Conversely, those populations with higher risk factors and subsequent higher prevalence of vascular disease are less likely to progress to older age bands. Age is a major predictor of both presence and severity of dementia.

This creates a relatively new problem for Lincolnshire going forward – the likely increased need for services and care in populations that are largely low users of services currently. This is evident in the forecasting of increases in dementia prevalence, for example in South Kesteven.

4.2 Screening and Early Diagnosis

There are evidently a range of tools available to assess risk of or actual functional change, and these may be backed up by higher tech diagnostic tools like brain scanning. However, proper diagnosis of dementia can only be achieved by the synthesis of information and observation from a range of sources, importantly including the person affected and those close to them.

Other than lifestyle interventions to support risk factors for vascular dementia there is no intervention proven to help reduce risk turning into actual disease or early disease developing into serious disabling disease. However, a number of benefits may be accrued from early diagnosis including instigation of treatments that delay functional impairment progression in mild or moderate dementia.

The time to prepare, plan for care and support in later disease stages and ‘grieve’ offered by early diagnosis should not be underestimated however and may have significant impact on resilience of informal caring in due course.

The disadvantages of early screening include depression and anxiety, time and cost of screening to the health care bill, negative labeling effects; positive screening would require referrals to specialists that increase anxiety and worry. Different types of dementia syndromes are often underdiagnosed in older people in routine care; formal detection may allow some better outcomes in mild dementia and delay permanent nursing care.
4.3 Early Treatment and Care

Despite advances in research there is no real scientific evidence that indicates any real benefit of pharmacological or non-pharmacological interventions or preventive strategies currently, and more research is needed to make fundamental changes in dementia diagnosis and management. Non Pharmacological interventions for people with mild to moderate dementia of all types would benefit from participation in structured group cognitive stimulation programmes, particularly when behavior becomes challenging with progression of disease. Physical activity is likely to prevent the development of vascular dementia and should be highlighted as part of secondary prevention in people at risk of cerebrovascular disease.

5. RECOMMENDATIONS

- The commissioners from health and social care organisations and wider stakeholders review the results of this needs assessment in the development and continued delivery of the action plan driving the Lincolnshire Dementia Care Strategy.

- Needs assessment information on dementia is updated on at least an annual basis to the Joint Strategic Needs Assessment. This must include both qualitative updates on diagnosis rates; prevalence rates etc but must also seek to continuously update the qualitative input and reality check from patients and carers experiences of living with the condition.

- Review the outcomes and delivery of the Lincolnshire Dementia Care Strategy alongside the results of the needs assessment. This should be considered alongside other interdependent LCC commissioning strategies to include: Carers, Wellbeing, Community Assets and Resilience, CCG Commissioning Strategies and the work of Lincolnshire Health and Care. This will ensure the continued delivery of the outcomes of the action plan for the Lincolnshire Dementia Care strategy.
6. REFERENCES


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i ONS, UK Standard Area Measurements (SAM), December 2011, land only
ii ONS 2011 Mid Year Population Estimates
  Based on ONS 2011 Interim population projections for local authorities, counties and regions, single year of age
iii ONS, 2011 Census
iv ONS, 2011 Census
v Alzheimer society, Dementia UK, 2007
vi Dementia Partnership, Dementia Prevalence Calculator for Clinical Commissioning Groups
vii ONS 2011 Mid Year Population Estimates
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x ONS, 2011 Census
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